Inequities in cancer care among transgender people: Recommendations for change

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ABSTRACT
Owing to a shift in social attitudes and human rights standards, health inequities experienced by gender minorities are gaining an increasing spotlight globally. Transgender (trans) is an umbrella term used to describe individuals who have a dissimilar sex, gender identity and/or gender expression than what was designated at birth. Recently, studies have sought to identify health disparities and barriers to care among this population. While oncology-focused research remains limited, the social determinants of trans health elicits a significant impact on transgender people across the cancer continuum and, thus, requires further examination. The purpose of this paper is to explore the issue of trans health inequity in the context of Canadian cancer care highlighting current clinical practice, as well as gaps in research, provider education and health care policy. The paper will conclude with recommendations for policy development and a reflection on the oncology nurse’s role in advocating for change.

Owing to the increasing visibility of gender minorities in popular culture, a shift in social attitudes has pushed health disparities experienced by transgender people to the forefront of global responsibility (Thomas, Pega, Khosla, Verster, Hana, & Say, 2017; James, Herman, Rankin, Keisling, Mottet, & Anaf, 2016). Transgender (trans) is an umbrella term used to describe individuals with non-traditional genders including those who have a dissimilar sex, gender identity and/or expression than their natal assignment (Lombardi & Banik, 2015). According to Thomas and colleagues (2017), there are an estimated 25 million transgender individuals globally and the population is growing. Existing literature highlights the extreme physical, functional and behavioural health disparities experienced by transgender people prompting advocacy groups to push for additional research addressing the health care needs of this population (Gonzales & Henning-Smith, 2017; Levitt, 2015).

Although there is a growing body of literature investigating trans health issues, studies to date have focused primarily on mental health and substance use, as well as sexual health and its related infections (Braun, Nash, Tangpiracha, Brockman, Ward, & Goodman, 2017). While oncology-focused research remains limited, recent literature highlights several barriers to care that can elicit a significant impact on transgender people across the cancer continuum (Lombardi & Banik, 2015). Through advocacy and education, oncology nurses are uniquely positioned to improve access to transgender-sensitive environments and address the health disparities experienced by this population (Levitt, 2015). The purpose of this paper is to explore the issue of trans health inequity in the context of cancer care highlighting current clinical practice, as well as gaps in research, provider education and health care policy. Through a social determinants of health lens, I will identify the importance of policy development to improve cancer care among transgender people and conclude with a discussion of the oncology nurse’s role in advocating for change.

CANCER DISPARITIES AMONG TRANSGENDER PEOPLE: LITERATURE REVIEW

Barriers to Care and Discrimination
While trans people encounter similar cancer care needs as the general population, they are faced with a multiplicity of challenges contributable to social and institutional factors (Thomas et al., 2017; Lombardi & Banik, 2015). Lombardi and Banik (2015) argue, the social determinants of health elicit a significant impact on access to care and, consequently, trans health outcomes. Evidence suggests trans individuals experience elevated rates of violence, stigmatization and marginalization, as well as legal, economic and social deprivation (Thomas et al., 2017; Levitt, 2015). In fact, a recent survey of nearly 28,000 trans individuals in North America revealed that this group suffers three times the rate of unemployment compared to the general population and nearly one-third of respondents live in poverty (James et al., 2016). This serves as a barrier to cancer care, as a result of limited access to social services and health resources, insurance, and mental health support (Lombardi & Banik, 2015). Notably, rates of discrimination and poverty are compounded in trans people of colour and individuals with disabilities (James et al., 2016).

Discrimination can also have a significant influence on help-seeking behaviours and patient retention (Lombardi & Banik, 2015). Evidently, nearly 25% of survey respondents reported postponing or foregoing needed medical attention due to fear of stigmatization. Furthermore, more than 30% of individuals noted a negative experience related to their gender identity within the health care system (James et al., 2016). In the context of cancer care, discrimination has been shown to adversely affect uptake of cancer screening, access to oncology services, treatment adherence and cancer outcomes (Lombardi & Banik, 2015; Levitt, 2015; Rice & Schabath, 2018).
Cancer Risk
While cancer prevalence in trans people is largely unknown, this population may experience risk factors and behaviours that predispose them to various cancers (Ceres, Quinn, Loscalzo & Rice, 2018). Existing literature argues trans people are disproportionately affected by anxiety, depression and suicidal ideation as a result of gender-related discrimination (Shetty, Sanchez, Lancaster, Wilson, Quinn, & Schabath, 2016). Consequently, evidence suggests trans individuals may disproportionately employ mechanisms of coping associated with cancer risk such as cigarette smoking, substance abuse and alcohol use (James et al., 2016). Furthermore, according to Ceres and colleagues (2018), trans individuals are five times more likely to be diagnosed with human immunodeficiency virus (HIV), which has been associated with an increased incidence of anal, lung, liver and cervical cancer, as well as Kaposi sarcoma and non-Hodgkin’s lymphoma. In addition, several studies have highlighted an increased prevalence of human papilloma virus (HPV) among this population, which is also associated with various cancers (Lombardi & Banik, 2015).

Although the use of gender-affirming hormones in this population may pose additional risk to developing hormone sensitive-cancers, research has proven inconclusive (Braun et al., 2017; Lombardi & Banik, 2015). Contradicting views within the literature highlight the urgency for higher powered studies that consider outcome differences among various demographics, as well as investigation into the long-term use of hormones, as individuals seek gender-confirming treatments at younger ages (Lombardi & Banik, 2015).

Current Cancer Research
Current research regarding cancer risk and treatment within the transgender community has several limitations. Markedly, there is an absence of large-scale prospective studies among transgender people (Braun et al., 2017). Furthermore, cancer incidence, prevalence and outcomes remain difficult to ascertain owing to a lack of sexual orientation and gender identity reporting on national cancer registries (Braun, et al., 2017). Consequently, research has been mostly limited to case studies and anecdotal references which, to date, have predominantly focused on biological risks for cancer among this group (Watters, Harsh & Corbett, 2014).

While transgender people have voiced the need for research to address the impact of discrimination within health care, there is a significant lack of data exploring the psychosocial aspects of cancer care in this group (Lombardi & Banik, 2015). Furthermore, despite evidence of increased marginalization and discrimination experienced by transgender people compared with other sexual minorities, cancer research has historically combined lesbian, gay, bisexual and transgender (LGBT) groups. Moreover, literature exploring the impact of intersectionality (the interconnected nature of different social groups including race, gender and class) among transgender individuals is also limited (Kamen, Mustian, Dozier, Bowen, & Li, 2015). Consequently, most available research has inappropriately assumed homogeneity within gender and sexual minority groups when variabilities in cancer care needs and risk are likely substantial and require further investigation (Braun et al., 2017; Ceres et al., 2018).

Recently, the American Society of Clinical Oncology (ASCO) articulated an urgent need to address the disparities experienced by sexual and gender minorities within cancer care. The position statement included a call for further research into cancer inequities in order to improve outreach, education and emotional support programming for transgender populations (Griggs et al., 2017). Notably, since the position statement was released, several articles have been published evaluating the current state of cancer care in sexual and gender minorities. Advocacy groups are hopeful that this call for research will provoke policy, procedure and education development regarding trans cancer care needs and improve access to culturally safe care for these individuals.

CURRENT CLINICAL APPROACHES TO TRANSGENDER CANCER CARE
Oncology Health Care Providers
Shetty and colleagues (2016) argued the absence of knowledge, familiarity and inquiry about LGBT care needs serves as a significant barrier to cancer care. In a recent study, 1,253 oncology health care providers (HCPs), including physicians, advanced practice professionals and nurses, were surveyed to assess for their knowledge and beliefs about LGBT oncology patients. Results showed that while more than 80% of participants have cared for LGBT individuals (28% had taken care of a transgender patient), fewer than half of the HCPs were able to correctly answer up to three out of seven knowledge questions (Banerjee et al., 2018). This finding is mirrored by results from the National Transgender Discrimination Survey where more than 50% of respondents claimed they had to educate their HCPs about transgender care (Levitt, 2015). Likely, this lack of knowledge is a direct result of the restricted sexual and gender minorities education in both medical school (~5 hours) and baccalaureate nursing programs (~2 hours) across North America (McDowell & Bower, 2016). Importantly, while the majority of HCPs are willing to care for gender and sexual minorities, most recognize the need for further knowledge, sensitivity and communication skills training to improve cancer care for LGBT individuals (Banerjee et al., 2018).

A pervasive theme in literature on transgender health inequities is HCPs’ expressed desire to “treat all patients the same” (Shetty et al., 2016). This is problematic because it disregards patient diversity, neglects the impact of social determinants of health on patient outcomes, perpetuates structural violence, and contradicts person-centred care. Evidently, fewer than 40% of transgender individuals report that their current HCP knew of their gender identity (James et al., 2016). Clinically, this has several implications in cancer care including patient comfort and patient-provider relations, referral to appropriate cancer screening, treatment adherence, and patient retention (Ceres et al., 2018).
Guidelines and Policies

Cancer screening. Owing to fear of discrimination within the health care system, difficulties disclosing gender identity, limited LGBT specific resources, and knowledge gaps by health care providers, cancer screening in trans communities is lower than the average population (Canadian Cancer Society, 2018). Consequently, cancers diagnosed in trans individuals are often found at more advanced stages and are, therefore, more difficult to treat. According to Rice and Schabath (2018), because trans people are at a higher risk for certain cancers, routine screening for breast, prostate, anal, and colon cancers could be instrumental in detecting potentially fatal malignancies.

To better improve cancer screening in trans gender individuals, Ceres and colleagues (2018) recommend that health care providers follow organ-based routine guidelines for cancer screening of all transgender patients. Specifically, they state that if an individual has a particular body part that meets the criteria for screening based on risk factors or symptoms, investigation should proceed regardless of hormone use or gender affirming surgery. Furthermore, the Centre of Excellence for Transgender Health and the Canadian Cancer Society have released comprehensive screening guidelines for the care of transgender individuals, specifically for individuals who have undergone gender affirming therapy. These are examples of helpful tools for both transgender individuals and HCPs to ascertain cancer risk and advocate for necessary screening (Canadian Cancer Society, 2018; Levitt, 2015).

Health Care Policy and Systems. While there is a push from advocacy groups for a greater awareness of transgender issues within the health care system, there is less evidence of support at mezzo and macro government levels. For instance, in a systematic review of Canadian policy and research documents, Mule and Smith (2014) argue that marginalization of the LGBT communities in federal policy renders this population invisible. Consequently, they state that while the federal government is not accountable for the distribution of health care to most Canadians, it is imperative to include sexual and gender minorities within health policy in order to set a discourse for provinces and territories to follow.

Despite the general lack of transgender issues in federal policy, there has been some progress at the provincial level. In 2012, Bill 33 “Toby’s Law” was passed by the Ontario government, which amended the human rights code to legally protect gender identity and expression from discrimination (Government of Ontario, 2012). However, the Ontario New Democratic Party states that, despite Bill 33, transgender individuals still experience extreme health inequities (including several barriers to care) and makes an urgent call for further inclusion in future health policies (Ontario NDP, 2017). Optimistically, at the micro level, several hospitals in downtown Toronto have created gender identity and expression policies to ensure discrimination-free environments for transgender people (Mount Sinai Hospital 2012; St. Michael’s Hospital, 2017; University Health Network, 2016). To date, there are no Canadian policies specific to transgender cancer care.

Recommendations for Change

Oncology nurses are ideally positioned to influence change within the health care system. As point-of-care staff, nurses bear witness to the impact inequity within the social determinants of health can have on marginalized populations. Historically, nurses have maintained a commitment to negate social injustice and inequity through holistic care and patient advocacy (Vacroe, Browne, & Gender, 2017). In order to reduce the inequities experienced by gender minorities in cancer care, oncology nurses should align with the transgender community to campaign for policy change at macro, mezzo and micro levels.

Mule and Smith (2014) argue that a macro-level discourse of transgender inequities is critical in the reduction of health disparities experienced by this population. Notably, transgender individuals encounter significant inequity within the social determinants of health, which have considerable implications on access to cancer care and cancer outcomes (Lombardi & Bank, 2015). The invisibility of gender minorities in federal health policy perpetuates the structural violence experienced by this population and, consequently, fosters discrimination in government, employment, education and health care institutions. Engaging with the transgender community, oncology nurses should advocate for policy change to legally protect gender minorities from discrimination in these institutions. In turn, this could improve education and employment rates of this population, therefore increasing access to insurance, mental health resources and HCP positions. Moreover, this will set the tone for provincial and municipal policymaking, which can improve access to care through gender minority research, provider education and culturally safe health care programming.

To date, credible research on transgender cancer care is sparse. Researchers have made several calls for further investigation into cancer risks, prevalence, treatment and outcomes in this population (Watters, Harsh & Corbett, 2015; Braun et al., 2017). Moreover, the transgender community has specified the need to assess discrimination within cancer care, as well as the psychosocial issues experienced by gender minorities in this context (Kamen et al., 2015). Consequently, oncology nurses should advocate to increase gender minority research funding and exploration. For adequately informed cancer research, Braun and colleagues (2017) argue that investigation must include larger sample sizes, records of natal sex and gender identities, as well as detailed data on treatment. Therefore, it is imperative to advocate for public health policy to promote sexual and gender minority disclosure within health care settings and include this information on national cancer registries (Braun et al., 2017). Better empirical data from large-scale studies can subsequently inform areas of need in provider education and transgender support programs. It can also evaluate the impact of trans-specific cancer care initiatives.

Policy change at the mezzo level should focus on improving HCP education. Nurse educators should advocate for policies to increase the number of education hours devoted to studying transgender health needs, as well as education funding to develop culturally sensitive health care curriculums (McDowell & Bower, 2015). To dismantle the discrimination
experienced by transgender communities within health care institutions, medicine and nursing curriculum must be informed by an intersectional lens that considers the impact of structural marginalization and the social determinants of health on gender, class, race, and ethnic minorities. Notably, Varcoe and colleagues (2014) argue, individuals who have personally experienced marginalization are likely more attuned to others’ similar experiences. Therefore, nurse educators should also advocate for policies that require educational institutions to recruit sexually and gender diverse students, as well as educators to decrease discrimination and improve cultural diversity within health care.

At the mezzo level, provincial cancer agencies set the stage for oncology care across health care institutions. Therefore, policy development should also be directed at these agencies to create trans-specific oncology resources for both HCPs and patients. Education regarding transgender risk factors, psychosocial care needs and the implications of hormone use on cancer treatment planning is required to better inform cancer screening, therapy, and future program development (Rice & Schabath, 2018). Furthermore, cancer agencies should serve as a source of information regarding local cancer support groups for gender minorities, survivorship resources, palliative care and referral to trans-sensitive HCPs.

Within health care institutions (micro level), nurse leaders should advocate for anti-discrimination policies that promote culturally safe and equitable cancer care for all. This should include regular training regarding sexual minorities that teaches transgender affirmative language and gender-sensitive assessments (Levitt, 2015). Furthermore, it should incorporate a mandate to hire sexually and gender diverse employees to improve cultural diversity within the institution. It is also essential that nurses advocate for the development of trans-relevant resources such as posters, pamphlets and online content that depict images of gender diverse patients and inclusivity. Most importantly, nurses must advocate for gender diverse individuals to sit on patient advisory committees in order to ensure trans patient engagement in quality improvement initiatives (Rice & Schabath, 2018; Lombardi & Banik, 2015).

Expected outcomes of policy change at macro, mezzo and micro levels include an increase in transgender cancer care research, improved cultural competency of HCPs through formal education and ongoing sensitivity training, as well as the development of culturally diverse and safe health care institutions. In turn, this should result in an increase of cancer screening among transgender individuals, better patient-provider relationships, and improved treatment adherence and cancer outcomes.

CONCLUSION

Transgender people experience some of the greatest health disparities in the world (James et al., 2016). While oncology-focused research is limited, drawing on evidence from the social determinants of health suggests gender minorities are at an increased cancer risk and experience several barriers to care. Oncology nurses can play a pivotal role in dismantling transgender cancer care inequities through advocacy for policy change at micro, mezzo and macro levels. Importantly, oncology nurses are well placed to engage with the transgender community in order to develop research, programming, education, and trans-relevant resources that can build accessible, culturally-safe cancer care.

REFERENCES


