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Creating a Sustainable Cancer Workforce: Focus on Disparities and Cultural Competence

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1. Introduction

While the role of culture in addressing health care disparities in general and, cancer health disparities specifically is increasingly recognized, a systemic approach aimed at bolstering the cultural competence of our nation's health care workforce is absent. Among the health outcomes, the impact of this gap is most pronounced in cancer. Ample scientific evidence exists affirming that eliminating cancer health disparities requires a multi-sectorial approach. The lack of cultural competence among frontline providers - physicians, nurses, pharmacists, health educators – is only compounded by the cancer workforce crisis, a national threat to assuring quality cancer care to a growing vulnerable and increasingly culturally diverse global population. Traditional solutions to the health care workforce crisis in general and that of the cancer workforce specifically have largely failed because of a silo- rather than a systems approach, focusing on one specific segment of the workforce or one specific aspect of cancer care. Furthermore, much of those efforts were limited to addressing the quantitative aspect of the problem – increase the number of cancer care professionals, ignoring the equally important qualitative component- assuring a health care workforce, *competent* in providing cancer care across the cancer spectrum to culturally diverse populations. (C-Change 2008; Lichtveld 2009)

The cancer workforce is faced with various obstacles as cancer prevalence and mortality rates swell worldwide and cancer patients and survivors are directly affected by the shortage in a workforce to provide care. Compounding the shortfall in health prevention and clinical care, the disproportionate impact of cancer on minorities and disadvantaged populations has been apparent for decades with few innovative cancer care delivery models implemented. A growing body of evidence indicates that in addition to race, and geo-socio-economic parameters, culture is a strong influencing factor on cancer outcomes.(Grouse 2005; Chin, Walters et al. 2007; Fisher, Burnet et al. 2007) Converting the role culture plays in eliminating cancer health disparities from a barrier to an asset, requires cultural competence from those providing care across the entire cancer care continuum – from prevention to survivorship. (Lichtveld 2009)

2. Racial, cultural and ethnic disparities in cancer care

Global health disparities is a critical area of concern and intensifies the issue of cancer in developed and developing countries.(Jones, Chilton et al. 2006; Kawahara, Masui et al. 2010) Cancer is the leading cause of death worldwide with mortality rates spiking in low- and middle- income countries.(Linkov, Padilla et al. 2010) Medical care alone cannot adequately improve health related quality of life or reduce cancer disparities without also addressing where and how people live.(Subban, Terwoord et al. 2008) As countries become more culturally diverse, taking action to train the future cancer workforce to better serve their changing communities is a top priority. (Dogra, Reitmanova et al. 2010) Public & private health systems need to move beyond identifying problems to development of novel interventions and their implementation. Additionally, genuine efforts need to be made to offer culturally & linguistically appropriate services to the world's most vulnerable populations.

Addressing global cancer health disparities requires a holistic solution to a complex and interdependent set of patient, provider, and health system factors. Through educational interventions, projects can aim to position the health care system to effectively serve patients and communities of color. The state of the cancer workforce displays a grim picture, with several shortages including oncologists, pharmacists and nurses. These shortages can be characterized as supply and demand determinants; the demand for oncologists – the lifetime probability of developing cancer is 1 in every 2 men and 1 in every 3 women - is expected to exceed supply by 25%-30% by 2020. Against this backdrop, bolstering the basic cancer care competency knowledge and skills of medical, nursing and pharmacy students is essential as an evidence-based prevention priority and sustainable capacity for cancer care.(C-Change 2008; Smith, Tyus et al. 2009)

Cancer health disparities in low- and middle- income countries provides a uniquely rich platform for educational interventions as reflected by the large number of physicians, nurses and pharmacists serving resource-challenged and underserved populations. By "mainstreaming" cultural competence-embedded cancer care education into health professions curricula, a competent cadre of health care providers produced as a result of revised competencies and cancer education curricula has a "ready practice setting" to implement those skills in a fashion that is measurable.

3. A balanced perspective: understanding the social determinants of health

To elucidate the global perspective of lower-resourced communities, the Social-Ecological Model of Health provides an applicable theoretical framework. The model proposes that individual health is influenced by biological and genetic functioning, social and familial relationships, the built environment, and broader psychosocial and economic factors (Figure 1). Health is influenced by multiple facets in the physical and social environment; the environment itself is multidimensional, incorporating social, physical, actual or perceived elements as discrete attributes or constructs. An individual's environment is influenced by the interaction with people who share that environment. Person-environment interactions occur in cycles in which people influence their settings; these changes in turn influence health behaviors.(Stokols 1996)
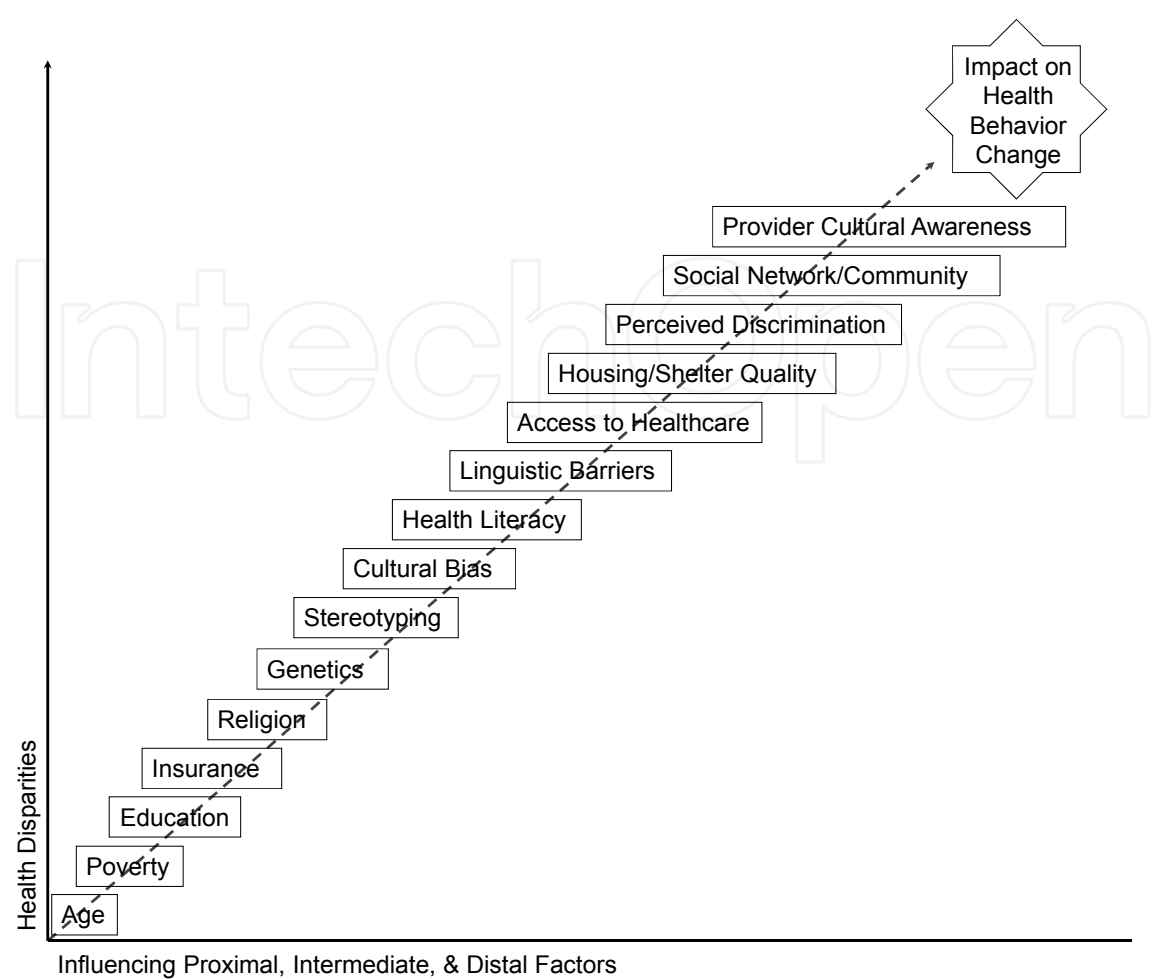
Fig. 1. Social-ecological model: reversing the social determinants that widen the healthy divide.

Social determinants are inextricably linked with socioeconomic disparities that impact every phase of the cancer care spectrum from screening to palliative care. (Smedley, Stith et al. 2003) Despite the United States nationally acclaimed decreases in breast and cervical cancer mortality due in large part to early screening and better therapeutics, African American Hispanic and American Indian/Alaska Native (AI/AN) populations have not enjoyed these same benefits. African American and Hispanic women have higher breast and cervical cancer mortality respectively despite similar screening rates to White women. Colorectal cancer screening rates are also lower while advanced stage at diagnosis higher within African American and Hispanic people. Treatment disparities are particularly concerning. The absolute proportion of African American and Hispanic women receiving radiation therapy less than 1 year after breast conserving therapy is 12% lower in African American and 19% lower in Hispanic women. There is no stable data for AI/AN women. (Natale Pereira, Enard et al. 2011) African American women with breast cancer were less likely to receive full course chemotherapy (Griggs, Sorbero et al. 2003)and more likely to receive non-standard chemotherapy regimens (OR 1.93 [1.11 – 3.36]). (Griggs, Culakova et al. 2007; Griggs, Culakova et al. 2007)This correlated with stage of disease i.e. Stage II and III OR 2.82 (2.01 – 3.95) and 7.95 (4.06-15.98) respectively, and lower education levels i.e. less than high school OR 3.24 (1.17 – 9.0), high school graduate OR 1.8 (1.08-3.0). These data in part,

may explain the lower survival rates in African American and Hispanic women although data in Hispanic women is lacking. System factors pose significant problems with lower proportions of Hispanic women reporting timely receipt of appointments (35 vs. 49%) and higher proportion reporting difficulty in getting care when needed compared to White women (66 vs. 55.8%). Higher poverty rates, lower insurance rates and higher discontinuously insured rates, decreased English proficiency when compared to White populations characterize African American and/or Hispanic populations. (Smith Bindman, Miglioretti et al. 2006; Elkin, Ishill et al. 2010; Miranda, Wilkinson et al. 2011) Effective cancer care cannot be delivered without a multi-tiered approach that effectively links and integrates the patient with all components of the cancer care delivery system. Patient navigation is a promising strategy that can affect this.

4. Addressing adversity: linking cultural competence to health disparities

Over the past three decades, efforts to meaningfully address health disparities have largely focused on exhaustive characterization and definition of health disparities through multiple lenses – community, social, demographic, environmental, economic, race/ethnicity, gender, age, disabilities – with significantly less attention, until recently, to outcomes and effective interventions to reduce and/or alleviate them. In part this results from the complexity of developing and implementing interventions that can effectively and seamlessly leverage opportunities and traverse barriers within and between the health care system, provider, patient, academic and at large community components. The economic climate is forcing a 'lean thinking' approach to intervention development that focuses on innovative process and resource reallocation that will lead to measured and sustainable improvement in health outcomes. (Womack and Jones 2003) The Patient Protection and Affordable Care Act (PPACA Public Law 111-148), though imperfect and controversial, is an important first step in systemic funding to address health disparities. Furthermore, relevant outcome evaluation that goes beyond traditional metrics is central to development and assessment of effective interventions. Past naïve and archaic approaches focusing on one sector of the health care system, trusting that passive diffusion will decrease disparities throughout the entire system have failed. The health care crisis will continue to mandate an integrated, non-silo approach that meaningfully incorporates traditional (physicians, nurses, pharmacists, health educators) and emerging non-traditional (navigators, community health workers) into traditional and most importantly, non-traditional highly innovative and meaningfully integrate roles within the health care team and care delivery model.

4.1 Cultural competence: the devil is in the details

Culture, "the integration of patterns of human behavior that includes language, thoughts, communications, actions, customs, beliefs, values and institutions of different racial, ethnic, religious or social groups" is a powerful lens through which patients make virtually every health care decision. (Matthews-Juarez and Weinberg 2004) Cultural competence, "acquiring and integrating knowledge, awareness and skills about culture and cultural differences that enables Health Care Professionals to provide optimal care to patients from different racial ethnic and cultural backgrounds", a bidirectional requisite for oncology providers and their patients has been largely overlooked within the clinical continuum.

Treatment outcome starts with the patient's first encounter with the health care system. The quality of that encounter, distinct from customer service, significantly impacts the subsequent patient-provider relationship, ultimate partnership, adherence to treatment recommendations, quality of life during treatment and the survivorship continuum. Qualitative factors have an equal if not greater role than quantitative information in patient decision making. Therefore, the qualitative approach that the provider chooses to communicate the quantitative information is paramount. The provider must understand the culture through which the patient relates and understands information about medical and social aspects of the disease process and treatment.

Cultural nuances differ ethnically as well as geographically a factor which becomes especially important when dealing with populations in various phases of acculturation in a country or community. For example, in the United States, all phases of the patient-provider interaction center on the implicit understanding that the patient will make the ultimate treatment decision. In certain Hispanic cultures, the husband might make the ultimate decision while in Asian culture, the eldest son will be the decision maker. In African American culture, the children and spouse collectively drive the treatment decisions of the patient. Failure to address these decision makers through all phases of the patient encounter and decision making process will negatively impact on the overall quality of the provider-patient relationship and ultimately treatment compliance by creating an environment of mistrust and devaluing the patient and their support system.

Understanding how people from different cultures actually make treatment decisions is critical. In western culture, the process is linear- treatment discussion, research treatment options via internet/publications, analyze the data and reach a decision within a defined, usually short, timeframe. If the provider does not realize that the doctor's opinion rather than the research process may be the deciding factor for Hispanic patients, that the American Indian patient may want to discuss their condition with the tribal elders or healer, that African American patients may want to discuss their options with the family matriarch/patriarch and obtain *their* treatment decisions before informing the provider of the patient's treatment decision then the delay in treatment decision will not 'make sense'. Furthermore, the questions posed to the provider through the patient may in fact emanate from these other individuals. This can result in mismatched patient-provider expectations leading to miscommunication and narrow, biased interpretations of how 'capable' a given patient may be to 'understand' their treatment.

Subtle aspects of the patient encounter engagement process are important. African American patients expect direct eye contact as lack thereof conveys the message that the provider cannot be trusted. Conversely, Asian patients will avoid eye contact as direct eye contact is a sign of disrespect to the provider who is perceived, in that setting to have higher status. Conversely, listening to the provider's treatment discussion with closed eyes does not signify disinterest or information/emotional overload for the Japanese patient but indicates that the provider has the patient's full attention. Failing to directly address the husband of a Hispanic woman when making treatment recommendations is an insult to her husband. The importance of cultural competence in the provider patient partnership cannot be overstressed and is critical to effectively address health disparities.

4.2 Eliminating disparities and enhancing diversity in clinical trials

The improvement in health status in a community, region or country can be measured in many ways. Sir Michael Marmot, WHO Chair of the Commission on Social Determinants of Health, posits that the health care system accounts for about 20% of this.(Wilkinson and Marmot 2003) Improved health status is greatly impacted through social policy such as controlling access to tobacco or designing communities that provide conditions that support walking rather than dependence on mass transit. Such environmental interventions do not eliminate the need or benefit of required individual application or adoption of preventive behaviors such as smoking cessation, increased exercise, better dietary choices, or breast feeding.

However, when someone is diagnosed with a life threatening disease like cancer, it is no longer a question of how to prevent an occurrence; it is time to provide access to the best quality of care. For this, the process of informed decision making begins with their clinician, and what do they offer? What are they required to offer? Unfortunately, there is less participation in clinical trials and often the clinician's failure to provide information as a part of their care options is at the root of the problem. Yet there are many others in the cancer workforce that have an equally important role in guiding patients, supporting their decision making process, and helping them as participants if they choose to enter a clinical trial.

Clinical trials are a critical resource for developing new lifesaving drugs as well as better prevention, diagnostic, and treatment methods. However, numerous demographic groups are underrepresented in cancer clinical trials. These include racial and ethnic minorities, the elderly, women, children and adolescents, low income and uninsured individuals, rural residents, and individuals with disabilities.

There is no single reason why the evidence consistently demonstrates widespread disparities in clinical trial participation. Rather, multiple factors coalesce to produce a system that features such disparities. Accordingly, the Eliminating Disparities in Clinical Trials (EDICT) Project sought to model an approach that would not merely address individual contributing variables, but would instead analyze the problem and proposed solutions via a systematic, multi-level approach.(ICC 2009)

Each of the more than 300 EDICT participants represented one or more of the many stakeholders who encountered the multiple factors that produce underrepresentation in clinical trials. For example, concerns of scientific validity suggest that protocol design include, from the outset, recognition of patterns of disease burden and, where appropriate, reflect those patterns in recruitment and retention strategies. In addition, members of underrepresented populations consistently report mistrust of medical and research professionals, in contrast to local community healthcare workers, who are rarely involved with clinical research. Finally, the mistaken belief that appropriate representation in clinical trials requires larger expenditures in conducting the trial(s) justifies the unwarranted assumption that ameliorating disparities in clinical trials is cost-ineffective.

These examples demonstrate how the factors contributing to the problem of disparities in clinical trials operate at different levels, across different sectors, and involve different stakeholders. The primary initial result of the EDICT Project is the 33 Policy Recommendations. There are both data and theory strongly suggesting that if relevant

stakeholders implemented even a minority of the recommendations, disparities in clinical trials could be substantially reduced. Because of this complexity, eliminating disparities in clinical trials requires a multi-level systems approach and certainly one that requires the creation of a fully engaged and competent workforce. (Wilkinson and Marmot 2003; ICC 2009)

The EDICT Credo can serve as a framework for training and sustaining a workforce that ensures the appropriate inclusion of under-represented populations are ameliorated in the future. The following beliefs guide the work of the EDICT Project:

- All individuals will have the opportunity and necessary support to participate voluntarily in clinical trials for which they are eligible.
- Participants and researchers will understand and promote the benefits of diversity in clinical trials.
- Results from clinical research will benefit the participants' communities and society at large.(ICC 2009)

Creating such a workforce will require attention to barriers related to researchers, referring physicians, and the recruitment process itself. For example, racial/ethnic minorities are underrepresented among researchers. Community physicians are often unaware of clinical trial opportunities and experience excessive administrative or financial burden related to clinical trials. Additional barriers include lack of institutional interest, infrastructure, staff time, sufficiently skilled research coordinators, and training in culturally competent communication skills related to clinical trial recruitment.

A competent workforce should be capable of understanding frequent patient barriers to recruitment that are exacerbated for underrepresented groups. These barriers include poor understanding of the research and its related risk; transportation difficulties and caregiver availability; participant fatigue and inconvenience; general lack of awareness that clinical trials are an option; mistrust due to previous unethical research experiences; cultural, linguistic, and literacy issues; inadequate paid work leave, childcare, or insurance coverage; misidentification of race/ethnicity; and relocations, extended visits, or return to countries of origin.

While helping potential participants to "navigate" their way into, through, and after the clinical trial process is critical to improving inclusion of these groups in cancer research. The task is complicated by the fact that there are multiple professionals and paraprofessionals involved in recruitment and retention of participants in clinical trials at different points of contact along the continuum of cancer care. These include, but are not limited to, clinical researchers, research administrators, community health workers and promotoras, nurses, patient navigators, physicians who refer patients, physician assistants, and social workers to name a few.

The Department of Health and Human Services (DHHS) Office of Minority Health (OMH) developed National Standards for Culturally and Linguistically Appropriate Services (CLAS) in 2000. The CLAS-And Clinical Trials (CLAS-ACT) Project helps to assess how well CLAS Standards are implemented in a single clinical trial or study as well as across multiple trials in an organization. CLAS-ACT materials may also be used to train research staff and administrators about CLAS standards. These standards are a straightforward method to support taking one significant step in providing a cancer workforce in general but in

particular for those involved in clinical research they can be instrumental in bringing the research experience into a comparable position with overall access to health care services in general.

"Imagine that you possess an indicator for a disease or illness that has nothing to do with your body. It is not a genetic predisposition to acquire cancer or a vice that raises the probability of contracting some dread disease, though estimates of its health risks have placed it on par with having diabetes. It has nothing to do with the environmental pollutants you are exposed to or whether you can afford health care. It is not a physical susceptibility that renders you more easily reachable by the clutches of pathology. No, this indicator of health hinges on certain learned abilities and skills, and it is a barrier to health that is totally within the health field's power and resources to lift. The condition hinted at above is the inability to speak English proficiently in the United States."(Bustillos 2009)

Correcting for this will not be easy. Little data exists on issues such as this in the clinical research enterprise. What will be important is the ability to recognize that it will be both a combination of policy and programs that culminate in a competent corps of health care workers. Indeed as an evidence base is developed we must recall that those currently in the cancer workforce can make a significant step by striving for cultural competence. The nature of funding and conducting randomized clinical trial research is changing to reflect the evolution of the science base, the need to increase diversity among study participants, to establish trust among certain communities by acknowledging the need for social justice and health equity, and of course the globalization of drug development and emerging markets. In response, there are significant efforts underway to address the barriers to participation in clinical trials, which remain low.(Wilkinson and Marmot 2003)

The National Cancer Institute recently conducted research with oncology professionals that identified unmet accrual needs. As a result they have developed a comprehensive platform for accrual resources, AccrualNet.(NCI 2011) Their methodology used a variety of techniques including literature and resource searches to identify the content for the site. Certainly, as noted throughout EDICT's recommendations, designing interventions to support a broader the workforce must meet different barriers AccrualNet represents a unique, centralized comprehensive-solution platform to systematically capture accrual knowledge for all stages of a clinical trial. It is designed to foster a community of practice by encouraging users to share additional strategies, resources, and ideas.(NCI 2011)

For those who recognize the importance of clinical trials there is an opportunity to educate, encourage, and inform others. It is important to learn how to intervene with members of the cancer workforce who today have the ability to increase awareness about clinical trials and provide patients the opportunity to consider participation in a clinical trial. We need to make this part of our education and training of future workforce, if not, we are likely to have medicine's role in improving the quality of life diminish rather than flourish.

The lesson of EDICT is that there are many things that need our attention if we are truly to overcome the barriers to increasing participation in clinical trials. However, it is clear that if those (our cancer workforce) who can do something will, ultimately we will succeed.

5. Revitalization of cancer care: cancer competencies framework

Nearly all of the professional disciplines that play a role in the delivery of comprehensive cancer services are experiencing a shortage including physicians, nurses, social workers, pharmacists, public health workers, researchers, technologists, and cancer registrars. The rising incidence of cancer, an aging population, and an increased rate of cancer survivorship all predict an increased demand for health services. These trends threaten our ability to provide timely and comprehensive cancer care. Many cancer-focused organizations are investing in efforts to expand the number of cancer specialists in anticipation of a worsening cancer workforce crisis.

5.1 Building a cultural bridge through a competency-based approach

Complementing other national efforts focused on the recruitment and retention of oncology health professionals, C-Change pursued the Cancer Core Competency Initiative to develop standards and tools for strengthening the cancer knowledge and skills of non-oncology health professionals, including generalist and other non-oncology specialists. Defining the core competencies needed by all members of the health workforce represents one important approach toward expanding the cancer workforce (Figure 2). A multi-disciplinary panel of national leaders and experts developed competency standards spanning the continuum of cancer care, basic cancer science, and communication and collaboration. Implementation tools included a logic model and curriculum validation template.(C-Change 2008; Smith, Tyus et al. 2009)

<div align="center">

Continuum of Care
Prevention | Early Detection | Treatment | Survivorship | Palliative Care
Basic Cancer Science
Etiology | Epidemiology | Clinical Trials | Cancer Surveillance
Communications & Collaboration
Inter-disciplinary Care | Psychosocial Communication
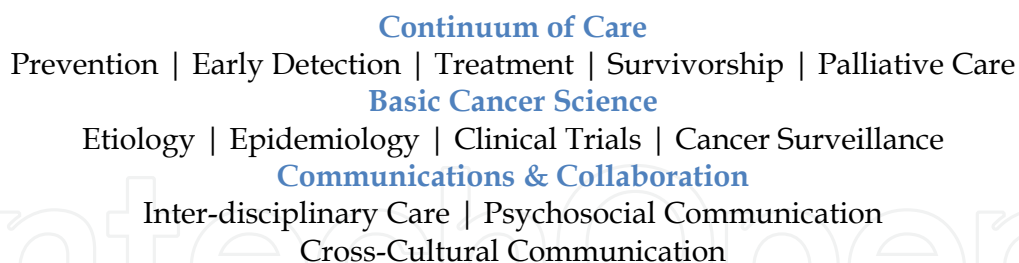Cross-Cultural Communication

</div>

Fig. 2. Scope of competency standards.

In an effort to test this approach, a grant program invited applicants from any academic, healthcare, cancer coalition, or voluntary/advocacy organization to apply the standards and tools to address a specific need in the professionals and, ultimately, the patients that they serve. Four grant-funded sites implemented the C-Change Cancer Core Competency Program in their organization by utilizing this rigorous set of competency standards, curriculum design tools, and evaluation methods to create their own programs. Each of the grant sites focused on a unique combination of a cancer topic, discipline, education/experience level, and practice setting.(C-Change 2008)

	Audrain Medical Center (MO)	Marshall University School of Medicine (WV)	University of Pittsburg Medical Center (PA)	California University of Pennsylvania (PA)
Cancer Topic	Skin cancer prevention and early detection	Breast cancer screening and patient communication	Survivorship	Cancer-related depression and anxiety
Healthcare Discipline	Nurses	Physicians	Physicians, Advanced Practice Nurses	Social Workers
Level of Education & Experience	Practicing professionals, Nurses, AD, BSN, MSN	Students, Year 2 Medical School	Practicing professionals, Masters	Graduate students, Practicing professionals/ field faculty, BSW, MSW
Practice Setting	Rural, Public health field workers	Academic training program	Urban/Rural, Primary care clinics	Rural, Social service agencies

Table 1. Scope of pilot site competency initiatives.

	Iowa Cancer Coalition (ICC)	University of Florida (UF)	Virginia Commonwealth University (VCU)	South Puget Intertribal Planning Agency (SPIPA)
Cancer Topic	Palliative and end-of-life care Hospice care	Pain and cancer-related symptoms and management resources	Pain management in pediatric patients	Culture-specific cancer pain
Healthcare discipline	Nurses, Medical Assistants	Physicians, Nurses, Social Workers, Office Staff	Medical Students, Pediatric Residents	Native Health Workers
Type / Level of education and experience	Practicing professionals AD, BSN Certificate	Practicing professionals MD, RN, MSW, Diploma	Students, Pre-Professional	Variable education and training as "lay" community health worker
Practice Setting	Rural long term care facilities	Rural health, primary care clinics (mostly Federally Qualified Health Centers)	Pediatric Clinic and Medical Center	Native American communities

Table 2. Scope of pain and palliative care grant site competency.

The pilot sites reported that the methods were flexible and useful when addressing various cancer topics, with a wide variety of disciplines, and within different organizational settings. Measureable gains in knowledge, skills, and attitudes were realized by all sites. In addition, all four pilot sites experienced benefits beyond those derived by the participant including positive effects such as professional development, institutional visibility, and community relations. A full description of the standards, tools, and pilot site results can be found at www.cancercorecompetency.org. (C-Change 2008)

As a continuation of this innovative program, C-Change invited grant applicants for a more focused purpose of strengthening the cancer pain and palliative care knowledge, skills, and attitudes of non-oncology health professionals. Program activities could focus on any relevant organization, discipline, or geographic area. This initiative was guided by a multidisciplinary, multi-sector advisory committee and managed by C-Change staff. Funding for the grant awards was provided through a generous donation from the Purdue Pharma L.P.

Through a collaborative process, four new grant sites worked with C-Change to plan and implement their programs. Again, the sites reported that the methods were flexible and useful when addressing various cancer topics, with a wide variety of disciplines, and within different organizational settings. Measurable gains in knowledge, skills, and attitudes were realized by all sites.

5.2 Cultural competency focus

One of the eight grant recipients, the South Puget Intertribal Planning Agency (SPIPA), indicated a specific cultural focus in meeting the needs of the population they serve. They recognized the need to understand cultural experiences and beliefs in order to equip health professionals with the most productive language, tools, and approach to reaching individuals at risk for and living with cancer.(C-Change 2010) The South Puget Intertribal Planning Agency (SPIPA), a Tribally-chartered nonprofit organization serves five Tribes, Chehalis, Nisqually, Shoalwater Bay, Skokomish, and Squaxin Island near Seattle, Washington. SPIPA's grant application described their aim to improve pain and palliative care management for community members.(C-Change 2010) They illustrated the existing cancer burden to their community in terms familiar to most health professionals:

"According to the Washington State Cancer Registry, American Indians/Alaska Natives (AI/ANs) have the highest incidence and mortality rate of cancer incidence of any racial group in our state[1]. Geographically the SPIPA service population is located in the area of Washington that has had higher than expected total cancer deaths for each year individually and for all years combined. For 2000-2004 combined, the relative risk (rr) was 1.14, or 14% more cancer deaths than expected; this equals about *290 excess deaths* per year. Survival is poorer in small rural towns compared to urban and large rural cities/towns. [2] The reservations served by the Tribal clinics are considered to serve rural populations; the majority is considered Health Professional Shortage Areas (HPSA)."(C-Change 2010)

5.3 Pre-assessment and program planning

The statistics alone were daunting, but as the planning process unfolded, cultural nuances emerged that made achieving their initial program goal more challenging. As part of the initial needs assessment process, the project leaders conducted a series of talking circles (focus groups) with each tribe. Initially, they gathered feedback that revealed some of the prevailing beliefs of the community, "[f]or Native Elders, pain is not discussed until it is severe, pain is believed to always accompany cancer, and it is not believed that it can be relieved, although traditional healers can help. Many have addiction concerns or concerns about being perceived as 'drug seekers'." This feedback was consistent with previous observations and reinforced the need to address myths in the competency training.(C-Change 2010)

Feedback that was not expected revealed a culturally-driven difference in basic vocabulary. The word "pain" had a different meaning to tribal members than what is typically understood to mean an unpleasant physical or emotional sensation occurring in varying degrees of severity as a consequence of injury or disease. The word "pain" meant historical trauma from past injustices experienced by Native Americans. Upon further inquiry, the term "discomfort" was a more accurate word for physical symptoms and the term "distress" was a more meaningful word for emotional symptoms. (C-Change 2010)

Initially, the program aimed to strengthen the competency of traditional western medical providers who serve the native community, but the need to empower native health workers with knowledge, skills, and tools to build a bridge between the patient and the medical provider emerged as a more strategic starting point.(C-Change 2010)

Project leaders refined the program goals and audience accordingly to: 1) Address community and patient understanding of cancer pain (distress and discomfort) assessment, communication and management of that distress and discomfort for survivors and caregivers in Native communities; 2) Improve communication and understanding about cancer pain, cancer related distress and discomfort, and palliative care, among Tribal members, their caregivers and the Tribal Health system by providing a common language; 3) Prepare a cadre of community members, targeting caregivers, at the local community level who will be community resources for cancer pain and can effectively provide peer level education within their communities and clinics; and 4) Empower Native people experiencing cancer pain to raise this quality-of-life issue with their health care providers.(C-Change 2010)

The competency goals set for participant included:

- Manage symptoms of the cancer pain, distress and discomfort / provide culturally appropriate tools for describing distress
- Describe the methods used to identify pain throughout the progression of the disease
- Differentiate between acute and chronic pain symptoms
- Perform pain assessment / train "Wellness Workers" (caregivers) on performing culturally tailored pain assessment
- Explain and explore the different treatment options for pain – including culturally appropriate as well as medical best practices
- Perform a pain related history taken during physical examination; teach patients how to document/ journal pain

Using a logic model, the program leaders designed an interactive workshop that would be delivered by trusted community members to an audience of community "Wellness Workers," caregivers, peer educators, and advocates as well as cancer patients and survivors. The objectives, inputs, outputs, outcomes (short-, medium-, and long-term), and impact are illustrated in Table 3.(C-Change 2010)

5.4 Workshop content and tools

The workshop content addressed the distinction between cancer discomfort, distress, and historical pain; the importance of treating pain as part of the healing process; myths about addiction; ways to communicate pain; and obstacles to seeking pain management in the

SPIPA
CCCP

Addressing Culture-Specific Pain Management: Creating a Common Ground between Community Members and Caregivers to Address Native American Cancer Pain and Palliative Care

Objectives/Aims:	Inputs	Outputs		Outcomes
Aim #1: Improve community and patient knowledge of cancer pain/distress assessment, communication and management for survivors and caregivers in Native communities, **Aim #2:** Improve ability to communicate about cancer pain, cancer related distress and palliative care between Tribal members, their caregivers and the Tribal Health system	**Course Materials:** Community input on curriculum (CCCP Advisory and Support groups) Unbroken Circle AI/AN Pain Mgt. Training **Presenters:** Oncology Nursing Association U. of Washington Traditional Healers **Other Assistance/resources:** Native People for Cancer Control **Communication Tools:** Community input on assessment tools Unbroken Circle assessment tools Cancer Pain Foundation resources SPIPA customized assessment tools	**Major Activities:** Formative Assessment of community needs Pre/post survey Training Curriculum Training Post assessment with support groups Final Report **Participation:** 25 AI/AN Wellness Workers AI/AN cancer pain training team, trainers and partners **Materials:** Cancer pain assessment tools collected and/or developed Digital stories as examples of communication	**AIM #1** **AIM #2** **AIM #1 and 2**	**Short term:** Improved knowledge of cancer related pain, discomfort and stress by AI/AN patients and caregivers Improved knowledge of treatment options for cancer pain and discomfort **Medium term:** Increased acceptance of cancer patients to work with health care team to address cancer related pain Culturally appropriate cancer pain assessment tools used by patient and caregivers to document pain Culturally appropriate mechanism for communicating cancer pain to health care providers implemented Improved communication about cancer pain between those with cancer and their caregivers **Long term:** Caregivers, patients & providers have improved core competency in culturally appropriate cancer pain assessment Curriculum, tools and resources available and used by other AI/AN communities to improve communication about cancer pain between patients, caregivers and providers

Impact:

AI/AN cancer patients are able to assess and communicate cancer related pain/distress to their caregiver and health care team

Every provider will ask the patient for their pain assessment checklist/journal

Table 3. SPIPA logic model.

health system. In preparation for the workshop, two important tools were developed, video segments of cancer survivors discussing their discomfort and distress and a pain journal. The videos were an important way to convey the patient experience with familiar community members and reinforced the importance of expressing, rather than suppressing, pain symptoms.

The pain journal was specially designed to provide a place for patients to record their symptoms and a tool to share their symptoms with their medical providers. The journal contains a variety of resources that prompt a patient to record onset, quality, intensity, duration, and the effect of relief interventions. The prompts included anatomical diagrams, vocabulary lists to describe the pain sensations, functional assessment of activities of daily living, and checklists to inventory other symptoms. In addition to addressing aspects of "discomfort," the journal also explored aspects of "distress" with functional and mood assessment tools.(C-Change 2010)

The CCCP (Comprehensive Cancer Control Program) Advisory Council made a specific recommendation to create a customized pain barometer, mirroring the classic Wong-Baker faces (Figure 3). They commissioned a local artist, Peter Boome, to create a culturally meaningful rendition of this scale using traditional Salish faces. The scale provided a more culturally familiar image and more direct connection to their pain experience. In a broader sense, the knowledge and tools for expressing pain provided in the workshop gave participants "permission" to talk about a subject that was not a cultural norm. (C-Change 2010)
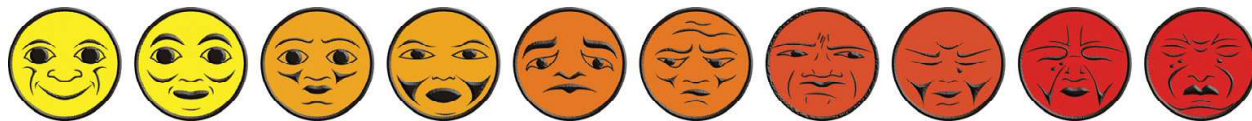

Fig. 3. Pain Barometer.

5.5 Evaluation methods and outcomes

Evaluation methods for the workshop training including a pre- and post-tests for participants, which included questions assessing perceptions, knowledge, and skills. The perception questions assessed changes in confidence in knowledge, ability to recognize distress and discomfort, and ability to communicate symptoms. Knowledge questions assessed definitions of types of discomfort and distress and common interventions to address these symptoms. Skills questions assessed the ability to report symptoms clearly and completely.

In total, 102 people participated in one of the five workshops held for each of the tribes. This represents approximately 3.5% of the combine populations of these communities. Confidence scores increased dramatically from pre- to post test, ranging from 129-233% change on individual questions. Knowledge and skills questions showed modest improvements averaging a 7.4% change. Upon further reflection, the program leaders recognized the role that the timing, format, and reading skills of the participants may have played in these results. During the workshop, the faculty used interactive verbal true/false questions to assess comprehension which anecdotally reflected a much stronger gain in knowledge and skills. When asked about the impact of the training experience, 68% of respondents were "very" or "extremely likely" to change their caregiving as a result of the

training. Eighty-seven percent were "very" or "extremely likely" to recommend the training to a friend.(C-Change 2010)

5.6 Conclusions

The impact of the workshop series has had a longer lasting and broader impact than expected. SPIPA has produced and distributed journals since the training within and beyond the SPIPA communities. In addition, they have received inquiries from other AI/AN communities interested in hosting a similar workshop. With these initial successes, they are turning back to their original goal of providing competency-based training for culturally appropriate pain management to western medical providers who serve the SPIPA community. The initial investment in the knowledge and skills of native healthcare workers and caregivers should provide an important cultural competency bridge for bringing patients and care providers together to improve patient outcomes

6. A roadmap towards culturally competent community based participatory cancer care

To date, health systems research has focused disproportionately more on health services research than community-based public health systems research. Likewise, funding for Community Based Participatory Research (CBPR) is orders of magnitude less than traditional biomedical research. In both instances failure to make progress is complex and advocating for one type of research over the other is counterproductive and may hurt rather than help strengthen the science base required to address cancer health disparities. Perhaps the most fundamental root cause of health disparities is infrastructure in general and the health infrastructure specifically: where you live indeed determines your health.

The three core components of the health infrastructure- workforce, organizational setting, and health system capacity- directly influence a community's health status. Overlaying this already complex relationship is the need to deliver culturally competent care to in our case communities with a historic burden of cancer health disparities. Figure 4 presents a multidimensional framework depicting the relationship among the three core components in the context of delivering culturally competent cancer care.

The most important perquisite for successful culturally competent care is the collaboration and active participation of the community. Rather than focusing on a community's needs only, asset-driven participation fulfills a pivotal role to inform the development of a culturally competent cancer care workforce on one hand and to embed community assets as an important component of the health system capacity portfolio on the other. Reciprocally, neighborhood community health centers can embed culturally competent care and serve as an anchor of community sustainability. This enriched portfolio can also form the nurturing professional workplace setting of a culturally competent health workforce. In turn, this workforce can also stimulate transformation leading to a better functioning culturally competent health system. This framework also allows for cultural *targeting*—focusing on a culturally-specific population—as well as culturally *tailoring* a health intervention or program to maximize community benefits. This conceptual framework goes beyond the role of cultural leverage in interventions to allow for assessing not only the impact of a health action or intervention as a silo effort; rather it operationalizes the three core components as

one interconnected health system: the community as health seeking beneficiaries, the health workforce as providers of culturally competent care, and the health system as the locus of health services within communities.(Fisher, Burnet et al. 2007) This interconnected system will facilitate what has eluded many cancer health disparities scientists to date: transforming impact ascertainment of health intervention from behavioral outcomes to functional health status. This paradigm shift will result in targeting the community rather than the individual to benchmark impact.
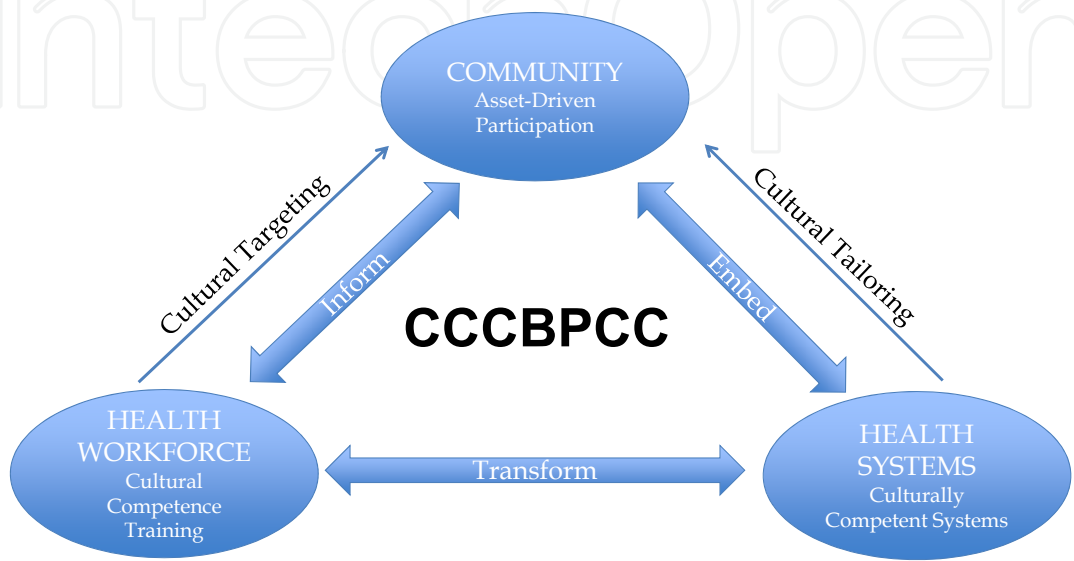
Fig. 4. Culturally competent community based participatory cancer care.

6.1 Creating a culturally competent cancer care workforce: forces of change and opportunities

Among the plethora of challenges are three forces of change directly affecting developing a cadre of culturally competent cancer care providers: the new primary care practice, the rapidly changing demographics, and cancer as a global chronic disease burden. The "new" primary care practice represents a "back to the future" phenomenon in some instances- the primary care physician's role becomes one of a communicator who empowers, informs, and engages patients in their care.(Fiscella and Epstein 2008) Team-based care requires skills in leadership, management, and coordination and a medical home as a one stop health care shop. Among the projected cancer care beneficiaries are two synergistic socio-demographic trends: an increase of minority populations, and a widening of the disparities gap, despite current, yet insufficient   investments in research.(Hobbs and Stoops 2002) For over a decade, the relationship between cultural competence and health disparities has been well documented.(Brach and Fraser 2000; Betancourt, Green et al. 2003; Goode, Dunne et al. October 2006)   Increasingly, developing nations are faced with diseases of the "developed world" and resource limitations rendering many such governments incapable of caring for their people. For example, cancer is the third leading cause of mortality in the Caribbean Region surpassed only by cerebro- and cardiovascular disease.(Phillips, Jacobson et al. 2007) Approximately 50% of cancer mortality occurs in developing countries and 60 to 70% of new cases are projected in those countries by 2020 (Jones et al 2006). In the case of cancer,

developing nations lack the resources to provide even the basic components of the cancer care continuum including screening mammography and radiation therapy. While there is a growing visibility regarding each of these three forces of change no comprehensive effort to derive community-based solutions has been undertaken to date.

From a health workforce perspective, efforts to counteract these forces have largely amounted to a number of training courses targeting practicing health care providers, "special" courses or lectures on cultural competence for those still in the pipeline, and research efforts which often last only until the end of the funding period. Exemplary exceptions targeting the practicing health workforce such as the cancer care competency case studies from C-Change are included in this chapter. The Interprofessional Education Collaborative spearheaded by the Association of American Medical Colleges (AAMC), and consisting of the Association of Schools of Public Health, American Association of Colleges of Nursing, American Association of Colleges of Osteopathic Medicine, American Association of Colleges of Pharmacy, American Dental Education Association has recently published a transdisciplinary competency model to guide the education of the represented disciplines with the desired outcome of more holistic frontline practice.(IPEC 2011) This signals an increasing realization that discipline-specific graduates may not adequately perform on today's practice frontline. A more persistent demand is coming from the increasingly culturally diverse consumers of graduate health education: the " is there and app for this" generation is not only calling for a change in instructional delivery, but is also more in tune with its future customers and the global health threats facing them.

6.2 A core set of cultural competencies for medicine and public health

AAMC and ASPH are engaged in a collaborative partnership to develop a set of core cultural competencies appropriate for medical-, public health students and those in other health-related educational institutions to bolster the delivery of health care services especially to underserved, diverse populations.(Lichtveld 2010) The overarching aims of the initiative were: to illustrate cultural competence as an effective cross over topic area for students in both academic medicine and public health; to demonstrate how cultural competence can advance health disparities research in medical and public health education; and to provided most needed examples of how to incorporate cultural competencies into curricula and practica to graduate more culturally competent practitioners. There are several unique features to this joint effort: there is full agreement from both organizations that the emphasis should be on embedding cultural knowledge, skills, and attitudes medicine and public health education and practice rather than creating separate, standalone courses; The explicit anticipated outcome is a patient-centered approach in a community setting embracing both the customers of medicine and public health in a holistic fashion; the competencies were designed deliberately broad to not only allow for integration and tailoring within the scope of practice but also support pedagogical approaches accommodating the progressive stages of learning. Therefore, the competency set is not intended to be implemented in its entirety giving schools of medicine and public health flexibility in application while providing benchmarks of learning performance.

The competencies are categorized in three domains: knowledge- focusing on educational learning outcomes-, skills- representing practice competencies-, and attitudes. Included in the competency set are bridging competencies, logically linking one domain to the other,

	KNOWLEDGE	SKILLS	ATTITUDES
At the completion of the program of study, (medical and public health) students will be able to	Define the dimensions of culture to include language, sexual orientation, gender, age, race, ethnicity, disability, beliefs, socio-economic status, and educational attainment.	Identify one's own assets and learning needs related to cultural competence.	Demonstrate willingness to apply the principles of cultural competence.
	Differentiate health, health care, health care systems, and health disparities,	Incorporate culture as a key component of patient, family, and community history.	Appreciate how cultural competence contributes to the practice of medicine and public health.
	Identify cultural factors that contribute to overall health and wellness.	Integrate patients/ families/ communities cultural perspective(s) in developing treatment/ interventions.	Appreciate that becoming culturally competent involves life-long learning.
	Describe the contributions of culture and resiliency to positive health outcomes.	Apply (community) constituent/ patient -centered principles to earn trust and credibility.	Demonstrate willingness to assess the impact of one's own culture, assumptions, stereotypes, and biases on the ability to provide culturally competent care and service.
	Examine factors that contribute to health disparities, particularly social, economic, environmental, health systems, and access.	Conduct culturally appropriate risk and asset assessment, management, and communication with patients and populations.	Demonstrate willingness to explore cultural elements and aspects that influence decision making by patients, self, and colleagues.
	Identify health disparities that exist at the local, state, regional, national and global level.	Contribute to the planning, implementation, and evaluation of culturally competent interventions.	Demonstrate willingness to collaborate to overcome linguistic and literacy challenges in the clinical and community encounter (note— this could be an example of a bridging comp).
	Recognize that cultural competence alone does not address health care disparities.	Communicate in a culturally competent manner with patients, families, and communities.	Appreciate the influence of institutional culture on learning content, style, and opportunities of professional training programs.
	Describe the elements of effective communication with patients, families, communities, peers and colleagues.	Employ self-reflection to evaluate the impact of one's practice.	
	Describe strategies to communicate with limited English proficient patients and communities, such as working with trained medical interpreters or translated materials.	Work effectively in a trans-disciplinary setting/team.	
	Describe the role of community engagement in healthcare and wellness.	Demonstrate shared decision-making.	
	Assess the impact of acculturation and immigration on healthcare and wellness.	Analyze illness conditions and health outcomes of concern at the patient and community level.	
	Articulate cultural humility, cultural diversity, and cultural competence and their roles in ongoing professional development.	Engage community partners in actions which promote a healthy environment and healthy behaviors.	
	Describe the values and limitations of evidence-based literature on understanding the health of individuals and communities	Communicate with colleagues, patients, families, and communities about health disparities and health care disparities.	
	Articulate the roles and functions of local health departments, community partners and organizations.	Establish equitable partnerships with local health departments, faith and community-based organizations, and leaders to develop culturally appropriate outreach and interventions.	

Table 4. Cultural competencies for students in medicine and public health.

often incorporating more than one domain. For example, a student's ability to "describe the elements of effective communication with patients, families, communities, peers and colleagues" requires both attaining the requisite knowledge as well as demonstrating the skill to successfully implement the role of communicator. In the context of cancer diagnosis and treatment, patient-physician communication can profoundly influence decision-making and consequently health outcome (Smith, Lichtveld, 2007). For example, recognizing cultural beliefs and practices guides health care providers to negotiate rather than demand a given course of treatment. Successful patient –physician encounters require both interpersonal- as well as instrumental communication (Manfredi et al 2010). Therefore, while *knowledge* about aspects of interpersonal communication such as respect will help make a patient feel more comfortable with the physician, instrumental communication is the dimension which most influences a patient's decision-making regarding cancer treatment for example—emphasizing a demonstration of effective communication *skill*s.

A series of transdisciplinary case studies currently in development will accompany the competencies listed below in Table 4 to demonstrate the translation into learner level-specific educational modalities.

7. Applications in the field

Patient navigation is an emerging component of the cancer care delivery team and system that offers an innovative solution to decrease cancer health disparities by bridging the chasm between access to and optimal utilization of services through sustainable and culturally relevant mechanisms. Embedding cultural competence in medical education has been a long-standing objective, reinforced by the painful disparity in outcomes that perpetuate excess morbidity and mortality among underserved minority populations (Betancourt 2003; Smedley, Stith et al. 2003; Betancourt 2006; Betancourt 2006). This section will discuss the role of culturally competent patient navigation and cultural competence training in the era of health reform.

7.1 Navigation

There is perhaps no other area in health care in which active patient participation through screening, diagnosis and treatment phases is as important as in cancer care. Cancer treatment is multidisciplinary (radiation, chemotherapy, surgery) and requires the patient, in equal partnership with the oncology provider, to make complex treatment decisions and participation in clinical trials - decisions that can impact survival. Cancer centers are highly specialized and therefore quite distinct from the broadly focused community based medicine environment. Primary care practitioners may be reluctant to actively engage oncology team physicians due to unfamiliarity with cancer treatment approaches, protocols and successful cancer center navigation and therefore unable to provide needed support. Navigators can bridge the gap in cultural competence, health care access and coordination, insurance coverage and continuity, prevention and early detection and treatment.

For patients, the navigator operates in two environments- health care system and caring companion and provides "insider" information about system access and navigation and

advocacy while simultaneously building trust that will extend to the larger health care system. Navigators who are representative community members who understand the culture in the patient and provider communities and function within a biopsychosocial theoretical framework (Engel 1977; King, Miranda et al. 2010) are critical in facilitating effective bidirectional patient provider communication and, most importantly, treatment *partnership.*(Carroll, Lardiere et al. 2010)

Patient perception of health care system and services access directly correlate with utilization. Navigators who know the local environment can navigate financial/insurance issues, cultural beliefs and language barriers, childcare and transportation issues, identification of a medical home and provide the necessary patient education and support to assure healthcare access and continuity of care. (Dohan and Schrag 2005) Utilization of screening and early detection has improved but remains problematic in rural and minority populations. This is the point within the health care delivery system at which the navigator can have the highest, sustainable community impact. Patient navigation is critical within the Federally Qualified Health Centers which provide services to high needs populations. Navigators connect patients with education, outreach, screening, diagnosis and treatment resources and provide advice tailored to individual patient needs. Studies to evaluate navigation effectiveness are underway.

7.1.1 Evaluating navigation effectiveness

Navigation has improved survival via detection of early stage disease, better follow-up of abnormal screening and diagnostic tests through reduction in the time interval between tests, improved utilization and treatment adherence to multidisciplinary cancer treatment regimens and clinical trial participation. Navigation has also resulted in improved patient satisfaction with respect to health care delivery, decreased anxiety as well as doctor and waiting time concerns. (Guadagnolo, Dohan et al. 2011) Patient outcome evaluation is critical for assessing the effectiveness of navigation. Most efforts have targeted screening and diagnosis aspects of cancer care i.e. number of people served, screening tests and biopsies performed, cancers diagnosed etc. However, identification of successful navigation strategies that result in *sustained* improvements in access, utilization and health behaviors, requires the identification and utilization of tailored metrics that better qualitatively and quantitatively evaluate quality of care from the system, provider and patient perspectives. Candidate treatment tracking metrics include receipt of appropriate radiation and/or adjuvant chemotherapy after cancer surgery, guideline concordant treatment rates and adherence to treatment regimens, care coordination (provider notification, discussion at multidisciplinary tumor conference, receipt and type of ancillary services, medication and devices. Patient reported care metrics could include satisfaction with cancer related care and navigation, functional health status and symptom burden, coping skills and co-morbidity, quality of life during treatment and palliative care.

7.1.2 Financing navigation

The Patient Protection and Affordable Care Act (PPACA) addressed 4 key issues: prevention and early detection, access and coordination, insurance coverage and continuity and diversity and cultural competency. The PPACA provided infrastructure development

support through grant funding to establish medical homes for Medicaid patients with chronic diseases, community based, interdisciplinary teams to provide support services to primary care practices and health care provider consortiums to coordinate and integrate health care services for low income under- and uninsured populations which collectively will enable comprehensive, multidisciplinary case management. Navigator integration into the PPACA infrastructure will create sustainable changes in the health care system and promote health behavior modification. Most importantly, it establishes a matrix structured platform that will reward innovation in streamlining health care delivery, promote the development of fiscally accountable and efficient health care delivery and in the mid and long term the resurrecting a "healthy America".

7.2 Embedding cultural competence in cancer care education

Substantive training relevant to culturally competent communication in schools of medicine, nursing, dentistry, public health and social work has been an elusive goal, awaiting, perhaps, consensus agreement on competencies as a framework upon which to build an evidence based curriculum (Beach, Price et al. 2005; Lichtveld, Boulton et al. 2008) Yet, health care preparation in all disciplines acknowledges and emphasizes shared decision making as the effective method by which patients receive the best care and, long term, the best outcomes (O'Connor, Wennberg et al. 2007; King, Eckman et al. 2011) Why then is there a reluctance to launch curricula in cultural competence – a fundamental component of communication aimed at shared decision making?

It is generally acknowledged that the effectiveness of health care provider communication is dependent on the health literacy of the patient and the ability of the provider to a.) recognize the level of health literacy and b.) tailor the communication appropriately (Dewalt, Berkman et al. 2004; Weiss, May et al. 2005) There are well-established health literacy tools to guide providers in tailoring communication. Understanding health literacy and the tools available for assessment is a key element to successful training in cultural competency (Shaw, Huebner et al. 2009)   Moreover, knowledge of health literacy and its importance in achieving the level of communication that results in shared decision making is a "prerequisite" for embracing cultural competence. A recent study by Price-Haywood, et al. (2010) combined the evaluation of special physician training by a measure of effectiveness – cancer screening behavior – in patients stratified by their health literacy score. (Price-Haywood, Roth et al. 2010). The model was colon cancer screening, a preventive behavior that is an excellent paradigm for shared decision making since there are several acceptable options for screening. The physician training based on attention to health literacy alone was successful measured by surrogate-reported progressive change in physician behavior and communication during the study period. An important finding, however, was that the low health literacy patients did not feel satisfied with the communication of risk reduction with screening, though the "trained" physicians rated their communication as effective (Price-Haywood, Harden-Barrios et al. 2011) Moreover, the early results demonstrate that patient screening behavior among the low health literacy patients had not changed at 1 year of follow-up. The investigators acknowledge the need to enrich the physician training based on the racial, ethnic, and cultural characteristics of the patient population.

The lack of linkage between training in communication and positive changes in patient outcomes seems to plague educators, psychologists, and health service researchers

(Betancourt 2010; Lie, Lee-Rey et al. 2011) Ineffective curricula, as measured by positive changes in health outcome, thus far appear to be common to both health literacy and cultural competence training. Despite academic "longing", there has not been evidence based tools that can guide health care workers to influence health behavior in a manner that improves outcomes. The literature is rife with "assessments", but outcome thus far belies success.

Nevertheless, some ongoing efforts are encouraging. Lichtveld and colleagues are planning to build a curriculum based on healthcare provider competencies. The 'competencies' will provide the metrics to measure the didactic effectiveness of the curriculum. A second order of assessment will determine linkage between health outcomes and provider/learner achievement. Price-Haywood proposes a physician practice guide and didactic curriculum built on self-expressed needs and expectations of the target population obtained through analysis of information obtained from focus groups of various health literacy.

What is most encouraging is the movement from assessment to plans for action and measurement of health outcomes. (Chun 2010; Echeverri, Brookover et al. 2010; Kamaka 2010; Wilkerson, Fung et al. 2010; Crenshaw, Shewchuk et al. 2011) These evolving tools will enrich the health care provider and enhance the relationship between diverse patients and the health care system. The next five years should be exciting as these tools, guides, and curricula emerge. Today, however, health care providers remain confronted by their ineffectiveness in normalizing the disparate outcomes and their impotence in fostering better health behaviors among their patients. What can the 2012 graduate from medical school, dental school, nursing school, pharmacy school and school of public health do to optimize communication and shared decision making? (Kumagai and Lypson 2009) As we enter the era of "team care" the challenge intensifies because responsibility may become diffuse. The team leader should be the primary care giver with the appropriate knowledge base. The team leader should assess and define the patient's knowledge base and then – and only then – involve the appropriate team members to work with the patient. The team leader should begin by asking the patient to ask any questions and to speak his understanding of his condition and the advice he has received. Often, the patient is or should be accompanied by family or friends who will play an important role in the shared decision making. These principles are fundamental to all courses teaching history, physical examination, and medical decision making. Our professional schools should reinforce the fundamental didactics while preparing for the enhancements which will come from ongoing research into more effective, more focused communication and more elegant science that will combine to contribute to the elimination of outcome disparity.

8. Acknowledgement

About C-Change: The vision/mission of C-Change is to eliminate cancer as a major public health problem at the earliest possible time by leveraging the expertise and resources of its members. C-Change is a 501(c)3 organization comprised of leaders from public, private, and not-for-profit organizations. The organization convenes multi-sector leaders in the cancer community to address issues that we cannot affect alone. For more information about C-Change visit www.c-changetogether.org.

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