

Lower-Income Women with Breast Cancer Interacting with Cancer Treatment and Income Security Systems

JUDY GOULD

On ne connaît pas très bien la situation des femmes à petits revenus face au cancer du sein. L'auteure assure que parce que les cancers du sein ne sont pas diagnostiqués aussi fréquemment chez elles que chez les mieux nanties et que leur chance de survie sont moins élevées, il est important de comprendre l'expérience du traitement du cancer du sein et la survivance de la patiente.

A recent survey distributed to 397 Canadian men and women with cancer revealed that 50 per cent of those individuals encountered financial need at some point during their cancer diagnosis and treatment (Canadian Cancer Society). The financial burden for cancer patients is an under-investigated area of research (Moore 1998). In a few existing studies, financial burden is assessed by cataloguing direct costs such as expenses related to treatment (or out-of-pocket-expenses), rehabilitation, loss of savings, liquidation of assets, loss of income, and/or loss of a caregiver's income (Stommel, Given and Given). The out-of-pocket-expenses for a breast cancer survivor undergoing chemotherapy can include transportation, dispensing fees, medications, food and parking costs incurred at cancer centres, child care, home health aides, wigs, prosthetics, and alternative medicines/supplements (Moore 1999; Berkman and Sampson; Given, Given and Stommel).

Financial stresses also follow cancer treatment and can include perceived threats to job security and increased insurance premiums once, and if, cancer survivors return to work (Chirikos, Russell-Jacobs and Cantor; Hewitt, Breen and Devesa). The costs and loss of income that are related to cancer treatment and the financial stresses that occur following treatment have an even more profound effect on lower income women (Kasper).

Though lower-income women are diagnosed with breast cancer less frequently than are higher income women (Gorey, Holowaty, Laukkanen, Fehringer, and Richter), lower-income women have higher mortality rates (Lannin,

Mathews, Mitchell, Swanson, Swanson, and Edwards; Macleod, Ross, Gillis, McConnachie, Twelves, and Watt). The five-year survival rate for women with household incomes of less than \$20,000/year is 64 per cent compared to 76 per cent for women with household incomes of over \$50,000/year (Mackillop, Zhang-Salomons, Groome, Paszat, and Holowaty). Explanations for higher risk of death include that lower-income women have higher rates of co-morbidity (Kasper) and are more likely to present with advanced cancers than are higher income women (Farley and Flannery). Presenting later with cancer does not account fully for higher mortality rates. In one study with a sample of over 10,000 patients, researchers concluded that while lower-income women took longer to seek medical attention, stage differences at diagnosis could not fully explain differences in mortality (Karjalainen and Pukkala). Linda Wang, Katherine Arnold and William Mackillop *et al.* offer the viewpoint that differing mortality rates reflect systemic practices. Mackillop *et al.* posits that, "although Canada's health care system was designed to provide equitable access to equivalent standards of care, it does not prevent a difference in cancer survival between rich and poor communities" (1680).

This contention of unequal access despite a universal health care system is well-founded in epidemiological comparisons between those screened for breast cancer and those with breast cancer in the United States and in Ontario (Boyd, Zhang-Salomons, Groome, and Mackillop; Gorey *et al.*; Katz and Hofer; Mackillop *et al.*). For example, Chris Boyd *et al.* found that the poorest 20 per cent in both the U.S. and in Ontario had the same relative risk of death. Stephen Katz and Timothy Hofer discovered that lower-income women from the U.S. and Canada were less likely than higher-income women in those two countries to be screened for breast cancer. These authors believe that systemic barriers such as inability to leave work and difficulty with transportation or individual behavioral barriers such as the lack of knowledge

about breast screening and self-care practices could account for this discrepancy.

Most of the information collected about lower-income women with breast cancer in Canada is epidemiological. Relatively few studies document the experience of living with breast cancer for individual women. One survey investigation conducted in Canada revealed that lower-income women with breast cancer were less likely to seek supportive care services (Gray, Goel, Fitch, Franssen, Chart, Greenberg, Bakker, Labrecque, Holloway, Godel and Hampson). Another Canadian study concluded that

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lower-income men and women were less likely to seek services from medical specialists (Veugelers and Yip). Three investigations conducted in the U.S. found that compared to higher-income patients, lower-income patients more often encounter difficult interactions with health care providers (Lannin *et al.*; Underwood, Hoskins, Cummins, Morris, and Williams), have greater difficulty persuading their insurance companies to pay for their treatment, and have higher out-of-pocket treatment-related expenses (Kasper).

The information gathered from the aforementioned research provides an entry point to understand the barriers for individual women once they are diagnosed with breast cancer. The purpose of this study was to qualitatively explore the financial issues and concerns of individual lower-income Canadian women who have experienced breast cancer diagnosis and treatment in order to make visible their marginalized knowledge.

Method

Fourteen women who had a breast cancer diagnosis were consulted about their financial experience of breast cancer diagnosis and treatment as well as the financial resources they drew upon for support during and after their treatment. The women who participated in this study were, at minimum, one-year post-diagnosis and had lived below the Lower-income Cut-Off (LICO)¹ for at least the year of diagnosis and treatment for breast cancer. Because Canadian cancer centres do not collect information about a patient's income, the author relied on nurses from a community-based cancer organization, and primary care nurses from a local cancer institution to recruit women who they thought might be living in lower-income circumstances.

The author held in-depth interviews with ten of the 14 women. These interviews were between one to two hours in length. The author met with the remaining four women in a three-hour focus group. The women in the group opted to meet with the author in a focus group because all were members of the same support group they had founded years earlier and wanted to be interviewed simultaneously. All consultations were audiotaped and the author recorded field notes.

At the conclusion of the interviews/focus group the women completed a demographic form (including current age, age at diagnosis, education, relational status, diagnosis and treatment information, main work activity, and access to health insurance). Other demographic information such as employment prior to diagnosis, number of years living above or below the LICO, and relational status at diagnosis was collected during the interview. Following the interview/focus group all participants were offered a small honorarium. Once the analyses were completed all participants were mailed a summary report and all were encouraged to provide feedback to the author about the accuracy and relevance of the findings. The supervising health institution reviewed and approved the ethics application. Informed consent was sought and gained from all participants.

All participants completed a demographic form. The average age of women at diagnosis was 51.6 years of age. Twelve women identified themselves as Caucasian, one as West Indian, and one as Japanese-Canadian. All participants lived in a large urban centre in Canada. Eight of the women were diagnosed with Stage I or II cancer (i.e., they did not present with advanced cancers). The majority of the women had a secondary school education and eight women did not have an income-earning partner.

Nine women lived below the LICO before, during and after their diagnosis and treatment. The employment/income security for many of the women fluctuated over time. Six women did not have health insurance beyond that provided by the province.

A paid transcriptionist transcribed all interviews. The author analyzed the data from the transcripts, field notes, and demographic forms that were collected at each interview/focus group consultation. The author and a research assistant each read the first four transcripts and then met to formulate the coding framework (Patton, 1990). The codes developed initially were used to do a more detailed coding of the remaining transcripts using the NVivo qualitative software package. Once the detailed coding was completed, the author categorized and documented meaningful patterns found in the data.

Findings

The major theme found in all transcripts is entitled *Systemic Liabilities*.² This theme reveals how during the time of cancer diagnosis and treatment women reported

experiencing financial shortfalls that were either caused or exacerbated by the cancer treatment system, their workplace, the public insurance system and/or the private insurance system. This theme and its associated contexts are described next. All names associated with quotes below are pseudonyms.

Cancer Treatment System

All of the women discussed the fact that they could not afford the costs associated with cancer treatment. Women lacked access to money for transportation and medication-related expenses and fewer than half of the women knew of free services such as, breast cancer support groups. Only one woman knew of and used a free transportation service provided by a local cancer organization.

Traveling to Treatment

Adjuvant cancer treatment typically requires an individual to travel to a cancer centre or hospital to undergo surgery and/or chemotherapy and/or radiation which can take up to one year of time. Radiation treatment alone is generally administered five days a week for four to five weeks. Twelve of the women in this study needed to travel to receive adjuvant treatment. Though cancer institutions might offer reduced parking fees to patients, many women described having to pay for even these reduced fees as a “hardship.”

Five of the 12 women requiring transportation reported driving to the cancer treatment centre and were unconcerned about parking expenses. Of the remaining seven women, two women walked to and from treatments, three used public transit, one had friends drop her off and pick her up, and one woman took a state-funded taxi until she could no longer afford to pre-pay for this service. Pre-paying for transportation is a requirement of that particular provincial income support program.

In order to cope with the expense of getting to and from the cancer centre, the women asked their friends for rides, left their caregivers at home and took public transit alone, or missed their treatment appointments.

... the transportation thing ... that's a problem cause there's days I don't have the money ... one week I had a bone scan one day, the next day I had some other tests, then I had another test the third day and chemo ... I [would] phone and say I'm sorry but, it's not like I don't want to come but ... I was only getting \$500 [a month] at the time [from the provincial income security program] ... I go to [the cancer treatment centre] it's \$10 there, \$10 back. If I go three times a week there's \$60, four times \$60 is \$240. (Deanna)

Medication-related Expenses

The second financial liability introduced by the cancer treatment system to the women was the unanticipated costs of treatment medication. Women found it difficult

to pay the dispensing fees and those who did not have private insurance (n=3), could not afford supportive-care drugs, such as, anti-nausea pills.

... it's ten or eleven dollars depending which pharmacy you go to. And then even once my insurance ran out in February, I still had to have the drugs. So I still had to pay the dispensing fee on it...even that can be a hardship... (Rose)

So you're not anticipating that there's [anti-nausea]

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drugs out there that cost one hundred dollars a pill, you know? (Rose)

At the time of their treatment, four of five women from this study who were prescribed Tamoxifen—an adjuvant treatment medication typically prescribed to women for five year—were required to pay for it out of pocket. Although Tamoxifen is now covered by the Ontario provincial drug program and by most private health insurance plans, this happenstance illustrates that a gap exists between the time that medications are newly prescribed to patients and when basic provincial or private health insurance covers them. The Ontario drug program still does not cover some anti-nausea pills and other supportive care or “non-curative” drugs (such as anti-anemic agents) on its general formulary.

Workplace

The primary source of income for most of the women in this study came from part-time (n=8) or full-time (n=3) work. Because adjuvant treatment taxes bodies physically, many women who can afford to, take time away from work. For two women, leaving work during chemotherapy was not an option. Incidentally, both women required hospitalization mid-way through treatment: one woman suffered from exhaustion, the other woman, anemia.

And there were times that I was here [at work] that I shouldn't have been ... I mean, there were times that I couldn't even walk from my desk to the computer which was about three feet. [Would there have been another choice for you? Could you have not come to work?] Well ... financially no. There was no way... (Rose)

Returning to work following treatment was a physical and/or emotional struggle for most women. Following adjuvant treatment, many women left their paid workplaces because of debilitating side effects such as lymphedema (the painful chronic swelling of the lymph nodes restricting the range of motion of the arm [Swirsky and Nannery]), fatigue, and depression. Only one of three women maintained full-time employment. Of the eight women who had part-time employment prior to diagnosis, following treatment, five women resumed their part-time work, four women attempted to claim long-term disability, and

Just to get the unemployment benefits, the twelve weeks, which by law they have to give you.... I had to fight for it, and it took me about two months to fight for it. (Joanne)

One woman waited five months after filing for her Employment Insurance to commence. When EI did arrive, women reported that the financial compensation wasn't enough to cover expenses. Women also lamented that they needed to draw on their savings during the required 180-day lag time that occurred between the end

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one decided to volunteer (though her family needed her income, she couldn't find flexible part-time work). Moreover, when two women returned to work (one full-time and the other part-time) they faced what they felt was discrimination related to their cancer diagnoses.

Things started happening around that company in the fall and I found out ... in October that I was one of the first to be laid off... But we thought, because I'd been sick and I was senior that I did have grounds [to fight it], but I just didn't have the energy to do it... (Sally)

Public and Private Insurance Systems

Income security programs can alleviate financial concerns for those who have no other source of income. Types of income security include contributory social insurance programs (e.g., Employment Insurance or Canada Pension Plan), contributory private individual and group insurance programs normally offered through employers (e.g., long-term disability insurance), and non-contributory programs (e.g., provincial and welfare assistance programs) (Steinberg, 2001). Nine of the 14 women experienced a number of difficulties associated with acquiring income to replace lost wages. The participant's descriptions of their encounters with the public insurance system (contributory social insurance programs and non-contributory programs) and the private insurance system (private individual and group insurance programs offered through employers) will be considered next.

Public Insurance System

Women reported experiencing delays in receiving, or received less than they were entitled to, from Employment Insurance (EI).

of sick pay and the commencement of long-term disability insurance. Additionally, three women reported great difficulty accessing the Canada Pension Plan-Disability (CPP-D). Another two women stated that they were dissuaded from either applying to, or appealing declined decisions from the CPP-D.

Three of the study participants, Lucy, Marilyn, and Deanna, were participating in public insurance programs prior to their cancer diagnoses. Because these women were already "in the system" none of these women experienced income disruption. Although they all had difficulty affording transportation to and from the cancer centre, Marilyn, who was retired, remarked that she did not experience financial hardship throughout the time of diagnosis and treatment.

... I think I'm better off now than I ever was, even with the low income that I get ... I wouldn't dare think what it would be like if I didn't have that pension from the government.... It's just too horrible to think, I don't know where I'd be ... be on welfare.

Though her perspective is positive, it indicates the negative stigma of having to secure income from a last-chance source relied upon by many lower-income women in Ontario.

Private Insurance System

Following treatment, three of the 14 women found they were too ill to return to any form of employment. All three women had private insurance either through full-time work (n=1) or through their husband's insurance (n=2), all applied for long-term disability insurance, all were declined and so these three women were engaged in litigation with their private insurance companies. Vera,

who was suffering from lymphedema and who, at the time of the interview, was in the process of suing her private insurance company and had this to say:

... [the oncologist] told [the insurance company], not only could I go back to work, I could go back to my old job [but] I was the admin assistant for a community school where I was in there by myself for three quarters of the day.... I can't answer the phone and take messages down at the same time. I cannot bend down and do the filing. I cannot sit at a computer for long periods.

At the time of the interview the remaining two women had successfully settled their claims. These women discussed several problems associated with pending claim decisions and prolonged court proceedings. Consequences included the discontinuation of prescription coverage (while litigation was in process), the lack of income security from any source, and the stress associated with a court battle.

Discussion

All of the women in this research framed their financial experience around their interactions with health and income security systems. Many women concomitantly relied heavily on the systems for physical and economic survival and were pitted against them. Most women in this study incurred unanticipated treatment related costs and failed to obtain access to financial resources and/or seamless service from cancer treatment and insurance systems. Women in lower-income circumstances have lower survival rates relative to the survival rates of middle- and upper-income women. I cannot say with any certainty whether or not the resource and service barriers discussed in this paper increase the likelihood of a lower survival rate. However, disrupted treatment plans (due to the inability to pay for transportation or supportive care medication), and women's financial need to work through treatment with compromised health are of great concern and future research is warranted to understand how survival rates are affected.

Health professionals within the cancer treatment system must rally to assist women who have the least chance of surviving a breast cancer diagnosis. If cancer institutions recognized the shortfalls of the universal health care system, their health professionals could devise a system to flag patients who are at risk of financial distress and then refer those individuals to social workers or supportive care professionals. Health professionals could also work with community-based cancer organizations to arrange free transportation services and they could connect lower-income women with other women in similar circumstances (either in person or by telephone). Additionally, cancer treatment centre systems could work to organize the distribution of compassionate use (free) anti-nausea

medications and medical appointments could be arranged to take place on the same day. Health professionals located either in cancer institutions or in community based cancer organizations might also band together to advocate for the inclusion of supportive care drugs (such as, anti-anemic medication) on the provincial drug program's general formulary.

Ideally, given the rampant financial need, provincial and federal spending should focus on the funding of a resource centre created to tackle financial dilemmas of cancer patients. Staff at this centre could then advocate with, or on behalf of, women and men with cancer in order to agitate for increased access to services within the cancer-care treatments systems, workplaces, and the public and private insurance systems.

Lower-income women with breast cancer do not only struggle with a cancer diagnosis. These women are also sometimes winning, and sometimes losing a battle with large, unwieldy financial and health care systems. Health professionals must be aware of the repercussions of these experiences and be part of the solution to increasing the survival rates and quality of life of lower-income women with breast cancer.

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Judy Gould is a Social Scientist with the Ontario Breast Cancer Community Research Initiative (Sunnybrook and Women's College Health Sciences Centre), and an Assistant Professor in Public Health Sciences at the University of Toronto. Her qualitative dissertation work was completed in Psychology at York University. During the tenure of her graduate studies she was involved in several community-based and participatory projects with hospitals, school boards, community agencies, and mental health centres. Her post-doctoral fellowship included investigating the effects of psycho-education and support group participation on quality of life for individuals living with cancer. Recently, Judy has focused on understanding the issues/needs of low-income women, young women, and rural women who have experienced breast cancer.

¹The LICO entails spending more than 56 per cent of household income on food, clothing and shelter and is determined by Statistics Canada (Centre for International Statistics). LICO's vary by community and family size. Women from a large urban centre were considered to be lower-income if they made less than \$17,132/year (before

tax) and lived alone or if they made less than \$21,414/year (before tax) and lived with an income-earning adult.

²Other themes derived from the data and documented elsewhere include Claiming/Blaming; Below their Notice; Indebtedness, Job Fair?, Common Cents and Bankrupt Options (Gould).

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