Health disparities in cancer care: Exploring Canadian, American and international perspectives

CANO/ACIO's vision is to be "a driving force nationally and an influencing force internationally in advancing excellence in cancer nursing across the cancer control spectrum." We want to see "Canadians across the cancer spectrum have timely access to high quality nursing" (CANO/ACIO, p. 8*). With this end in view, a panel of experts came together to explore health inequities in cancer care from a variety of national and international perspectives at the 25th Annual CANO/ACIO conference, held in Vancouver in October 2013. Represented on the panel were experts in health disparities research (Dr. Colleen Varcoe and Dr. Christina Sinding), past presidents of the Oncology Nursing Society (ONS) (Dr. Mary Gullatte) and the International Society of Nurses in Cancer Care (ISNCC) (Dr. Greta Cummings), and leadership from the Canadian Partnership Against Cancer (CPAC) (Dr. Margaret Fitch). Oncology nurses are uniquely positioned to positively influence health equity in cancer care at national and international levels. What follows are summaries of the panelists' presentations.

Health disparities in cancer care: Foundational concepts

by Dr. Colleen Varcoe, RN, PhD
(with Dr. Sanzida Habib, PhD)

It is exciting to see nurses in cancer care increasing their attention to health equity and social justice. Such concerns have not dominated research and practice in relation to cancer; perhaps, in part, because cancer carries less social stigma than health issues where equity concerns are foregrounded such as mental health problems, violence or HIV (with exceptions such as lung cancer in people who smoke). Cancer nurses are amplifying their attention to health inequities (or disparities) at a time when understanding of the foundational concepts is becoming increasingly robust. The purpose of this introduction is to review the concepts foundational to integrating health inequities in health research and practice and to consider their specific relevance to cancer care.

The terms '*disparities*' and '*inequities*' are often used interchangeably and both must be distinguished from inequalities. 'Inequality' is a broad term referring to differences between groups, whether or not they are unfair. Inequities or disparities refers to differences that are a) unfair and, thus, morally concerning, b) caused by social arrangements, and c) potentially remedial (Whitehead & Dahlgren, 2006).

This understanding of inequities is founded on a critical conception of *social justice*, which differs from the idea of distributive justice underpinning much of western thinking in health care ethics, research, and practice. Distributive justice focuses on *fair allocation of resources* in society (Hoedemaekkers & Dekkers, 2003). Distributive justice begins by considering the available resources in a society, and evaluates how they are distributed among groups. Importantly, in health care, distributive justice draws attention to fairness in health care access. In contrast, social justice begins with understanding *differences between subgroups, particularly power,* and highlights the *structural conditions that shape inequities* (Young, 1990, 2001). For example, considering prevention of breast or cervical cancer from a distributive justice perspective draws attention to the number of practitioners, screening, treatment and laboratory facilities, and how they are distributed. A social justice perspective considers how particular sub/groups are positioned differently and how such positioning shapes health care access and health outcomes.

Social justice begins with the *social* rather than the goods to be distributed. As Kirkham and Browne (2006) explain, "...while justice has to do with fairness *social* draws our attention to the application of justice to social groups, [and] brings into focus how justice and injustices are sustained through social institutions, and social relationships; and highlights the embeddedness of individual experience in a larger realm of political, economic, cultural, and social complexities" (p. 325). Using a social justice perspective broadens understanding of health care access and, as Figure 1 suggests, draws attention beyond fairness in health care access, to health outcomes and access to the social determinants of health and the social determinants of inequities. In cancer care, a social justice perspective draws attention to how cancer risk and outcomes are shaped by social determinants of health and inequities. So, for example, from a social justice perspective, differences in smoking patterns between subgroups are understood to be shaped by power relations along the lines of age, gender, occupation, ability, racism, colonial relations, and poverty.

Research and practice from a social justice perspective require attention to the social determinants of health and inequities. Studying the problem of poorer access to breast
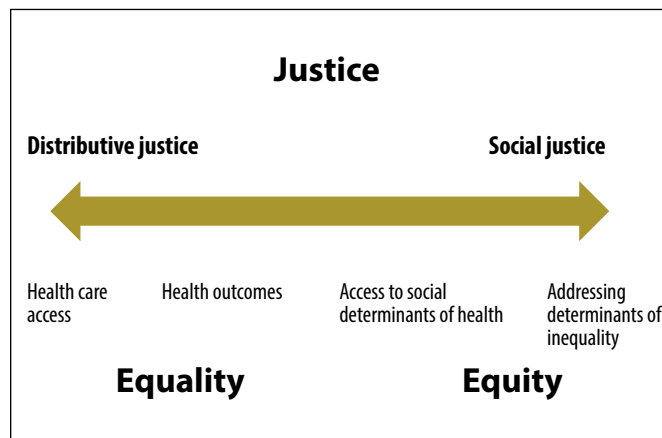

Figure 1: Equity, equality and justice in health care

and cervical cancer screening for South Asian women, Habib (2011) looked beyond the focus on women's knowledge or language barriers that typically are used to explain both poorer access to preventive services and poorer health outcomes. She found that access to cancer screening and other health care services was shaped by intersecting dynamics including gender roles and norms, category of immigration admission to Canada, age, financial in/stability, education level and English language skills, access to income, settlement services and other resources. She drew attention to how *unfair social arrangements* related to race, class and immigration status intersect with gender in diverse and complex ways in the material and everyday lives of South Asian women to put them in racialized and disadvantaged situations as the 'other' where access to preventive cancer screening becomes especially challenging.

The concepts of social justice and health inequities/disparities are complemented effectively by two other concepts: intersectionality, and structural violence. *Intersectionality* offers a critique of the primacy of *any* social category (such as race, class, gender, ability, size, geography), and draws attention to how power relations along these dimensions are inseparable (Hankivsky & Christoffersen, 2008; Varcoe, Pauly, Laliberte, & MacPherson, 2011). Intersectionality views these categories and systems as simultaneously co-constructed at both macro (social institutions) and micro (individual identities) levels

(Weber & Parra-Medina, 2003). It places an explicit focus on differences among, as well as within groups and seeks to illuminate interacting social factors that affect human lives, including social locations, health status, and quality of life (Hankivsky et al., 2010). *Structural violence* refers to harmful social arrangements that serve the interests of the powerful and are embedded in political and economic organizations, such as extreme and relative poverty, racism and gender discrimination that result in violations of human rights (Farmer, 2003). Together, these ideas shift analyses from an emphasis on group membership to emphasis on marginalizing conditions (e.g., from 'race' to 'racism'). Thus, for example, rather than looking for explanations of differential cancer care outcomes in South Asian *women*, explanations are sought in the effects of social and organizational arrangements related to gender, migration, racism, and so on.

Solutions to health problems from a social justice perspective are 'upstream'. That is, when the complex intersections among social arrangements are seen to be at the root of health problems, then those arrangements must be addressed. Rather than assuming that lack of understanding or language barriers explain differential access to cancer screening, and producing more cancer screening brochures in diverse languages, a social justice perspective guides health care providers to address structural factors such as systemic racism in health care.

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Disparities in cancer care

by Dr. Christina Sinding, PhD

Some researchers argue that the best way to address cancer disparities is to address social disparities—to address the 'upstream' structural factors, as Dr. Colleen Varcoe (this issue) describes them. Many studies show that income, education, age, gender, ethnicity, and place of residence are linked

with cancer survival. Stage of the disease matters in this association—people who receive care when their cancers are more advanced do not, on the whole, do as well, and people who are disadvantaged in social terms often have their cancers diagnosed later than their more advantaged counterparts.

Some researchers argue, then, that the best way to address cancer disparities is to address social disparities. Equity-promoting initiatives like Living Wage Campaigns are underway in many cities across the country and merit support, as do

efforts to improve transfer payments that moderate inequality between rich and poor, between men and women, and between white people and people who are racialized (Stanford, 2008). Occupational links to cancer are also considered relevant to cancer disparities. Research in the Windsor area has shown, for example, an elevated risk for breast cancer among women working in farming, automotive plastics, and food canning (Brophy et al., 2012). Oncology nurses interested in these issues can watch the compelling documentary by ecologist and cancer survivor Sandra Steingraber called *Living Downstream* (Steingraber, 2014).

While we are contributing our voices to these broader issues, we must also work on transforming the health care system, because cancer disparities do not occur just when some people's cancers are more advanced when they are diagnosed. A review of dozens of articles confirms that at least part of the association between social deprivation and cancer survival is due to "differences in access to optimal treatment" (Woods, Rachet, & Coleman, 2006, p. 16). The black box question is why: why do people who are disadvantaged in socioeconomic terms receive optimal treatment less often than their more advantaged peers in the cancer centre waiting room?

Some of the explanations are relatively straightforward. The out-of-pocket costs for cancer care can be considerable. Transportation costs, for example, add up quickly. A qualitative study with women living on low incomes found that some skipped treatments because they could not afford to travel to the cancer centre, or could not afford the cost of anti-nausea drugs (Gould, 2004). Various programs offset cancer costs, but people with cancer do not always know about them, and costs remain for the patient.

Concerns about managing at home during treatment are also relevant. In a study with women diagnosed with cancer in their 70s and 80s, some women chose not to have recommended treatments (Sinding & Wiernikowski, 2009). Irene explained her decision this way:

> *Quality of life with chemo didn't appeal to me at all. I live alone, I like it and I know many people who have gone through it and depended on whoever's handy … I know my hairdresser told me about her friend and how his children abandoned him and he, of course, didn't have much to eat even (p. 626).*

When Irene was making decisions about treatment she was taking into account the kind of support she could expect at home. Her decision to forego chemotherapy, while at some level a personal one, occurs within a broader context: over the last several years public funds for homecare (and the scope of what's funded) have been eroded (Aronson & Neysmith, 2001). Social workers at cancer centres help patients identify and mobilize formal and informal supports at home but, again, patients are not always referred to supportive care, and community resources are not always adequate.

Another explanation for disparities in cancer treatment has to do with the idea that certain groups of patients are "passive," that they participate less actively in their health care or are less active in seeking information or asking for health care resources. This is a theory that begs the question: do we require patients to act in a particular manner in order to receive health care? It seems absurd, but this message appears more and more frequently. Pamphlets in waiting rooms and websites encourage people with cancer to collect copies of their health records and reports, track their test results, call to follow up on appointments, and know what symptoms merit attention and from whom. The message to patients is that they must 'be active', they must 'take charge' if they are to receive the care they need.

This is a problem for people with cancer, and it is also a problem for equity. Our research team interviewed women with breast cancer at both ends of the socioeconomic spectrum, looking carefully at the work they did in relation to the processes, timelines, and quality of care. We found that some women appeared to realize the promise of 'patient empowerment:' they told stories of achieving more, better and faster care through their own actions. And yet, as we examined these stories, we traced consistent links between this sort of 'successful' involvement, and particular capacities and resources: ease in speaking English, material resources, knowledge of the health care system and medical knowledge, experience and confidence negotiating institutions, and professional work roles (Sinding, Miller, Hudak, Keller-Olaman, & Sussman, 2012). Simply put, more privileged patients can more easily work the system to get what they need. This would not matter so much if health professionals were well able to provide the care coordination and monitoring that we should be able to expect from them. But when professionals are stretched and not attending specifically to quality of care that the most marginalized patients are receiving, disparities can emerge.

Disparities occur for other reasons, as well. In a recent study (Sinding et al., 2013), social workers were interviewed about their experiences working with people who had a diagnosis of serious mental illness, as well as cancer. In several situations, the mental illness diagnosis—the label on a chart—meant that health care teams failed to recognize symptoms that later turned out to be cancer. One social worker spoke about a patient who was 'written off' by her family doctor as depressed, her longstanding physical symptoms (later diagnosed as advanced cancer) not investigated. Another described a situation in which specific physical symptoms were attributed to the mental health disability (the patient in this case had a brain tumour). A patient in persistent pain was dismissed as an addict and did not receive the medication that the social worker we interviewed knew she needed.

'Diagnostic overshadowing' is the term that describes situations in which health care providers attribute an individual's account of symptoms to her or his mental illness diagnosis and, thus, overlook or dismiss important health problems. And while there is evidence of 'diagnostic overshadowing' in cancer care, it is also the case that health care teams actively work to make receiving cancer treatment possible for patients, consulting with the patients' other health care providers and working to ease patients' fears, often by involving someone the patient trusts in the process. One article described how an oncology team accompanied people who were especially afraid of

radiation (because of their life circumstances or certain impairments) through the treatment area to familiarize them with the space and discuss their concerns, such that fear could be eased and taking treatment became possible (Howard et al., 2010).

Health providers can (and often do) intervene in the processes by which health care disparities come about. They often find ways to genuinely welcome all kinds of people with cancer into care settings, to level the playing field regarding care access, and to challenge the all-too-common practices of exclusion. With the support of health system administrators and explicit institutional commitments to equity, oncology nurses play a vital role in ensuring that differences between people do not result in disparities in cancer care.

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Health disparities in cancer care: A Canadian perspective

by Dr. Margaret Fitch, RN, PhD
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The Canadian Partnership Against Cancer is a **partnership** of cancer experts, charitable organizations, governments, patients, and survivors, determined to bring change to the cancer control domain. The primary focus of the Partnership is on the implementation of best available knowledge about cancer control across Canada.

The Cancer Journey Action Group had the mandate of providing leadership to change the focus of cancer care, so that patients' and families' needs are better served. We wanted to optimize quality and access, thus enhancing the quality of life for those affected by cancer and improving the cancer experience for Canadians. We focused on embedding a person-centred approach within cancer control. This approach means providing care that is respectful of, and responsive to individual preferences, needs and values; and ensuring those values guide all clinical decisions. It means consciously adopting the person's perspective about what is important and what matters to that individual, and working **with** individuals rather than doing things to or for them.

Several reports commissioned by the Cancer Journey Action Group speak to the issue of disparities in cancer. Each will be highlighted below.

1) Providing culturally competent supportive care for underserved populations

This literature review of best practices in supportive care for underserved populations identified many gaps in care provision and areas in need of further study. Interventions were identified as effective (patient navigation, community outreach, and remote cancer support groups) and potentially effective (face-to-face support groups, internet-based support groups, 1-1 peer support groups and counselling, E-health platforms, and sports teams/recreational competitive events) in the delivery of culturally competent care. Understudied interventions included spiritual and palliative care in underserved populations.

The report outlined the essential elements in culturally sensitive programs: information provided in culturally appropriate ways/attention to literacy level, tailoring of messages to populations, recognizing spiritual needs, involvement of members of the community, use of patient navigators from the population, and involvement of the extended family.

The report also focused on interpreter services. These services remain unavailable in many cancer centres. To date, there is no evidence supporting a specific model as the most effective, and the cost/benefit of services are largely unknown. However, it is clear the health care professionals are not trained to use and work effectively with interpreters.

2) Supportive care resources and services for non-English-speaking populations in Canada

This report described the experience of non-English-speaking populations interacting with English-speaking professionals, and how the discomfort they experience influences decisions about when, and if, they will seek information and/or care. Many lack awareness of existing resources and do not ask about what is available to assist them. Services for non-English-speaking individuals are rather piecemeal and "patchy"

across Canada and there are financial barriers to accessing the programs. Clearly needs exist for effective interpretation and translation services, community-based programming, and consideration of traditional medicines.

3) Cancer care for ALL Canadians: Improving access and minimizing disparities for vulnerable populations in Canada

This report emphasizes the error in making assumptions about what services will be effective for vulnerable populations. It encourages health care planners to involve members of the population in their own care and in the planning and designing of health services. There is a need to go into the community to understand the populations and to provide services. *"Even when supported by strong evidence, issues related to cultural diversity, language barriers, and the experience of marginalized populations are rarely integrated into policy planning and practice"* (Sarah Bowen, Winnipeg).

Providing culturally competent care means understanding culture (unique characteristics that all of us possess that distinguish us as individuals, and identify us as belonging to a group or groups) and cultural competency (involves a set of behaviours, attitudes and policies that enable working effectively in cross-cultural situations; includes abilities to respond respectfully and effectively to unique needs of culturally and linguistically diverse populations; and ensures cultural sensitivity, cultural awareness, cultural safety). Principles of culturally competent care are described in the report.

To improve the cancer control system and provide culturally competent care, we need enhanced:
- Access (entry into the system, equality of outcomes, responsiveness, design and delivery of programs that is appropriate and relevant)
- Language access
- Patient navigation

4) Addressing disability in Canada

Disability is defined by Statistics Canada in the Participation and Activity Limitation Survey (PALS) as 1) *an activity limitation or participation restriction associated with a physical or mental condition or health problem, 2) the relationship between body structures and functions, daily activities, and social participation, recognizing the role of environment, and 3) includes persons who experience limitations or barriers related to vision, hearing, mobility, agility, pain, memory, learning, developmental or emotions/psychology*

Approaching disabilities and cancer means two populations need to be considered:
- People with pre-existing disabilities (4.4 million) prior to their cancer diagnosis
- People with disabilities experienced as a result of cancer and/or its treatment (1.1. million)

This report outlines the results from interviews and focus groups with individuals who have disabilities about their cancer experience. Individuals who came to the cancer experience with a pre-existing disability reported: delayed detection and diagnosis, complicated treatment experiences, and altered treatment choices. Those who experienced disability after cancer treatment described, for example: facial paralysis, hearing impairment, and organ damage after radiation; mobility impairment after limb amputation; difficulties eating and drinking, and mental health conditions and fatigue. The following quotes illustrate the types of experiences these individuals underwent.

Positive experiences:
- I said, "Okay, you're going to do a surgery on me. If you take my hearing aids away, how am I going to hear you?" So they decided to let me keep one. They took it off during the surgery, then put it back on before I woke up, so when I woke up I could hear.
- When they tried to talk to me with their masks on, I said, "I can't figure out what you're saying with your masks on. [I cannot read your lips.]" And they said they couldn't take their masks off. So I said, "Tell me before we go in what you are going to do."

Challenging experiences:
- I was getting profoundly weak and pale, and I had a lot of fatigue. I had asked my doctors about it, but they just kept saying my MS was getting worse.
- I was told that the pain and everything I was having was just because I was sitting for too long in my wheelchair...but I was not having these problems before.
- It was so hard to explain about the cancer and the treatment to him because of the intellectual disability. And he is older now and bigger, people sometimes do not remember that he is really a child. [Parent]
- When I was diagnosed with leukemia, my oncologist had never treated anybody with my disability [MS]...he looked everywhere for a basis of treatment... it was basically trial and error.
- My surgeon chose to do a radical mastectomy rather than a lumpectomy, because I am on a ventilator...radiation could have a potential impact on my lungs.
- I could not lie on my back or stay still for radiation. I get spasms.
- I am on dialysis and it was tough to organize the chemotherapy with the dialysis.
- When I started chemotherapy, I must have told 35 people the list of drugs that I take and all the dosages. I had to tell my story over and over again every time I met a new person in my treatment...one drug they gave me was supposed to help my nausea, but it interacted with one I was already taking... it was scary.

Recommendations about what can be done include:
- Providing more time for appointments and treatments
- Seeking assistance from family members
- Making information more accessible
- Adapting treatment environments
- Coordinating care.

Completed reports are available at **http://www.partnershipagainstcancer.ca**

Disparities in cancer care: Challenges and opportunities facing the United States of America

by Mary Magee Gullatte, PhD, RN, ANP-BC, AOCN, FAAN, President from 2012–2014 and currently Past President, Oncology Nursing Society

Each year, the American Cancer Society (ACS) publishes estimates of new cancer cases and deaths for different racial and ethnic populations living in America. These data are generated from several sources on cancer incidence, mortality, survival, and screening prevalence: the National Center for Health Statistics, Centers for Disease Control, National Cancer Institute and the Surveillance, Epidemiology, and End Results (SEER) program. Cancer centres and State Health Departments throughout the USA submit their cancer statistics to the SEER program registry. The tumour registries conduct follow-up on cancer patients and submit their data to each state, which, in turn, submit to the SEER program.

In 2014, the estimated new cancer case total was more than 1.6 million in the U.S. (Siegel, Ma, Zou, & Jemal, 2014). Of those cases about 176,620 occurred in African Americans; more in men than women (DeSantis, Naishadham & Jemal, 2013). Overall cancer mortality in the U.S. in 2013 was estimated at 580,350 (DeSantis et al., 2013), while the estimated number of deaths among African Americans was 64,880 (DeSantis et al., 2013).

While the overall cancer death rate is declining and the number of cancer survivors is estimated to be more than 1.3 million, there are data-driven disparities in both the number of new cancer cases for some cancers and cancer mortality. Certain cancers affect minorities and underserved populations disproportionately. For example, the incidence in breast cancer among African American women is less than among white Americans, yet the mortality is higher. Among African American men there is an unexplained disparity in both the incidence and mortality of prostate cancer.

The National Institutes of Health (NIH) define disparities as "differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States" (NIH, 2014). In the declaration of the Healthy People 2010 initiative, a set of health objectives is outlined for the U.S. to achieve over the first decade of the new century. Cancer is prominently mentioned as a priority to develop initiatives to improve health and eliminate health disparities (NIH, 2014).

The American Cancer Society CS (2013) reports African Americans are less likely to survive cancer than whites. The relative five-year survival rates are less for almost every stage of cancer. Tables 1 and 2 depict the ACS data related to incidence and mortality by race and gender in the U.S. between 2005 and 2009.

Contributing factors to health disparities

A number of factors are believed to explain some of the social and political contributors to the health disparities seen among racial and ethnic minorities and underserved Americans. These include: (1) inequities in access to health care such as screening, early detection, and treatment [46 million uninsured and under-insured Americans]; (2) inequities in quality of care within health care institutions and access to clinical trials; (3) less likely to be diagnosed early stage; and (4) less likely to receive the standard cancer care than whites for lung, breast, colorectal and prostate cancers (Gullatte, Brawley, Kinney, Powe, & Mooney, 2010; Underwood & Powell, 2006).

Table 1: Cancer incidence by race and ethnicity, United States, 2005 to 2009

Site	White	African American	Asian American & Pacific Islander	American Indian * Alaska native	Hispanic/ Latin-American
All : M/F	543.1/424	619.7/397	328/286	423/360	419/333
Female breast	123.3	118.0	85.9	89.1	93,0
Lung and bronchus M/F	21.2/11.2	23.3/12.1	10.1/5.1	29.0/16.6	19,8/11,4
Prostate	141.0	228.7	77.2	98.8	124,9

* Rates are per 100,000 population and age adjusted to the 2000 US standard population. Race and ethnicity are not mutually exclusive of Hispanic origin.
Ca Cancer Journal for Clinicians (2013). Cancer Statistics, 2013, American Cancer Society, 62(1), 25.

Table 2: Cancer mortality by race and ethnicity, United States, 2005 to 2009

Site	White	African American	Asian American & Pacific Islander	American Indian * Alaska native	Hispanic/ Latin-American
All : M/F	217/151	288/175	133/93.2	185/136	146/101
Female breast	22.4	31.6	11.9	16.6	14.9
Lung and bronchus M/F	65.3/40.8	82.6/38.0	35.9/18.5	48.3/33.2	30.8/14.1
Prostate	21.7	53.1	10.0	19.7	17.8

* Rates are per 100,000 population and age adjusted to the 2000 US standard population. Race and ethnicity are not mutually exclusive of Hispanic origin.
Ca Cancer Journal for Clinicians (2013). Cancer Statistics, 2013, American Cancer Society, 62(1), 25.

Reducing disparities in cancer incidence and mortality

Oncology nurses are key members of the interprofessional team. They are positioned to make a difference in reducing and eliminating health disparities and improving outcomes of cancer care. The CDC and other public health agencies, health care providers, and communities of all racial and ethnic groups must become partners in a national effort to:

1. improve early detection of cancer through routine mammography, Pap tests, and colorectal cancer screening;
2. implement evidence-based community interventions to increase screening and modify risk behaviours;
3. develop research projects that will encourage minority groups to participate in clinical trials for cancer prevention to ensure that significant differences between minority and ethnic groups are identified;
4. undertake research that will inform decisions about interventions to reduce cancer disparities and improve health (currently, there is a *shortage of data on interventions* available to people regardless of socioeconomic status or behaviour and that addresses the social environment); and,
5. use a variety of media and channels to "market" cancer information to diverse populations in a variety of settings.

Report delay in breast cancer early detection in African American women

Delay in breast cancer detection has been cited as a significant factor in late stage disease (Bibb, 2001; Burgess et al., 1998, 2001). In a mixed methods study by Gullatte et al. (2010), a statistically significant difference was found for delay in seeking medical care for self-detected breast changes and stage of breast cancer. The study further examined religious and spiritual beliefs among African American women and the likelihood to delay seeking medical care. There was a statistically significant difference regarding delay in seeking medical care for those women who responded on the questionnaire as having *only talked to God* about their breast change. The time delay among the study participants ranged a few weeks to 18 months. In addition, the study tested cancer fatalism beliefs among African American breast cancer survivors undergoing their first year of treatment. While the women were found to be highly religious, there was no statistically significant evidence of cancer fatalism beliefs among the study participants.

The participants in the study were a convenience sample of 129 women, between the ages of 30 and 84 years, who reported detecting a breast symptom themselves before the diagnosis of breast cancer and within the preceding 12 months leading up to the study. This study represented a breakthrough in efforts to identify the depth at which religious and spiritual beliefs in some African American women could negatively impact cancer mortality based on delay in seeking medical care. At present, there is a lack of consistent rigorous measurement of the influence of religious and spiritual beliefs on time to seek medical care for self-detected breast changes in African American women. No studies were found that specifically measured the influence of religious, spiritual, and fatalism beliefs on time to seek medical care for actual self-detected breast symptoms in this population. Most of the research studies reported religious, spiritual, or cancer fatalism beliefs as barriers in a woman's intention to seek medical care. However, the participants based their answers on a scenario and not the actual experience. Delay in diagnosis is a problem for African American women. This finding supports results from other studies where delay in treatment from time of symptom discovery results in a later stage of breast cancer at diagnosis (Richards, Westcombe, Love, Littlejohns & Ramirez, 1999; Facione & Giancarlo, 1998).

It is important for providers to be aware of these data and seize opportunities to intervene with African American women in terms of breast cancer risk, screening, symptom recognition, and early detection. Faith-based interventions have been successful at reaching African Americans with health messages. An additional approach might be to partner with the clergy to educate them about the problems of African American women who choose religious intervention exclusively or delay conventional treatment while waiting for religious intervention. Many of the women did talk to their clergy and received prayers, but perhaps were not directed to also seek medical treatment. Clergy can be instrumental, when they are consulted by a woman for religious guidance, to also encourage medical intervention. Clergy may have an important role in helping women see that medical care is consistent with their religious and spiritual beliefs of healing.

Women who had a family history of breast cancer were no more likely to seek medical care sooner than women who reported no family history. This speaks to the possible need to increase education for women about breast cancer symptoms and adherence to the recommended breast cancer screening guidelines.

Studies are needed to understand the influence of religiosity, spirituality, and cancer fatalism beliefs at the time of symptom discovery. This study was limited by measuring the constructs after seeking medical diagnosis and treatment; it is not known if the scores on the measures had changed since initial symptom detection. Such a study would be somewhat difficult to do. Perhaps reaching out to women during a faith-based health program could recruit women who had noted some breast changes or, though less ideal but perhaps more practical, women could be recruited once they had taken action on an observed change, but prior to their diagnostic mammogram.

An opportunity for further study is to understand what factors are associated with a shorter time to seeking medical care. The role of social support, and identifying whether encouraging women to tell someone about breast changes would lead to less delay, is a potential area of new investigation.

Further, there is a need for more qualitative study to understand the experiences of the women who hold high religious and spiritual beliefs, yet do not delay seeking medical care, and those with the same profile who do delay. This could yield important insights about how religious beliefs interfere for some, but not others. New strategies are needed for educating and supporting African American women to use their religious and spiritual beliefs to complement medical intervention, rather than instead of medical intervention. For example, "put in God's hands" does not have to mean "in lieu of" seeking medical care. They need to appreciate that to "put *it* in God's hands", when the 'it' refers to physical symptoms, may mean seeking medical care sooner rather than later. From a community-based intervention perspective, partnering with the clergy of African American places

of worship to educate women about health and healing could be an avenue in reducing the delay in seeking medical care for self-detected breast changes.

Success strategies to decrease disparities and improve outcomes

Strategies oncology nurses and interprofessional team members can employ to address common barriers to cancer and improve outcomes include: (1) expand access to quality cancer care and clinical trials to ensure that minority groups are provided the same care and access to state-of-the-art technology that patients in major care centres receive; (2) address the fear of

cancer, increasing cost of care, and lack of provider referral; (3) offer screening services to all who need it; and (4) recommend an increasing use of preventive services (Centers for Disease Control). The U.S. National Institute of Health has a division for Minority Health and Health Disparities that has as its mission to lead scientific research to improve minority health and eliminate health disparities. The hope is that the patient Protection and Affordable Care Act, passed on March 23, 2010, will help shift the unequal burden of cancer and other diseases, among America's underserved and poor, when more Americans have access to care through affordable insurance coverage.

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Health disparities in cancer care: International perspectives

by Dr. Greta G. Cummings RN PhD FCAHS President from 2010–2014 and currently Past President, International Society of Nurses in Cancer Care (ISNCC)

We live in a world of growing disparities. More than 1.3 billion people lack access to clean water, 3 billion lack adequate sanitation, 2 billion have no access to electricity, and 3 billion live on less than $2 a day (World Bank, 2003). As recently as 2000, a billion people were unable to read or sign their own name (INCTR, 2013). The impact of disparities is overwhelming. Approximately 11 million children die each year due to poverty (UNICEF, 2006), and another million children for want of clean water and adequate sanitation (UN, 2008).

Disparities arise from many factors, including socioeconomic status, ethnicity, country resources, and cancer diagnosis, treatment and palliation services. For example, in England people living in deprived areas received 70% less health care relative to need, compared with affluent areas (WHO, 2008). Ethnic disparities are seen when 2,946 white patients and 367 black patients, aged 65 years or older, were diagnosed

with loco-regional oesophageal cancer; elderly black patients were less likely to visit a surgeon, radiation oncologist, or medical oncologist after a diagnosis of oesophageal cancer (Steyerberg, 2007). Ashford and Collymore (2005) provide an example of disparities based on country resources. Most cases of cervical cancer can be prevented or treated effectively, yet 274,000 women die from the disease yearly; of these, 241,000 are among women in low- and middle-income countries. Disparities in cancer treatment are reflected in treatment for pain. Eighty per cent of the world's population, including >5 million patients with terminal cancer, do **not** have access to pain treatment. In >150 countries, morphine is simply **not** available (Lamas & Rosenbaum, 2012). Low- and middle-income countries have less than 5% of world resources available for cancer control, yet 70% of cancer deaths occur there (WHO-Globocan, 2012). More than 80% of their cancer patients will be beyond cure at time of diagnosis (UICC, 2013).

International Society of Nurses in Cancer Care: Approach to cancer disparities

The approach by the International Society of Nurses in Cancer Care (ISNCC) to managing cancer disparities includes

several strategic initiatives: advocacy and influencing policy, emphasizing and clarifying the role and contribution of oncology nurses to cancer control and outcomes, sharing resources to educate nurses to build capacity, teaching nurses to be advocates, calling for research in cancer nursing to build the body of evidence, and supporting the use of evidence.

ISNCC is taking action on these by developing partnerships with other global/ international and regional cancer agencies, as we believe that resources, passion and influence go farther when we all work together. ISNCC's global partners include the *International Psycho-Oncology Society (IPOS)* — to recognize and enhance nursing roles and effectiveness in psycho-oncology; *International Council of Nurses (ICN)* — to influence policy related to cancer; the *Union for International Cancer Control (UICC)* — in advocacy; and the *Multinational Association for Supportive Care in Cancer (MASCC)* — to recognize and enhance nursing roles in multidisciplinary oncology teams. We also have partners in regional arenas — European Oncology Nursing Society (EONS), Oncology Nursing Society (ONS), Asian Oncology Nursing Society (AONS), foundations, and corporate members.

An example of a partnership program with EONS and Bristol Myers Squibb Foundation is *Managing Cancer Disparities in Eastern Europe*. Some projects presented at the Bridging Cancer Care Session in Amsterdam, Netherlands, 2013, were:

- Project Hope: Improving Early Detection and Diagnoses of Childhood Cancer in Five Regions of Poland
- Cancer Care Capacity Building for Nurses in Romania

- Motivating Roma people in Hungary to get involved in cancer prevention and early detection
- Collaborative Education to Improve Safety and Quality of Care for Patients with Cancer in Russia.

ISNCC is also building capacity in oncology nursing globally by developing train-the-trainer programs for nurses in cervical screening (with UICC), oral therapy (with Novartis and GSK), and smoking cessation programs (with BMS Foundation, Drs. Bialous and Sarna). We also aim to access as many oncology nurses globally as possible, because membership provides access to information. Through membership, nurses are empowered with knowledge, opportunities to influence, and access to resources. Taking advantage of opportunities for nurses to influence requires development of leadership (power) in their health care system to be effective, as cancer nurses. Some of ISNCC's approaches are to assist nurses to develop cancer nursing societies in their community/country, influence cancer control policies, develop and present train-the-trainer programs to build capacity in oncology nursing, and provide opportunities for nurses to develop leadership skills. Leadership is being able to see the present for what it *really* is, see the future for what it *could* be, and then, take *action* to close the gap (Cummings, 2012). Listening to the advice of Mei Krishnasamy, Robert Tiffany lecturer for the 2012 International Cancer Care Nursing conference, some of the things that we can each do to change disparities are: to be vigilant to inequity, work with colleagues to put inequity at the forefront of your language of care, and put inequity at the forefront of your team/unit/organization's language.

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