

Global Perspectives on Cancer Health Disparities: Impact, Utility, and Implications for Cancer Nursing

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ABSTRACT

This paper examines cancer health disparities and contributing factors at national, regional, and international levels. The authors all live in different countries and regions with different health-care systems and practices. Despite the shared cancer nursing perspective, each country or global region approaches cancer disparities differently. With globalization the world is becoming smaller, and in

turn becoming interconnected and interdependent. This article focuses on cancer health disparities and global cancer nursing, exemplifying these concepts about the impact and implications of person-centered care.

Key words: Cancer health disparities, cancer nursing, impact, implications, utility

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Introduction

Over the past 40 years, cancer nursing care has changed immensely and radically from a gross understanding of the disease to a refined knowledge of molecular and genetic changes occurring at, in, or on the cell. Parallel to this expanding biological knowledge comes growth in other areas of oncology nursing knowledge, as well. This growth in understanding of disease, treatment, and clinical nursing care has allowed a focus on other, albeit different, topics.

Over the past few years, health disparities, social determinants of health (SDH), and person-centered care have emerged as areas where nurses can have an impact. Cancer care around the globe is changing at a rapid pace. Yet, these topics have been addressed from a primarily Eurocentric perspective. At the 2016 Oncology Nursing Society, the authors, leaders of global oncology nursing societies, were invited to be on a panel to discuss health disparities from their respective society's perspectives.

Each Oncology Nurses Association is constituted in a different way and for a different purpose. These differences make us similar but not the same, especially when asked to discuss health disparities, SDH, and person-centered care. There were representatives from the Asian Oncology Nursing Society (AONS), the Cancer Nurses Society of Australia (CNSA), the Canadian Association of Nurses in Oncology (CANO), the International Society of Nurses in Cancer Care (ISNCC), and the Oncology Nursing Society (ONS). The various societies work with nurses who are different from each other as well. The differences arise from the level of education, the oncology nurse role, the geopolitical situation, as well as the health-care and cancer-care systems. This paper outlines health disparities, SDH, and person-centered care through the lens of global cancer nurse leaders of oncology and cancer nursing organizations. We examine cancer health disparities and contributing factors at national, regional, and international levels. We offer possible solutions, like navigation, from an international perspective, focusing on the impact and implications of health disparities and SDH.

The authors all live in different countries and regions with different health-care systems and different clinical practices; yet we all share a cancer and oncology nursing paradigm. With globalization, the world has become smaller, more interconnected, and interdependent.^[1] This article illustrates our interconnectedness, interdependence, and differences

from the perspective of cancer health disparities and global cancer nursing.

Canadian Perspectives on Cancer Health Disparities

The CANO is a national organization established in 1985 with a mission to advance oncology nursing excellence through practice, education, research and leadership for the benefit of all Canadians, and a vision of being an influencing force internationally in cancer control. The association is member-led and takes direction from its membership in formulating activities and initiatives.^[2]

One of these initiatives is working with the Canadian Partnership Against Cancer on a pan-Canadian strategy with the goal of all Canadians having access to equitable, person-centered, safe, and high-quality cancer care.^[3,4] Increasingly, however, health disparities are being documented among cancer survivors who live in rural and remote settings, those with lower socioeconomic status, or who are older, with advanced disease at diagnosis, and in Indigenous and ethnic minority groups, as well as immigrants.^[3-11]

Factors and contexts contributing to health disparities in cancer survivors include (1) personal attributes (biological/genetic endowment); (2) health-care accessibility; (3) acquired health behaviors; and (4) the social, economic, and cultural resources and environments (ie., SDH) of where people live.^[5,12,13] Efforts to address cancer disparities in Canada largely have been aimed at improving access to care, such as through the introduction of nurse navigator roles.

In response to a fragmented system of care that marginalizes vulnerable individuals and populations, an evidence-informed Canadian cancer patient navigation agenda has been articulated.^[14] Navigation is considered a part of an integrated cancer service delivery program, where navigators, usually oncology nurses, work with patients and families to assess needs, provide supportive care, answer questions, identify and address any barriers to quality care, and facilitate access to needed resources and services. Competencies for nurse navigators align with the CANO Standards and Competencies for Specialized Oncology Nurses^[15] and can be found in Box 1.^[15]

Various navigation models and programs exist across Canada, contextualized to the unique needs of populations

and designed to fit within existing cancer care services. Nurse navigators are placed at different points along the cancer trajectory (from diagnosis, through treatment, and transitions to survivorship), in various care settings (rural, urban, community, and hospital), and to serve diverse populations (grouped by type of cancer, vulnerable groups, or complex health needs). Evaluation of navigation roles and programs is in the nascent stage in Canada with little published evidence related to the impact on reducing disparities. Most studies focus on demonstrating system efficiencies through improved care coordination and timely access to care.^[2,15,16] Impacts on patient outcomes have been reported, such as decreased anxiety, improved self-reports of feeling prepared for consultations, and patient satisfaction.^[3,16]

Furthermore, even with improved access to care, it is anticipated that navigation will not be the single answer to addressing cancer care equity. A broader approach to addressing root causes that contribute to the development of inequities is needed.^[4-6,8] Understanding the SDH [Box 2],^[17] including the factors, contexts, and structures that influence opportunities for health, is an essential foundation for moving the health equity agenda forward in Canadian cancer care.

Australian Perspectives on Cancer Health Disparities

The CNSA was founded in 1998. Its beginnings were in the Nurses Group of the Clinical Oncological Society of Australia. Today, CNSA is an independent member-based organization of cancer nurses with over 1000 members throughout Australia. The CNSA is committed to achieving and promoting excellence in cancer care through the professional contributions of nurses. The society acts as a resource for cancer nurses around Australia, whatever the geographical location or area of practice and works with other Australian cancer agencies to address health disparities as a key priority.

The CNSA is very cognisant of outcome disparities in Australia and its role in addressing these through the contribution of cancer nurses. Cancer Australia is the lead national government agency that makes evidence-based recommendations to the Australian Government about cancer policy and priorities, and Cancer Australia identified key outcome disparity issues in their 2014–2019 strategic plan.^[19] Such key issues include people living in remote or very remote areas, those living in low socioeconomic status areas, Aboriginal and Torres Strait Islander peoples, and those with certain cancer

Box 1: Competencies for specialized oncology nurses

Facilitating continuity of care and navigating the system
Comprehensive health assessment
Supportive and therapeutic relationships
Teaching and coaching
Decision making and advocacy
Management of cancer symptoms and treatment side effects
Professional practice and leadership

Box 2: Social determinants of health

Income and income distribution
Education
Unemployment and job security
Employment and working conditions
Early childhood development
Food insecurity
Housing
Social exclusion
Social safety network
Health services
Aboriginal status
Gender
Race
Disability

Box 3: Key evidence of cancer health disparities in Australia

- People living in remote or very remote areas have significantly higher cancer mortality rates than those living in major cities (196 and 171/100,000, respectively)
- People living in lower socioeconomic status areas have both higher cancer incidence and mortality rates than those in higher socioeconomic status areas
- Aboriginal and Torres Strait Islander peoples are 6% more likely to be diagnosed with cancer and 50% more likely to die from cancer than nonindigenous Australians
- Some cancers such as brain cancer, pancreatic cancer, and lung cancer have shown only small gains in survival while some other cancers had large survival gains over the past 30 years

diagnoses. Key evidence highlighted by Cancer Australia is summarized in Box 3.^[19-22]

The data listed in Box 3 highlights the privileged position that Australia has regarding available data and evidence to inform care and cancer service planning. However, it is important to acknowledge the lack of data concerning survivorship and supportive care outcomes due to a lack of relevant routine reporting mechanisms. Until such data are available, a challenge remains to identify and address survivorship and supportive care outcome disparities at the population level.

An evidence-based whole-of-system approach to address outcome disparities is critical. Researchers, policy-makers and clinicians are required to work together to ensure that multi-level strategies are informed by data and best practice

standards. It is imperative that we understand the experience of outcome disparities from the patients' and caregivers' perspectives. We need a deeper understanding of the potential causes or modifiable factors associated with outcome disparities. This will enable us to formulate appropriate strategies that are likely to make an impact. Moreover, we must continue to evaluate the effectiveness including the costs, of strategies using a range of robust research designs.

In Australia, navigation is known as care coordination - an intervention that may alleviate some problems associated with outcome disparities. However, given the limited evidence available, it is difficult to determine the extent of the impact that care coordination has on health outcome disparities.^[23] Therefore, care coordination alone is not the solution. It is critical to acknowledge that addressing outcome disparities requires a systems approach that requires collaborative efforts of government agencies, not-for-profit organizations, professional organizations, advocacy groups, local health-care executives/leaders, and health professionals.

Cancer Health Disparities across Europe

EONS is a pan-European organization dedicated to the support and development of cancer nurses and cancer nursing across its member countries. The membership of EONS consists of individual members, as well as multiple national societies like the Irish Association for Nurses in Oncology and Verpleegkundigen & Verzorgenden Nederland Oncologie (V&VN). Its strength comes from its partnership not just with cancer nursing organisations but with European multidisciplinary organisations with which it collaborates to optimise the nursing contribution of cancer care in Europe. Through individual membership and national societies EONS engages in large scale projects to empower nurses to better develop their skills, share best practice, network and raise the profile of cancer nursing across Europe.^[24] Therefore, EONS looks at health disparities, SDH, and person-centered

care through a different lens than CANO and CNSA. It must do so since, as an organization, EONS works at both the member level but more specifically at the organizational level.

Across Europe, cancer is the second most common cause of death after cardiovascular disease.^[25] In the year 2012, 3.75 million new cases were diagnosed with 1.75 million deaths.^[26] More worryingly, a European analysis shows a considerable disparity among the different countries. Data from EURO CARE 5, a European collaborative project monitoring population-based cancer survival, demonstrate the different survival rates between countries. For example, in cancers with a mostly good prognosis, the European average 5-year relative survival for breast cancer was 82% while in Eastern Europe it was 10%–15% lower. For prostate cancer, the European 5-year survival rate of 83% is to be compared with 72% in Eastern Europe. Similarly, colon cancer and skin melanoma have lower survival rate in Eastern Europe than the European average 5-year survival.^[27]

For cancers with a poorer prognosis, there appears to be less variation. The 5-year relative survival European average for lung cancer was 13%, with 11% in Eastern Europe, 10% in Denmark, and 9% in the UK and Ireland. For stomach cancer, the 5-year survival rate was 25%, with 19% in Eastern Europe, 17% in the UK and Ireland, and 16% in Denmark. The 5-year European ovarian cancer survival rate was 38%, with 35% in Denmark, and 31% in the UK and Ireland.^[27]

Reviewing the data from 7.5 million cancer cases across 29 European countries illustrates that Denmark, the UK, and Eastern Europe have lower survival rate than other parts of Europe.^[27] Of particular concern is the parts of Eastern Europe where mortality rates for many cancers are above the national average. For example, Poland has a lung cancer mortality rate of 83% versus the European Union (EU) average of 56.4%; Romania has a cervical cancer mortality rate of 14.2% versus the EU average of 3.7%.^[27] The best survival rates for most cancers are in the

Table 1: Examples of cancer survival across European countries

Region in Europe	Countries	5-year relative survival rates of selected cancer sites (%)					
		Breast	Colon	Lung	Ovarian	Prostate	Stomach
Northern (Nordic countries)	Denmark	81.5	53.6	10.3	35.5	69.3	16.0
	Sweden	86.0	61.1	14.7	44.1	87.5	21.7
	Iceland	87.2	62.0	13.9	39.1	82.5	34.5
Central	France	86.1	59.7	13.8	40.1	88.9	26.3
Southern	Italy	85.5	60.8	14.3	38.1	88.6	32.4
	Croatia	76.3	49.6	14.8	38.6	71.3	21.3
Eastern	Bulgaria	71.7	45.2	6.2	33.4	50.5	11.9
	Poland	71.6	46.7	14.4	34.5	66.6	15.6
United Kingdom	United Kingdom	79.2	51.8	9.0	31.0	80.6	17.2

Nordic countries except Denmark, Central Europe, and some countries in the Southern Europe, particularly Italy, Portugal, and Spain [Table 1].^[27]

The evidence for cancer health disparities between different European countries appears to be influenced by SDH (see Box 2). In Europe, they include lifestyle factors, socioeconomic, and health status, as well as age. While it is tempting to link health care spending as a proxy measure with poor outcomes, such as in Eastern Europe with a shortage of public cancer funding, this does not seem to correlate with the low survival of the UK and Danish cancer patients.^[28] Extensive analysis would appear to suggest delayed diagnosis possibly linked to advanced stage at presentation and unequal access to treatment.^[29] In Eastern Europe, cancer health care may be further compromised by poor infrastructure - no national cancer strategy, poorly implemented screening programs, and fragmented service delivery - less developed cancer clinical pathways and inequitable access to care.^[30]

Closing the cancer disparity gap across Europe will remain extremely challenging. Strategies will need to be developed internally and targeted at the micro, meso, and macro environments within each country (recognizing that cancer will not be a priority health care issue for all). Workforce and clinical pathways remain fragile in some places and will require strengthening. While health-care resources may need to be increased in some localities, it is possible that best practice sharing and collaborative projects between differently resourced countries may lead to improved outcomes.

Cancer Health Disparities in Asia

AONS, was founded in 2013 which is a regional organization with a vision to support cancer nurses in providing high-quality and scientifically-based care to cancer patients in Asia. AONS is committed to advancing cancer nursing in the Asia region through collaborative exchange of clinical practice, education and research among AONS members, developing and disseminating the latest evidence-based nursing practice, and preparing future nurse leaders for cancer care in Asia. Similar to EONS, AONS works more specifically at the organizational level across countries in the Asia region.^[31]

Asia bears a significant cancer burden compared with other world regions, with 48% of new cancer cases and 55% of cancer-related deaths reported in Asian countries.^[32] This cancer burden may be fueled by a more pressing problem that of cancer health disparities.

In Asia, cancer survival rates in high-income countries (HICs) were found to be considerably higher than those in low- and middle-income countries (LMICs). Indeed, HICs appear to have a smaller mortality-to-incidence ratio, one indicator of cancer survival,^[33] than do LMICs.^[32] Moreover, ethnic and rural-urban disparities in cancer survival were reported in Asian countries. For example, Uyghurs, an ethnic minority group in China, appears to have a higher cervical cancer incidence than other ethnic groups in the Xinjiang region.^[34] Meanwhile, in India cancer survival, rates of rural residents are lower than those of their urban counterparts^[35] providing evidence of health disparities across and within countries in Asia.

Several factors may contribute to cancer health disparities in Asia. There is a lack of governmental health-care funding, a prominent phenomenon in LMICs, and ultimately leading to out-of-pocket health-care expenditure among individuals in LMICs.^[36] It may be difficult for individuals to pay for services such as cancer screening. Moreover, there is a lack of access to health information for ethnic minorities and rural residents in certain Asian countries. Individuals generally possess limited knowledge about cancer and prevention strategies.^[34,37] Individuals in different countries may not appreciate the importance of adopting a healthy lifestyle and may not use cancer screening and prevention practices. Most health-care professionals prefer to work in urban areas,^[38] and advanced medical facilities are located in metro areas.^[39] This lack of health-care access becomes a barrier for rural residents, who may be reluctant to utilize health-care services including cancer screening, due to lengthy travel.

Strategies to reduce cancer health disparities include government involvement in screening programs, registries, treatment, survivorship, and palliative care. Asian LMICs should allocate resources to health care despite the costs, enabling individuals to use cancer screening programs. Cancers found through screening programs should be registered. The Cancer Atlas 2016 reported that in Asia only 6% of countries (or regions) have a high-quality cancer registry, compared with 95% of North America and 75% of Oceania. Increasing the number and quality of cancer registries in Asia would provide evidence (data) about the scope of the cancer incidence.

As mentioned earlier in this paper, various factors contribute to cancer health disparities and one size does not fit all when considering person-centered care, which should be rooted in the needs of the disadvantaged. Stakeholders should be engaged from nongovernment organizations, ethnic minority associations, government, and health

professionals. Navigators may provide low health-literate individuals with information on effective cancer prevention in such a way that they understand cancer. Navigators could facilitate access to health-care services such as cancer screening leading to increased utilization of screening services and effective early detection of cancer. This is especially true of individuals in disadvantaged groups, including ethnic minorities. However, cancer navigation is underdeveloped in Asia when compared with Western countries.

Cancer Health Disparities - The Worldview

The ISNCC is an international membership organization dedicated to improving the health and well-being of people at risk of, or already living with, cancer. It is composed of nursing associations and individual members, and associate members and corporate partners. Through its strategic partnerships and members' related initiatives, the society influences and participates in setting directions for cancer nursing, health policy, and cancer control initiatives that are intended to improve the health and well-being of people around the world. By promoting the nurse's role in cancer care, ISNCC leads a global community of cancer nurses to share, discuss, and debate strategies and innovations that advance clinical practice, education, research, management, and leadership.^[40]

The issue of global disparities in cancer care goes beyond disparities to the need for a serious conversation about health justice. Data from the World Health Organization *GloboCan* for the year 2012 demonstrate that a significant proportion of new cancer cases is found in HICs. The highest proportion of cancer mortality is found in LMIC demonstrating, once again, that in LMIC a combination of late stage diagnosis, low access to treatment, and a myriad of challenges to the health-care system indicates that where you live when you receive a diagnosis of cancer will determine your chances of treatment and survival.

This difference was perfectly illustrated by the International Atomic Energy Agency as displayed in Table 2.^[41] Furthermore, the Council on Foreign Relations estimates that from 1990 to 2010, there was a higher than 100% change in disability-adjusted life years, i.e., years of healthy life lost, due to leukemia, breast cancer, and lung cancer in several of the poorest countries in the world.^[42] Despite evidence of the devastating impact of cancer in LMIC, the vast majority of international aid programs for LMIC remains focused on communicable diseases. In

Table 2: Examples of cancer survival based on country of residence, International Atomic Energy Agency Programme of Action for Cancer Therapy

Type of cancer	Country	Expected 5 year survival rate (%)
Prostate	Australia	89
	Uganda	46
Breast	USA	89
	Jordan	43
Childhood leukemia	Germany	92
	Mongolia	34

addition to the existing lack of equity between countries, there are huge disparities within countries, regardless of level of income.

An example of the global disparities in cancer is lung cancer, which is the leading cause of cancer death globally, and among the top 5 cancer diagnoses in men and women. Tobacco control decreases the incidence and improves the survival of people already diagnosed. Thus, conceptually, a care coordination and integration, or navigation, program could address lung cancer prevention, screening, diagnosis, treatment, recovery, or palliative care. The reality, however, is that prevention is seldom integrated into a navigation program and tobacco dependence treatment, when available, is seldom integrated in the continuum of care.

An opportunity for this integrated and coordinated, evidence-based approach to care therefore exists, but a few challenges need to be addressed. First, the nursing shortage, which is severe in several parts of the world where there is a desperate need for nurses at the bedside carrying heavy patient loads. Second, nurses themselves, who may not see their role as navigators in some countries. Third, nurses in many countries may see the care coordination activities of a navigator as beyond the scope of standard nursing practice. Last but not least, nurses' basic and postbasic education varies globally, and not all may feel prepared to embrace a navigator role.

The cancer health disparities seen in cancer care globally in many ways mirror and are intrinsically related to the disparities we see in the availability of professional nursing globally, particularly nurses that can assist patients throughout the cancer care continuum. Nevertheless, opportunities exist to accelerate the professionalization and implementation of diverse roles for cancer nurses. We have professional organizations that can support each other in building leadership. We have new ways to share expertise through the internet, mobile health, and other innovations that could help nurses, particularly those in

LMIC and in deprived areas within HIC to make huge strides toward the implementation of excellence in cancer care.

Conclusion

This paper examined cancer health disparities and SDH at national, regional, and international levels. Possible solutions were suggested to address these disparities and improve access to cancer care. Although one size does not fit all, strategies should be focused in the needs of the disadvantaged. The oncology nurses associations are joining hands to support global cancer nurses strive for excellence in cancer care, and to work with all stakeholders together to reduce the global cancer burden.

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Conflicts of interest

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