

# Cancer and social justice: What's advocacy got to do with it?

by Andrea Knox, Joanne Crawford, Gabriella Wong Ken

## ABSTRACT

*Advocating for all people affected by cancer has been identified as a priority for CANO/ACIO in its 2021–2025 Strategic Plan (CANO/ACIO, 2022). Acknowledging the need to address social injustices and health inequities in cancer care for underserved and/or vulnerable populations, CANO/ACIO convened a national Underserved and Priority Population (UPP) Working Group to create guiding principles and actions related to CANO/ACIO's activities. To support achieving its mandate, the working group hosted a workshop at the 2022 CANO/ACIO Annual Conference where members explored cancer as a social justice issue and the role of nursing advocacy as a tool for advancing social justice in oncology. Video case studies were used to facilitate large and small group discussion, which included an exploration of barriers to advocacy and mitigation strategies at the individual, interpersonal, and organizational levels. Findings from the workshop discussions and post-workshop reflection will be used to inform the ongoing work of the UPP Working Group, which includes creating actionable recommendations for CANO/ACIO's advocacy activities. This work is an important step*

*towards ensuring those affected by cancer have the resources and tools needed to access high-quality care at any point of their cancer journey.*

## INTRODUCTION

When you think of social justice issues, does cancer come to mind as a social justice issue?

Health disparities among those who are underserved, or those who experience social disadvantage exist. The literature has identified that certain populations are more likely to be diagnosed with cancers that are preventable, be diagnosed with late-stage disease, receive no treatment or poor-quality treatment, and die from cancers that are may be curable (Canadian Partnership Against Cancer [CPAC], 2019). Health inequities are increasing among underserved populations diagnosed with cancer, and action is needed to reduce disparities in cancer care. Enhanced access to equitable and high-quality cancer care for all Canadians is a key priority identified in the Canadian Strategy for Cancer Control (CPAC, 2019).

Within cancer care systems, leaders, health professionals and nurses have a responsibility to uphold social justice by advocating for the equitable distribution of health resources; and that genuine efforts and procedures are put in place to remove system barriers (Purificacion et al., 2015; World Health Organization, 2019). Ethical nursing practice requires that nurses be mindful of the expansive social justice issues that impact the social determinants of health and the wellbeing of individuals, groups, and populations (Canadian Nurses Association, 2017). Advocating for structural and social changes that lead to improvements in practice, education, or policy are important activities to tackle the health inequities that persist within cancer care. This paper will discuss the CANO/ACIO National Underserved and Priority Population (UPP) Working

Group role function, and provide a description of the aim and the delivery of the CANO/ACIO Board sponsored workshop, the barriers and mitigation strategies discussed by workshop participants, the post workshop reflections, and next steps for the working group.

## CANO/ACIO NATIONAL UNDERSERVED AND PRIORITY POPULATION WORKING GROUP

It is the position of CANO/ACIO that all Canadians deserve access to comprehensive oncology nursing care, committing in its 2021–2025 Strategic Plan (CANO/ACIO, 2022) to advocate in support of all people affected by cancer. Acknowledging the need to address social injustices and health inequities in cancer care for underserved and/or vulnerable populations, CANO/ACIO convened a national Underserved and Priority Population (UPP) Working Group. The purpose of the working group is to create guiding principles and actions related to CANO/ACIO's activities with a focus on underserved and priority populations across the cancer continuum within Canada.

Recognizing there are varying terms and definitions used when referring to individuals experiencing health and healthcare inequities, the working group focused initially on defining underserved populations in the oncology nursing context. As a result, the working group defined underserved populations as those who are not well served by the healthcare system because of a constellation of:

- Socioeconomic, demographic, and geographic factors,
- Racism, stigma, and other forms of discrimination, and
- Disparities between the design and delivery of healthcare services and the actual healthcare needs for these populations.

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Operating under this definition, the working group considers both national and global relationships with community groups, interdisciplinary organizations, educational facilities, and other professional nursing organizations; strategizing on how CANO/ACIO may formalize collaborations with these groups to advance CANO/ACIO's mission and vision.

### CANO/ACIO Board Sponsored Workshop

To support achieving its broad mandate, the UPP Working Group was invited to host a board-sponsored workshop at the 2022 CANO/ACIO Annual Conference. In this workshop, members of the working group led an exploration of cancer as a social justice issue, with the role of nursing advocacy as one tool among many to work towards advancing social justice in oncology. Advocacy is vitally important to ensuring that patients have the resources and tools they need to access high-quality care from diagnosis to treatment and throughout survivorship (McCanney et al., 2018).

The learning objectives for the workshop focused on developing foundational knowledge on social justice and advocacy in the cancer context. Specifically, participants would be able to (1) explain why cancer is a social justice issue; (2) describe how advocacy can be used as a tool to address social

injustices across the cancer care system; (3) and describe strategies for oncology nurses to advocate with/for underserved populations in cancer care.

After introducing the concepts of social justice and advocacy, participants were invited to answer the question, "What does advocacy mean to you?" with one word. The responses were used to generate a word cloud (Figure 1), which was shared with participants at the end of the workshop.

Participant engagement was an integral part of the workshop and was facilitated utilizing two case study video clips created specifically for viewing and discussion during the workshop. The case studies reflected personal stories of individuals with varying perceptions of the healthcare context. The first case study shared the story of SB, a professional Ojibway woman from the Mississauga First Nations who self-identified as a status band member, and Bear Clan and intergenerational residential school survivor. With education in social services and experience in child welfare, SB shared her experiences and perceptions of healthcare in relation to biases and discrimination towards her people, and her concerns of potential mistreatment in the healthcare system on a personal level. Her story reflects the impacts of historical colonialism that continues to permeate our healthcare system, and the role of advocacy in our efforts

toward reconciliation. The second case study was the story of TR, who self-identified as a transgender male, lawyer and judge, who was diagnosed with cancer. TR's cancer journey focused on the stigma, objectification, and feelings related to the experience and need to educate healthcare professionals. While TR shared that not all these experiences were difficult, there were aspects of his story that highlighted the emotional distress of how ignorance among healthcare professionals negatively impacts patients during a time when their priority is to cope with the diagnosis of cancer and treatment. TR provided insights into how healthcare professionals may improve their care in making patients feel culturally safe in an oncology and healthcare context.

After viewing SB's and TR's case studies, workshop participants were tasked with forming small groups to respond to a key question: What factors may have contributed to SB and TR's experiences? A facilitated large group discussion was held after each small group discussion, where participants were asked to explore: (1) what external systems may have impacted SB and TR's experience; (2) what are some actions you, in your role (or your colleagues in their roles) could take to advocate and support; (3) what are possible points to advocate and interrupt these situations. The resulting large group discussions were thoughtful, active, and enthusiastic.

### Exploring Barriers and Mitigation Strategies

An overarching aspect of the workshop was to address key barriers to advocacy and potential strategies to mitigate these within the context of individual, interpersonal, organizational, and structural/system level barriers. Participants were asked to consider how they could use the power and privilege of their role to advocate for change. In the following section, the outcomes of the large group discussion will be presented; this includes the barriers and mitigation strategies that may be useful to understand how best to support oncology nurses in their efforts to advocate in oncology practice settings.

Figure 1



### Barriers

Over the course of the workshop, participants reflected on their practice and identified important individual, interpersonal, and organizational level barriers. At an individual level, one barrier identified was the perception of “stirring the pot”, which related to advocating for something that would be perceived by others as causing trouble or controversy. This was also related to an individual’s underlying degree of confidence in taking the initiative to lead and advocate. Readiness was another barrier identified at the individual level, and discussion focused on the self-perceived ability of nurses to advocate in a meaningful way which may include having the knowledge, tools, and support of others or colleagues.

Readiness was also identified as a barrier at an interpersonal level, specifically within the context of the practice culture and the collective support of all being at a stage where they could successfully move to planning and action. Another interpersonal barrier was related to limits of education, not only in relation to taking on an advocacy role, but also background knowledge of the “how” to advocate for social justice in the context of their work environment.

From an organizational perspective, workshop participants identified a common belief that the hierarchical nature of the organization creates a barrier to advocacy in the sense of not knowing who to engage to pursue social justice initiatives. Another organizational barrier is that oncology nurses are not always represented at decision-making tables in relation to patient care or inclusive services. Lack of knowledge regarding a specific patient’s past experiences with health care was also acknowledged as a barrier. This relates to the belief that gaining insights from the patient perspective and relational experience are vital to being an ally in advocating for issues that require change at the organizational level. Lastly, oncology nurses spoke about organizational resistance to change as a barrier, a perception that may reflect many complex interconnected system issues that were not expanded upon in depth at the workshop, likely due to time constraints.

### Mitigation Strategies

Strategies to mitigate the barriers to advocacy and social justice were also considered at an individual, interpersonal, organizational and system level. At the individual level, participants discussed methods of supporting oncology nurses to build trust and rapport in relationships with patients so they could truly understand their perspectives and health equity experiences. This way of knowing is seen as enhancing the ability to gain knowledge and insights in order to identify where changes need to be made. This is congruent with another strategy that entails focusing on the person and using nursing skills to listen, attend to, and provide care to meet the unique needs of the individual patient. Patient-centred care was also reinforced as a strategy, and this reflects utilizing a relational approach to gain a deeper awareness of the patient’s needs and concerns.

An interpersonal level strategy proposed was to “call out” behaviours or decisions that are unjust, and to “call in” the healthcare team to discuss inequities in cancer care and educate each other. As a profession, nurses abide by a code of conduct, and this would entail recognizing, approaching, and advocating on behalf of the client based on an action or behaviour of a colleague providing care in real time. For example, calling out someone who is using a derogatory term when addressing a patient. In turn, this example could be brought up in a staff meeting as a learning moment for everyone; not to be punitive, but to facilitate learning about how to ensure that we provide culturally safe client care. This reflects approaching advocacy using a collective response, where all oncology nurses and allied health clinicians can be part of embracing advocacy as a social justice tool.

From an organizational level, a number of strategies were identified. Across participants, there was a common belief that the leadership within one’s institution should be active in any form of advocacy. Policy changes were an important point of discussion, as this suggests changes that are more powerful sources of action. This may involve

simple tasks of making changes to documents, followed by educating staff and implementing those changes across the organization. One example provided is to be more inclusive of diverse patients by increasing options for self-identification of gender through documentation. Another example was to initiate incident reports that represent misconduct of care (i.e., discriminatory comments).

Structural (system) level strategies reinforced relationships with those whose voices were important and would thus be heard in the context of oncology care as a means to advocate for change and health equity. Implementing policies and resources to promote cultural safety was another strategy proposed to ensure that all oncology health care providers were aware of and followed the principles of cultural safety to improve care. Another strategy was related to capitalizing on many voices to advocate for change as this was important to create tensions, hear the reality of the system culture to raise awareness and motivate changes that would foster health equity. And last, intersectoral collaboration was proposed as a core primary health care principle that is valued in the Canadian healthcare system, to enable all organizations to work together in advocating for social justice and health equity.

### Post-Workshop Reflections

At the end of the workshop, participants were asked to evaluate their experience in the session and provide recommendations for future educational opportunities. Participants were asked; 1) what they liked about the session, 2) what they did not like, 3) what type of education related to the topics discussed would they like to see moving forward, and 4) what they would like to see at future sessions.

The ability to engage in conversation within small groups and with the larger group resonated well with participants. Small group discussions allowed individuals to focus on the case studies and concepts, exploring them in a meaningful way. The large group discussions provided an opportunity to hear the experiences of other participants, bringing to life the issues discussed through

sharing authentic situations and strategies for advocacy. Participants valued the case studies (i.e., video clips), and felt that the experiences, perspectives, and storytelling shared by SB and TR brought the workshop topics to life. Case studies were relevant to their practice and the specific accounts of the patients' experiences challenged their beliefs.

Multiple participants shared that they would like a longer workshop with more time for discussion and conversation. Specifically, they felt that they would have liked more time discussing strategies and how to be a better advocate for patients. Participants stated that having more resources that they could take with them to their practice would be something they would like to see at future sessions. Consideration should also be given to planning for more small group discussions at future sessions to make space for those participants not comfortable with public speaking in a large group. Overall, the majority of participants felt the workshop was a safe and open space for them to explore the concepts in the context of the patient stories and share their personal experiences and feelings around social justice.

Moving forward, participants said that they would like to see more education, direction, and strategies on how to advocate for patients in real time and implement changes within their health organizations. Specific suggestions for education included more tangible resources that may be used in practice to advocate for patients and educate others (i.e., co-workers) on

social justice, education on biases, and advocacy for other underserved populations. For example, participants mentioned patients with disabilities, and those experiencing homelessness and/or substance abuse as presenting challenges. Also, the participants wanted more opportunities to 'dive deeper' into the challenges the 2SLGBTQIA+ community faces, and further education on communicating using appropriate concepts, such as pronoun utilization. Future workshops, intensive learning opportunities, and the creation of advocacy tools were also suggested. Participants also recommended that this work and resources should be brought to oncology centres across Canada, and that in doing so, this would allow engagement of the multidisciplinary team. In their evaluations, participants stated that they would like to see more information on how to make changes in their healthcare organizations, and the nursing profession as a whole; providing specific strategies at each level, individual, organization and health system would be helpful.

#### Next Steps

Advocating for all people affected by cancer has been identified as a priority for CANO/ACIO in its 2021–2025 Strategic Plan (CANO/ACIO, 2022). Addressing social injustice and health inequities in cancer care for underserved and/or vulnerable populations through advocacy is one tool nurses can use to work towards advancing social justice in oncology. It is clear from the rich discussion and evaluation of the 2022 workshop that advocacy and social

justice in cancer care are key areas of interest across the CANO/ACIO membership. As oncology nurses, we have a professional responsibility to address social injustices for underserved and priority populations across the cancer continuum within Canada. Findings from the discussions at the workshop and the post-workshop reflections will be used to inform the ongoing work of the CANO/ACIO UPP Working Group. We anticipate this will include creating actionable recommendations for CANO/ACIO's advocacy activities. This work is an important step towards ensuring those affected by cancer have the resources and tools needed to access high-quality care that is culturally safe at any point of their cancer journey.

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