

## ***Socially-based Inequities in Breast Cancer Care: Intersections of the Social Determinants of Health and the Cancer Care Continuum***

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*Rapid advances in the field of medical imaging, drug development and genomics have paved the way for revolutions in the way breast cancer is treated and managed, such that the five-year survival for breast cancer in Canada averages 88%. Despite advances in treatment and overall survival, vast disparities by material advantage or disadvantage, occur across the entire breast cancer care continuum. As a result, individuals who are lower down the socioeconomic ladder are more likely to have cancer diagnosed at a later stage, and have less availability to basic resources such as nutritious food and prescription drug coverage. In Canada, increasing austerity measures have resulted in higher levels of income inequality, deepening poverty, homelessness and growing precarious working conditions. By applying an ‘intellectual double shift’ on the breast cancer care trajectory, this paper serves to advance the discussion of what it means to consider the intersections of power, resources and opportunities in creating gendered social and health inequalities. It is through this illustration that we are able to conceptualise how the foundations of health equity are built upon social equity, and one cannot be achieved without the other.*

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For each woman, her perceptions of life, and the very realities that exist for her are unique, and depend on the social and political constructions of gender and gender roles within the context of her environment (Hankivsky et al., 2010; Lincoln & Guba, 1985). At the macro level these realities are shaped by women’s interaction with institutions and providers; whereas, at the micro level power relationships within a household delineate a different pattern of existence (Rogers & Kelly, 2011). Gender roles are known to influence women’s susceptibility to disease, opportunities to access care, and associated morbidity (Iyer, Sen, & Ostlin, 2008).

Gender has traditionally been thought of as a dichotomy between male and female. Increasingly however, there is a call to refrain from categorizing women as a single group (Hankivsky, 2005), and to recognize the intrinsic heterogeneity that exists between women as a result of their social location (Hankivsky et al., 2010). In this regard, intersectionality theory has been instrumental in teasing apart some of the complex and compounding factors that determine women’s health (Hankivsky et al., 2010). When viewed via an intersectional lens, gender is not essentialized. Rather, elements of social class, race, sexual orientation, and disability are viewed

as working in tandem with gender, creating opportunities or challenges at the point at which they intersect (Hankivsky et al., 2010). This point, the social location, is the crux of where oppression transpires. It is the point where social inequities arise.

From a critical social theory perspective, one must consider, in addition to social identities, the role of the dominant social relations (Young, 2002; Smith 1990). Society is structured in a way that imparts privilege and advantage to some at the expense of others. Common practices, availability of resources such as time and money, and the opportunity of choice, have all been defined as “structures of constraint” (Young, 2002). For women, these structures add an additional layer of complexity to their social location and can be conceptualised by considering the intersections of power, resources and opportunities (Weldon, 2006; Young, 2002).

The term “intellectual double shift” was first introduced by feminist criminologists (Daly & Maher, 1998) to illustrate their dual task of unpacking gender and gender roles as defined by discourse, and then describing in addition to this the impact of gender inequality in ‘real life.’ This meso-level of theorizing is important to integrate into overarching descriptions that may not capture variations between different population groups, and is particularly useful in understanding specific social contexts and situations (Cullen, Wright, & Blevins, 2011).

By using social location as a point of reference on which to base intersections of power, resources and opportunities, we can begin to understand how structural inequality, as represented by the social determinants of health, can influence opportunities for care. Exploring socially-based inequities in breast cancer care is an example of a ‘real world’ situation. An illustration of where the rubber hits the road on when, how, and which, women can survive cancer; conferring a relative advantage to some over others.

As such, this paper seeks to become the analytical lens through which we can apply an “intellectual double shift” (Daly & Maher, 1998) in the process of cancer care in Ontario. First, by demonstrating how social inequality creates “structures of constraint” (Young, 2002) for the socially disadvantaged, and second, by illuminating through the example of breast cancer care how the process is highly gendered, placing some women in positions of extreme vulnerability.

### ***Social Determinants of Health and Cancer***

The social determinants of health are the living and working conditions in which we are born, grow, work and age. These conditions shape our daily lives and impact our opportunities for health. They are themselves determined by social and economic policies of the jurisdictions in which we live (Marmot, Friel, Bell, Houweling, & Taylor, 2008). Intermediate indicators of the social determinants of health, such as income and education, have been used to demonstrate how significant material advantage is for the health and well-being of populations. These indicators highlight how the unequal distribution of resources can lead to a two to three-fold higher risk of age-adjusted mortality for the socially disadvantaged versus those at the highest rung of the socioeconomic ladder (Marmot et al., 2008). For cancer, the lack of material resources places individuals at an increased risk of cancer (Hiatt & Breen, 2008), poorer quality of life (Fenn et al., 2014) and a higher rate of cancer-related mortality (Booth, Li, Zhang-Salomons, & Mackillop, 2010).

In Canada, despite a publicly funded health system, population-wide cancer disparities persist (Maddison, Asada, & Urquhart, 2011). The “synergies of oppression” framework

illuminates the intersections of social identities, social geography and the social determinants of health (McGibbon & McPherson, 2011), and can be useful in understanding these disparities. For starters, it has been hypothesized that social group membership influences cancer-related outcomes through: (i) increased discrimination against individuals based on social identity, leading to higher levels of stress; (ii) similar patterns of disease awareness and prevention habits within a group that can be detrimental to cancer detection; and (iii) differences in biomedical approaches to treatment for different groups (Harwood & Sparks, 2003). This is particularly apparent when considering cancer mortality differences between Black and White racial groups. Statistics continue to demonstrate poorer cancer outcomes in ethnic minorities such as Blacks, who tend to present with more advanced stage tumors that are biologically more aggressive and resistant to treatment (Gerend & Pai, 2008). In addition, screening is particularly troublesome for ethnic minorities and new immigrants due to cultural and linguistic barriers (Canadian Partnership Against Cancer, 2014), and may partially be due to lower levels of health literacy (Groome, Schulze, Keller, & Mackillop, 2008)

Social geography is a spatial construct through which we are able to contextualise differences in cancer outcomes and care. For example, the stage at presentation, and preferred treatment modality can vary based on urban or rural location (Canadian Partnership Against Cancer, 2014). In addition, increased exposure to environmental carcinogens disproportionately affects the poor and working class (McGibbon & McPherson, 2011). Furthermore, racial segregation and ghettoization of neighborhoods leads to geographical polarization of ethnic groups into economically-deprived areas that can limit their ability to access fresh food, recreation, and healthcare (O’Keefe, Meltzer, & Bethea, 2015), all of which are known to potentially increase the risk of cancer.

While education and income have both been used as intermediary indicators for the social determinants of health, income and other measures of economic deprivation such as poverty, have shown to correlate well with socioeconomic status (O’Keefe, Meltzer, & Bethea, 2015). Studies using income to highlight disparities in cancer care have demonstrated how individuals from lower socioeconomic groups are more likely to present with advanced stage cancers than those from higher income strata (Woods, Rachet, & Coleman, 2006). It is postulated that this result is due to an overall lack of awareness of screening programs, and unavailability of resources such as transportation and childcare, that can facilitate the utilization of diagnostic services (Canadian Partnership Against Cancer, 2014). Overall, low-income groups participate less frequently in preventative screening for cancer than higher income groups (Canadian Partnership Against Cancer, 2014).

Interestingly, socioeconomic differences in cancer-related mortality are still observable if we control for tumor stage and size. In a study of 38,000 cancer patients in Ontario, variations in tumour stage at the time of diagnosis by socioeconomic status were minimal, but a survival gradient from the lowest to the highest income quintile was clearly apparent (Booth et al., 2010). It is suggested that socially disadvantaged cancer patients have more aggressive tumors (Booth et al., 2010), compromised immune systems (Groome et al., 2008), associated comorbidities (Booth et al., 2010) and differential access to treatment (Woods et al., 2006).

Several theories elaborate how social inequalities create both absolute and relational deprivation resulting in poorer health outcomes for the socially disadvantaged (Wilkinson, 1997). In 1998, Dr. Samuel Broder, in his position as the Director of the National Cancer Institute, USA declared that, “Poverty is a carcinogen”. Indeed, poverty and cancer are deeply

intertwined such that poverty becomes a precursor to biological risk through mechanisms such as: (i) increased workplace and household environmental exposures to carcinogens (Hiatt & Breen, 2008); (ii) higher levels of stress which downregulate the immune system enabling tumor growth (Woods et al., 2006); and (iii) an increased uptake of risky lifestyle behaviors such as smoking which directly trigger cancer-causing gene mutations (Hiatt & Breen, 2008). Furthermore, poor income is directly associated with a lack of material resources such as nutritious food and prescription drug coverage (Marmot et al., 2008) which can result in adverse cancer-related health outcomes.

It is questionable whether social identities are more powerful in determining tumor biology and clinical behaviour, or whether it is the social constructs of marginalization, deprivation and poverty, all of which are known to occur disproportionately in ethnic minorities, recent immigrants, the elderly, disabled and women (McGibbon & McPherson, 2011). It is plausible that indeed it is the intersections of these elements working in tandem, and often synergistically, that pattern cancer risk, burden and survival.

### ***Socially-based Inequities in Breast Cancer Care***

Approximately 70 women are diagnosed with breast cancer in Canada every day (Canadian Cancer Statistics, 2015) Furthermore, it remains the most common cause of cancer-related mortality in women after lung cancer (Canadian Cancer Statistics, 2015), and on average one out of nine women will face the diagnosis of breast cancer over the span of their lifetime (Canadian Cancer Statistics, 2015). Significant research and development in breast cancer management and control have successfully decreased the mortality rate from 30.4 per 100,000 in 1992, to 21.7 per 100,000 in 2007 (Canadian Partnership Against Cancer, 2012).

Incidence and survival rates for breast cancer vary depending on income. In a study conducted in 2007, the incidence rate for breast cancer for women in lower socioeconomic groups was 93 per 100,000 women, versus 108.5 per 100,000 women in higher socioeconomic groups (Canadian Partnership Against Cancer, 2012). The increased incidence of breast cancer in higher socioeconomic groups has been attributed to increased awareness and utilization of screening mammography (Canadian Partnership Against Cancer, 2012). Surprisingly, despite the elevated incidence of breast cancer in higher socioeconomic groups, this same group of women has an almost five percent higher relative survival rate compared to women of lower socioeconomic groups (Canadian Partnership Against Cancer, 2012). Evidently, socially vulnerable women have poorer cancer-related outcomes. Indeed, disparities by material advantage or disadvantage occur across the entire breast cancer care continuum conferring a survival benefit to some women over others (Bigby & Holmes, 2005).

### ***Risk Reduction***

In a systematic review of the literature, Terry & Rohan, (2002) found that smoking for long periods as well as passive smoking can be linked to a higher risk for breast cancer. In addition, alcohol consumption increases the risk of benign breast disease that is a precursor to breast cancer, and the amount of alcohol consumed is directly proportional to the risk of developing breast cancer (Berkey et al., 2010). Furthermore, a 13 year follow-up study of invasive breast cancer found that grade two plus obesity is associated with: an elevated risk of breast cancer, more advanced stage at diagnosis, larger tumour size at diagnosis, increased risk

of metastasis and earlier death (Neuhouser ML, Aragaki AK, Prentice RL, & et al, 2015). Increased physical activity has been found to be protective against breast cancer and is associated with a reduced risk of both premenstrual (Maruti, Willett, Feskanich, Rosner, & Colditz, 2008), and postmenopausal breast cancer (Fournier et al., 2014).

As a result of these studies, and several others, cancer care experts preach the importance of the so-called “modifiable risk factors”: obesity, lack of physical activity, unhealthy diet, alcohol consumption, and occupational and environmental exposures (Canadian Cancer Statistics, 2015). However, health promotion activities which are strongly geared towards changing individual behaviours have been ineffective in influencing health risk (Scott-Samuel & Smith, 2015). On the contrary, they have shown to increase levels of stress and guilt as the ability to change health behaviours is patterned more by social structures such as class, gender, low income and social support, rather than individual choice (Daykin & Naidoo, 1995).

Risky lifestyle behaviours, such as smoking and alcohol consumption, are structured by the social determinants of health, and as a result, they are more common in lower socioeconomic groups (Marmot & Wilkinson, 2005). In Canada, women living in low-income neighborhoods are more likely to smoke, and have a higher incidence of obesity, leading to an inherently higher underlying risk of cancer to begin with (Canadian Partnership Against Cancer, 2014). Smoking is heavily class based and is often a coping mechanism in women experiencing the burden of care, lack of social supports, and financial constraints (Daykin & Naidoo, 1995).

Austerity measures that result in rising levels of poverty, homelessness, and an increase in precarious jobs that come without benefits, disproportionately affect women as a social group (Bezanson, 2006). The implications of deprivation and marginalization have long-lasting impacts on health. A nutritious diet that is rich in fibre and fresh fruits, for example, has been shown to reduce the incidence of breast cancer (Su et al., 2010). Clearly, this is a recommendation that is not plausible for women experiencing food insecurity. Furthermore, socially disadvantaged women may not have the option to choose their working conditions even if they were made aware of the increased risk of breast cancer that is associated with environmental exposures such as gamma radiation, and occupational hazards such as night-shift work (Weiderpass, Meo, & Vainio, 2011)

### *Access to Care*

In a report published by the Canadian Partnership Against Cancer (2012), disparities in breast cancer screening rates were observable between low income (61%) versus higher income groups (77%). In addition, screening rates for recent immigrants are approximately 30 percent lower than for long-term Canadian residents and citizens (Canadian Partnership Against Cancer, 2012) Studies have also demonstrated that women from lower income groups are less aware of screening programs, and lack material resources such as transportation or childcare (Douglas, Waller, Duffy, & Wardle, 2015), hindering their utilization of public health screening programs.

Social barriers to care such as racialization, marginalization and cultural misgivings of the health system disproportionately affect ethnic minority groups (Gerend & Pai, 2008). This finding is reflected in the widening disparity between Black and White patients with breast cancer, where Black breast cancer patients typically present at a younger age, and with a more aggressive phenotype that is resistant to treatment (Gerend & Pai, 2008). While this has been considered a racial difference in tumour incidence, social structural forces distinctly shape

opportunities for cancer risk and care. Higher levels of obesity and comorbidity in Black women play a role in elevated breast cancer risk; whereas, lower utilization of screening mammography, diagnostic delays and inadequate treatment protocols have been implicated in the poorer survival of Black women with breast cancer (Harper et al., 2009). Furthermore, the racialization of poverty, such that women of color are more likely than White women to be underemployed, underpaid, and discriminated against (McGibbon & McPherson, 2011) represents a distinct social disadvantage that likely underpins all other inequalities.

Advances in breast cancer treatment mean that 50% of intravenous chemotherapeutics can now be delivered orally and taken at home (Zurrida & Veronesi, 2015). Furthermore, breast cancer patients are more likely to take oral medications for prolonged periods of time, often several years (Zurrida & Veronesi, 2015). Lower income, high levels of co-payment, and lack of health insurance are all associated with lack of adherence to oral anti-cancer drugs (Taylor, 2014), which in turn is detrimental to long-term disease-free survival (Partridge, 2006).

In Ontario, the health intake assessment is a tool that is used to admit cancer patients into the system. Sinding (2010) used institutional ethnography to study the use of this document for the planning and delivery of treatment to cancer patients. Textually, the health assessment includes a detailed social history including the identification of emotional, physical and financial supports available to the cancer patient. However, in practice, Sinding (2010) found that only questions related to drug coverage and ease of transportation were regularly documented, and support services in the form of prescription medication, or free transportation to and from the center, were planned into the treatment protocol for these patients.

Support services are beneficial to women who are correctly identified and linked to relevant programs. They do nothing, however, to challenge or change underlying root causes, and are an example of biomedical hegemony, where elite groups make assumptions about the needs and wants of the less privileged. Such practices become norms and are reciprocated within institutions, and amongst providers, saliently placing socially disadvantaged women in a position of subordination and constraint (Young, 2002).

### ***Financial Implications of Cancer***

On average, cancer patients participate 36% less in the labour market, and lose about 26% of their income during the course of their illness (Bradley et al., 2008). Circumstances such as low levels of workplace flexibility are associated with increased job-loss, and a greater delay in return to work (Reeder-Hayes, Wheeler, & Mayer, 2015). Furthermore, when work absenteeism implies loss of income, cancer patients may choose to prioritise work over treatment (Sinding, 2010). In Canada, employment is not just a means of secure income, but also a means of procuring health benefits and entitlements that are not provided by the government.

In Canada, 70% of health care is currently covered by public funds, one of the least in the OECD nations (Bryant, Raphael, Schrecker, & Labonte, 2011). A further 16% of health care coverage comes through employer-based benefit plans (Taylor, 2014), whilst the remainder constitutes out-of-pocket costs paid by individuals themselves (Taylor, 2014), and include an array of expenses such as: prescription drug coverage, home nursing, rehabilitative services, devices, transportation, parking, food, accommodation, and family care (Longo & Bereza, 2011).

Several studies now document the financial burden of cancer such that one in six cancer patients in Canada feel that out of pocket costs are “significant” (Taylor, 2014). In Ontario, the

average cancer patient spends approximately \$600 out-of-pocket per month to cover all medical and non-medical expenses (Longo & Bereza, 2011). Interestingly, monthly out-of-pocket costs for breast cancer patients are significantly higher than for other cancers, and approximately 30% of breast cancer patients report these costs as “unmanageable”(Longo & Bereza, 2011).

Women with breast cancer pay an average of \$142 per month on personal devices such as wigs and prosthetic implants (Longo & Bereza, 2011). For other cancers, the monthly expense for personal devices is \$12 and pales in comparison (Longo & Bereza, 2011). The feminization of the female body, with societal pressure built around the norms and desirability associated with sexuality, create and drive these needs and norms (Drageset, Lindstrøm, Giske, & Underlid, 2011). In addition, breast cancer patients spend an average of twelve times more per month on family care than patients with other cancers (Longo & Bereza, 2011). This increased expense is not surprising given that caregiving is gendered, such that the role of social reproduction is predominantly taken up by women (Giesbrecht, Crooks, Williams, & Hankivsky, 2012). The economic burden of family care is a direct reflection of the unpaid caregiving provided by women to both children and the elderly of a household, and the vacuum that must be filled when the caregiver needs care.

In Ontario, Sinding et al. (2010) demonstrated how financially vulnerable women with breast cancer operate within a constrained budget, and how they often had to prioritize among medications, dietary needs and transportation. For these women, quitting work was not an option, despite increasing fatigue and nausea (Sinding, 2010). Breast cancer patients feel the economic pinch from both sides: On one hand they may have inadequate financial capacity as they are more likely to be uninsured and unemployed (Vissandjée, Weinfeld, Dupéré, & Abdool, 2001), and on the other hand they face higher monthly expenses due to the gendered nature of their disease (Longo & Bereza, 2011).

### *Quality of Life and Death*

Advances in therapy and prolonged survival of cancer patients mean that therapeutic goals are now increasingly concerned with the quality of life with cancer rather than just cure. Quality of life is a subjective experience that involves the physical, psychological, spiritual and social wellbeing for breast cancer patients (Maly, Liu, Liang, & Ganz, 2015). The empowerment of individuals to make informed decisions related to their care, as well as competent and culturally sensitive communication with health care providers, have all been shown to enhance the quality of life in cancer patients (Maly et al., 2015). On the contrary, stress, depression and financial difficulties are significantly associated with a poorer quality of life with cancer (Fenn et al., 2014; Sharp, Carsin, & Timmons, 2013).

The social determinants of health also predict the quality of cancer-related death, such that income, education, and social identities intersect to determine the location and level of palliative care received by terminally-ill women (Berger, Pereira, Baker, O’Mara, & Bolle, 2002). Up to 75% of cancer patients would prefer to die at home however in Ontario only 9% of cancer patients are able to do so (Barbera, Paszat, & Chartier, 2006). For women, social circumstances heavily influence this decision (Berger et al., 2002). Care at home requires caregivers. Studies have shown that caregivers who are younger, financially secure, and physically fit, are optimally placed to provide end-of-life care at home (Burge, Lawson,

Johnston, & Grunfeld, 2008). This is particularly so given that caregivers can lose up to 25% of their incomes as a result of caregiving responsibilities (Bradley et al., 2008).

Perhaps most disturbing are the indicators of a poor quality of end-of-life. The number of emergency department visits, and intensive care unit admissions within the last two weeks of life and death-in-hospital are used to measure the quality of end-of-life (Cancer Quality Council of Ontario, 2015). These indicators remain consistently higher in cancer patients from the lowest income quintile in Ontario (Cancer Quality Council of Ontario, 2015). Between 1998 and 2002, 52% of breast cancer patients in Ontario died in hospital, an average of 15% had a hospital admission prior to death, and approximately 12% experienced adverse events such as a bed sore, fall or injury during end-of-life care (Canadian Cancer Society's Advisory & Committee on Cancer Statistics, 2015).

## DISCUSSION

When we speak about health equity, we use phrases such as “horizontal” equity, implying that people with equal needs should receive equal amounts of treatment; and “vertical” equity, indicating that people may have unequal needs and that treatment should be proportionate to this need to create equality (Purificacion, French, & d'Agincourt-Canning, 2015). However, social inequalities that arise from hegemonic and oppressive relationships in society create a fractured and fragmented surface upon which we deliver healthcare. Therefore, the very concept of health equity, must itself be built upon a fundamental process of social equity.

One of the key features of the Ontario Cancer Care Plan IV (2015 to 2019) is its Equity Goal, through which Cancer Care Ontario strives to deliver “health equity for all Ontarians across the cancer system”(Cancer Care Ontario, 2015: p. 13). As a result, one of the direct objectives of the plan is to: “Develop locally relevant policies and programs in partnership with community service providers to improve access to services for specific populations and support healthcare providers with training, data and tools to deliver equitable services” (Cancer Care Ontario, 2015: p. 13). For Cancer Care Ontario, equity is discourses as access to care, and as a result high-risk populations are identified and targeted for priority interventions (Public Health Ontario, 2015).

By exploring the diversity that exists between women, and other structural forces that breed social inequality we can visualise what Harrison (2005) described as “lived experiences, social locations, and identities are, in various ways, conditioned by a matrix of power within which overlapping hierarchies of race, gender, and class are central” (p. 230). The process of cancer care itself is gendered, such that women are inevitably placed in positions of greater vulnerability as a result of low income and difficulties accessing care.

Within breast cancer, among women as a group, “relations of ruling” define which women are more likely to survive cancer and die with dignity. Bacchi (2004) encourages questioning the power of discourse, the ubiquity of affirmative action, and drawing attention to the underlying social inequalities. Indeed, to deliver cancer care that is equitable, and enables cancer patients to live and work in society. As such, cancer care must compliment social justice, and vice versa.

By identifying socially-based inequities in breast cancer care, the hope is to create a bridge between the biomedical and social aspects of cancer care. It is through this interface -that



successful healthcare can be achieved. To begin with, it is important to realise that the quality and distribution of the social determinants of health shape the degree of social advantage or disadvantage. These, in turn, produce inequalities in cancer risk, prevention, care and survival. This recognition has important implications. First, top-down interventions aimed at enhancing equity through the delivery of tailored solutions to priority populations is unlikely to redress disparities in cancer care. Secondly, the complexities associated with cancer morbidity and mortality can be illuminated by applying the lens of an “intellectual double shift”, and can be useful in policy development and evaluation. Finally, investments in social programs that reduce income inequality, and diminish social inequities, are a prerequisite to the attainment of health equity.

## CONCLUSION

Understanding the role of the social determinants of health as a driver of opportunities for health and recovery across the cancer care continuum has become critical, as therapeutic advances are shifting the location of cancer care from in-hospital to self-managed care at home. Furthermore, early detection and improved treatment mean that more people are surviving cancer and living with the implications of the illness across their life trajectory. Current public policy measures, however, have led to reductions in social spending that can significantly influence opportunities for cancer risk and survival. These measures do not consider the gender implications for women, and the diversity that exists among women. Austerity policies have the potential to increase the divide between rich and poor individuals with cancer. This public policy context must be recognized and resisted by those working in the cancer care community.

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