

***Cancer Professionals' Views on the Financial Issues of
Lower-Income Women with Breast Cancer***

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*Cancer Professionals' Views on the Financial Issues of
Breast Cancer Patients*

INTRODUCTION

A recent survey distributed to 397 Canadian men and women with cancer revealed that 50% of those individuals encountered financial need at some point during their cancer diagnosis and treatment (Canadian Cancer Society, 2003). The financial burden for cancer patients is an underinvestigated 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 [OOPs]), rehabilitation, loss of savings, liquidation of assets, loss of income and/or loss of a caregiver's income (Stommel, Given, & Given, 1993). The OOPs 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 & Sampson, 1993; Given, Given & Stommel, 1994).

In an Ontario survey cataloguing the OOPs for cancer patients (N=282: 74 breast, 70 colorectal, 68 lung, 70 prostate), Longo et al., (2004a) identified OOP costs for drugs, homecare, homemaking, complementary and alternative medicines (CAM), vitamins and supplements, family care, travel, accommodations, and devices. Patients reported mean monthly expenses of \$213 excluding travel costs and \$646 including travel costs. Over 20% of respondents reported their financial burden as either significant or unmanageable. The OOP expenses for these individuals ranged from \$452 to \$544/month excluding transportation costs. Additionally, Longo et al., (2004b) found that the highest costs were associated with travel and accommodation (with average reported costs per month of

\$372 for mileage (range \$0- \$6180), parking/fares (\$47, range \$0 -\$450), and accommodations (\$43, range \$0- \$1500). High average costs were also reported for drugs (\$45, range \$0 - \$1400).¹ Longo et al., (2004b) also found that factors associated with increased OOP expenses include: younger age, no private insurance coverage, longer distances to the clinic, and more intense treatment.

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 & Cantor, 2002; Hewitt, Breen & Devesa, 1999). 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, 2002).

Though lower-income women are diagnosed with breast cancer less frequently than higher-income women (Gorey, Holowaty, Laukkanen, Fehringer, & Richter, 1998), lower-income women have higher mortality rates (Lannin, Mathews, Mitchell, Swanson, Swanson, & Edwards, 1998; Macleod, Ross, Gillis, McConnachie, Twelves, & Watt, 2000). The five-year survival rate for women with household incomes less than \$20,000/year is 64% compared to 76% for women with household incomes of over \$50,000/year (Mackillop, Zhang-Salomons, Groome, Paszat, & Holowaty, 1997). Explanations for higher risk of death include that lower-income women have higher rates of co-morbidity (Kasper, 2002) and are more likely to present with advanced cancers than are higher-income women (Farley & Flannery, 1989). Presenting later with cancer does not account fully for higher mortality rates. In one study with a sample of over 10,000

¹ The data is skewed by the small number of patients who reported OOP expenses. For example, only 39 of 277 reported any costs for assistive devices, but those who did often paid significant amounts.

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 & Pukkala, 1990). Wang and Arnold (2002) and Mackillop et al., (1997) offer the viewpoint that differing mortality rates reflect systemic practices. Mackillop et al. (1997) 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” (p. 1680).

This contention of unequal access despite a universal health care system is well-founded in epidemiological comparisons between breast cancer patients in the United States and in Ontario (Boyd, Zhang-Salomons, Groome, & Mackillop, 1999; Gorey et al., 1998; Mackillop et al., 1997). For example, Boyd et al., (1999) found that the poorest 20% in both the US and in Ontario had the same relative risk of death. Relatively few studies document the experience of living with breast cancer for individual women.

LOW-INCOME WOMEN AND BREAST CANCER PILOT STUDY

In a pilot study conducted in Ontario, Gould (2005) qualitatively explored the financial issues and concerns of individual lower-income Canadian women who had experienced breast cancer diagnosis and treatment.

Fourteen women who had a breast cancer diagnosis were consulted about their financial experience related to their 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)² for at least the year of diagnosis and treatment for breast cancer.

The major theme found across interview transcripts is entitled Systemic Liabilities. 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 workplaces, the public insurance system and/or the private insurance system. Only the concerns related to the cancer treatment system are relayed in this report³. All names associated with quotes below are pseudonyms.

All of the women in the pilot study 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 reported knowing of, and using, a free transportation service provided by a local cancer organization.

Traveling to Treatment

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.’

...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 five hundred (a month) at the time (from provincial income security program)...I go to (cancer

² The LICO entails spending more than 56% of household income on food, clothing and shelter and is determined by Statistics Canada (Centre for International Statistics, 1997). 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.

³ Please see Gould (2005) for a full rendering of women's experiences with their workplaces and private and public insurance systems.

treatment centre) it's ten dollars there, ten dollars back. If I go three times a week there's sixty dollars, four times sixty is two hundred and forty dollars. (Deanna)

Five of the twelve 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 this 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.

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) 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 years - were required to pay for it out of pocket. Although Tamoxifen is now covered by the Ontario drug program and by most private health insurance plans, this happenstance illustrates a gap between the time that medications are newly prescribed to

patients and when basic provincial or private health insurance covers those medications. The Ontario Drug Benefit general formulary does not cover anti-nauseate drugs or drugs to assist with anemia.

Working through Treatment

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 here...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)

Upon learning about the systemic experiences of lower-income women with breast cancer the next step was to understand how cancer professionals understood lower-income women's financial experience with breast cancer treatment.

THE CURRENT STUDY

Description and Methods

In September of 2003, this current study was initiated to advance understanding of the role of institutional factors concerning the economic experience of women with breast cancer. To this end we endeavoured to explore the experiences and perspectives of health professionals regarding the financial experience of low-income women with breast cancer. This study sought to understand health professionals' (working both inside the cancer institution and in the community) responses to:

- ◆ the above mentioned pilot study (Gould, 2005),
- ◆ their personal experiences with low-income women with breast cancer,
- ◆ the barriers they perceive to exist in the cancer care system,
- ◆ the strategies they employ to alleviate barriers,
- ◆ the resources they would like to see in place to support professionals to better assist these women, and
- ◆ recommendations for systemic change.

Steered by a research advisory committee comprised of cancer survivors, academic researchers, institutionally-based and community-based health professionals, three focus groups (n=18) were facilitated with oncology nurses, oncology social workers and community-based health professionals. In addition, the team facilitated nine in-depth interviews with surgical, medical and radiation oncologists, pharmacists, pharmaceutical representatives, community-based cancer organization professionals (herein referred to as community organization professionals), and public insurance representatives. All professionals worked in the area of cancer care in southern Ontario and all had worked in their profession for a minimum of one year.

An ethics review application was submitted and approved by the Sunnybrook and Women's College Research Ethics Board. All participants provided their informed consent to participate in the study. All interviews and focus groups (N=27) were conducted between December 2003 and May 2004. With the exception of the interview with the pharmaceutical representative, all interviews/focus groups were audiotaped and then transcribed. During the interview with the pharmaceutical representative, the interviewer was invited to take notes of their dialogue.

Both the research assistant and the principle investigator read all interview transcripts. To initiate the development of the coding framework, the research coordinator (Cameron) and the principle investigator (Gould) each read four transcripts, roughly coded the transcripts for emerging themes, and then met to formulate the coding framework. Next, the framework was constructed using the NVivo program and the remaining transcripts were coded using this computer software program. The members of the advisory committee read excerpts from anonymous transcripts, provided feedback on the emerging coding framework, and commented on the distillations of the preliminary analyses (Patton, 1990). The themes related to the experience of the institutionally- and community-based health professionals only are discussed in this report.

Findings

This section is divided into three main areas: Barriers (Identification of Need and Service Barriers), Access Strategies, and Recommendations. Main themes and sub-themes are presented and discussed within each main area.

Barriers

Identification of Need

"I wish it were easier to identify these people." (Nurse)

"If you don't ask and the patient doesn't say, nobody knows." (Oncologist)

Nurses, social workers, oncologists, and pharmacists discussed several formal and informal pathways that they utilized to attempt to identify the financial need of breast cancer patients. These mechanisms are discussed next.

Formal identification of financial need.

Health professionals based in one cancer centre discussed only one formal mechanism for identifying the financial need of women with breast cancer.

“When (patients) come to the centre they actually fill out...(an intake) sheet...which goes into the chart... on the first visit to whoever they come to see first (the medical oncologist or the surgeon)...it asks specially says do you have health care coverage and do you have any financial problems.” (Oncologist)

Theoretically, if a patient indicated financial need on the intake form, the nurse would then ask whether or not the patient would benefit from help from staff in the cancer system. If the patient required assistance then the nurse would make a referral to social work or would notify an oncologist who would then make a referral to social work.

“I think the current system works provided somebody actually looks at the (intake) sheet and actually asks the patient.” (Oncologist)

Unfortunately, the health professionals working at cancer centres expressed several problems with this identification mechanism. If a breast cancer patient indicated financial concern on the intake sheet, a referral to social work would not necessarily be generated. Social workers and nurses explained that an indication of financial need might not be addressed if the patient’s physical needs took precedence or if the financial needs weren’t considered pressing enough at intake.

“(if a patient indicates) yes there are financial concerns, no there’s no drug coverage... until something else cropped up...It’s a matter of the hierarchy of concerns...(financial need) may have been identified initially...but there may be far bigger, pressing issues related to their health care...the physical problems might override everything else.” (Social Worker)

“...(it’s) difficult to think about (financial need) with breast (patients) because they look comparatively healthy...that’s why...it doesn’t come so readily to mind... ‘hey, I should get them a social worker.’” (Nurse)

Another barrier is the patient’s reticence to indicate a financial concern on the intake form. The patient is provided with the intake sheet on only one occasion - at intake – and so the form problematically provides only a “single snap shot”. Given that, at

intake patients are not typically aware of their treatment plan and thus that cancer treatment will necessitate out of pocket costs.

“(the sheet) says ‘do you have any financial concern?’ and almost everybody puts ‘no’, but I don’t think they know what the form means...you’ve got the money to keep your head above water but that’s because you’ve been working all your life. You’re now going to be sick and not working.” (Oncologist)

Additionally, patients might question why the medical system would be interested in their financial affairs; they might be too embarrassed to indicate need; health professionals might not have enough time to explain the questions on the intake form; or, patients might not be aware that financial help is possible from income security systems.

“I think it’s something that a lot of people are really embarrassed about and they’re ashamed of. There’s still this taboo around being impoverished.” (Community Organization Professional)

“There’s a magic (intake) sheet. On the new patient’s first appointment there’s all these questions, two sided and you get about, what, five minutes to quickly go over it with them...certainly not enough time, one little question ‘do you have financial concerns’. And a teensy little space to put yes or no - really inadequate. And lots of people don’t answer it.” (Nurse)

Because the cancer care system lacks a workable formal mechanism for identifying patient's financial need, health professionals discussed how they informally come to understand patients' concerns.

Informal identification of financial need.

Study participants discussed several informal and haphazard mechanisms used to identify need and initiate access to financial resources for patients. Though not expressly oriented for inquiring about financial need, these mechanisms include direct conversations, indirect need triggers, and patient advocacy.

Direct conversations

Since the intake sheet does not necessarily generate a referral or describe the extent/meaning of future financial concern for patients, a few health professionals, but not all, actively inform patients that they could be set-back by the costs of medications, transportation, and/or the loss of income due to time away from work.

“ I ask every patient what drug coverage she has and what limit is it and to make sure with the drug company whether it’s a lifetime limit or a yearly limit or unlimited.” (Oncologist)

“That’s part of every discussion now with every patient that’s going to go on chemo because not all drugs are covered so you need to know whether they need to fill out a Trillium form. So in a way you get into how much money they have right away.” (Oncologist)

“...sometimes it has to be (a) pretty obvious, blunt question and sometimes the patients don’t like it when you are clearly prying into their financial state of affairs but it’s essential...The worst situation to happen is you don’t ask them, they turn up for the chemotherapy and on that day they’re given a bill for three or four hundred dollars for their anti-sickness drugs... You’ve done them more harm by not asking.” (Oncologist)

One oncologist explained that if s/he knows about financial need prior to the first chemotherapy treatment then s/he can work with a social worker to access financial help for the patient. Most health professionals were concerned that discussing financial issues in addition to providing information about treatment took too much time and was best left to cover after the first consultation with the patient and only when the decision to provide chemotherapy and/or radiation treatment had been made. Other health professionals were concerned that to broach the issue of possible financial crisis would simply cause the patient too much stress during and following the first visit.

“I don’t think that’s a fair thing to drop on somebody when they’re already...stressed.”(Nurse)

Indirect need triggers

Health and community organization professionals admitted that financial need was usually identified during happenstance or informal situations such as indirect conversations, implied concern expressed through a consultation letter between oncologists, and off-hand observations and circumstances. The following snippets of indirect conversations generally help prompt health professionals to identify that a breast cancer patient might have financial issues.

- when a patient says, *'oh I have to work (during treatment).'* (Oncologist)
- when the patient experiences *"a meltdown that...everything's just too much."* (Nurse)
- when the patient retreats into silence

"it doesn't come out point blank, you'll just hear little, I don't know, you get this feeling, they won't be able to verbalize it necessarily right out, but they'll say little things you sort of pick up on and...then other times they don't. They stay very quiet..." (Nurse)

"that really does come with intuition cause they don't always volunteer it...you've got to try and have your antennae up." (Oncologist)

- during radiation treatments if the patient expresses a concern about traveling to the centre so often
- if a health professional learns that the patient is a single mother

It is also possible for social information, collected during an oncologist-patient consultation, to be documented in the patient's chart (e.g. "young woman is alone with a child").

Information about a patient's financial need is also collected in off-hand ways. Health professionals noticed financial need when the patient behaves in a particular way

such as arriving to the cancer centre in a taxi or finds herself in a particular circumstance such as attempting to fill a prescription and discovering that she cannot afford the pharmacy bill.

Should these or other unfortunate circumstances come to the attention of oncologists, nurses, pharmacists or community-based cancer organization professionals, a referral to social work or to other financial resources would likely be generated.

Patient advocacy

"It's like the onus is on (the patient) to ask the question to get the information rather than it being given..." (Nurse)

For several reasons, including the failure of formal and informal identification of need pathways, the onus is frequently on the patient to express financial issues. Though we heard little about patient's self-identifying financial need from the health professionals based in cancer centres, community organization professionals relayed stories of patients who contacted cancer organizations when they were distressed about the costs of transportation, the inability to pay for anti-nausea pills, or the inability to afford or access a media-heralded drug.

Health professionals did express concern about the fact that the onus for financial information rested with the patient, caregiver, and/or family member. They pointed out that many cancer professionals expect patients to be aware of the workings of cancer or income security systems (these expectations will also be discussed in the next section as they relate to service delivery). Health professionals also felt that patient self-advocacy was an unrealistic expectation given the fact that these women are also newly confronted with a breast cancer diagnosis:

"When you're just diagnosed with something it's so overwhelming to deal with that, so unrealistic to have to then go out and navigate through all these systems and programs that you never even thought you'd ever have to use before..." (Community Organization Professional)

Service Barriers

Fragmentation of services.

"it's a very fragmented system" (Community Organization Professional)

Not only is financial need identified in a haphazard way, but service delivery as it relates to financial resources is also hampered within the cancer community. Health professionals explained that financial services do tend to exist but a resource to 'connect the dots' is lacking. For example, if social workers refer a patient to home care, the Community Care Access Centre (CCAC) might deem the service as unnecessary. There is a feeling among social workers that there are increasing restrictions in the services provided by CCAC's which limits patient access.

In addition, the lack of coordination of treatment services within the hospital increases costs to and from the cancer centre for breast cancer patients. For example, nurses attempt to batch patient appointments on the same day but if medical oncology clinics are running behind schedule (due to demand of service), patients are required to come back another day.

Cost-shifting: Patient as payer.

The next barrier discussed by the health professionals concerns the payer of prescription medication. As these costs escalate, governments, insurance industries and hospitals attempt to offset their own costs or shift the responsibility of the payer from the hospital to another institution, such as public or private insurance, or to the breast cancer patient. Because of their lack of power relative to insurance, government and hospital

systems, individual men and women with cancer are at ever increasing risk of shouldering the costs of prescription medication. For example, only drugs administered intravenously are paid for by the hospital or cancer system. Currently, there are pressures to administer oral treatment drugs so that some combination of the breast cancer patient, private, or public insurance companies will be forced to pay for this drug. A health professional provided an example of this cost-shifting:

"We started charging patients for it (Ondansetron)...ten years ago, and it was a cost saver, it was a cost shifting measure, we were using the intravenous form, we switched to tablet, we charged the patient, and it was cost-shifting, in other words, that amount of money in our budget we will use to buy chemotherapy drugs...so it was an economic decision and it didn't reduce cost to the system, it just shifted it to somebody else. The payer becomes the patient. And you know what patients are part of their treatment, they have to assume some responsibility for it as well and I'm not ever prepared to go back on that decision...and so our way around it is through the compassionate supply so no one who needs that drug goes without it." (Pharmacist)

The respondents were also aware of the cost-shifting pressures outside of the hospital system. Some health professionals noticed that patients were concerned about the disparities between provinces concerning the public system coverage of prescription drugs. Other health professionals were troubled that drugs not on the formulary in Ontario but that could improve patient's experience of treatment, such as Neupogen or Eprex, require Section 8 or Individual Clinical Review⁴ approval. These professionals noticed a greater likelihood of Section 8 approval for patients needing Neupogen whose cancer had not metastasized. These professionals hypothesized that the approval rate of this drug for patients whose cancer had metastasized was much lower because the drug

⁴Through the Ontario Drug Benefit (ODB) program, the Ministry of Health and Long-Term Care covers the costs of most prescription drug products for the majority of illnesses and conditions. In rare circumstances, a person may be unable to use any of the drug products covered by the ODB program. In other cases, new drugs approved for sale in Canada but not yet covered by the ODB program may be, based on the prescriber's opinion, the only treatment available to improve a patient's health. In these exceptional circumstances, a request for special coverage of a non-listed drug product not normally covered under the

could not be administered with curative intent (a criteria for inclusion on the drug formulary and a reason supportive care drugs are not usually covered by the Ontario Drug Benefit Program). The same holds true for coverage of Eprex – a drug generally prescribed for anemia and fatigue. According to the pharmacists, the Section 8 approval rating for Eprex is approximately 50% regardless of whether or not the patient’s cancer has metastasized. This drug costs \$2,500 per month and while Eprex is not curative, patients have found it assists enormously with preventing fatigue and therefore, quality of life.

Finally, cost-shifting requires the patient to continually claim dependency upon one or more systems. To reduce or avoid personal costs associated with cancer treatment, breast cancer patients must complete paperwork to receive compassionate-use medications (free medications supplied by pharmaceutical companies for distribution to patients on an as-needed basis [more in the Access Strategies section below), or private or public insurance coverage. Patients must reveal their financial situation to any institution or department seeking to assist them. Individuals on social assistance are especially vulnerable to scrutiny. Health professionals were wary of supporting this practice.

"...the assumption is that (the patient) is trying to screw the system." (Social Worker)

"...now there is a compassionate-use program... where the patient has to disclose their mortgage...their liquid assets, their...loans, their gifts, their family income...how many cars they have, their car loans, like I think that's highly intrusive to get partial funding for a drug." (Oncologist)

ODB program can be made. This process is known as Section 8” or Individual Clinical Review (Ministry of Health and Long-term Care, 2004).

Unmet expectations.

The final barrier relayed by health professionals pertains to expectations (their own and those expressed by patients) associated with relieving financial distress. These mostly unmet expectations were communicated to the interviewers of this study in three ways: 1) what financially stressed patients expect that institutions or services cannot provide; 2) what institutions expect from financially concerned patients that patients cannot always provide; and, 3) what institutions expect from services that services cannot or are not providing. Each of these unmet expectations will be discussed in turn.

First, health professionals perceived that patients expect that any costs associated with their cancer treatment should be covered by their basic provincial health insurance.

"it's their first exposure to health care cause they've never been sick a day in their life...they haven't had to pay for any drugs ever, they've never been sick...why would they know what's covered and what's not covered."(Pharmacist)

According to health professionals, when patients realize this is not the case then they expect that some cancer organization or institution will reimburse additional unforeseen and ineligible costs.

Health professionals are also concerned that patients expect that other services, such as home care, will also be provided to anyone who expresses need. Conversely, participants in the community-organization focus group felt that patient's had a right to, but did not feel comfortable, accessing programs that could be useful to them. For example, they felt that some organizations oriented their services to higher-income individuals with cancer. These community professionals expressed the need for cancer organizations to do the following:

"...choose program locations and choose environments that are suitable and comfortable and welcoming to women from different cultures and women who have different income levels." (Community Organization Professional)

Second, health professionals inside institutions discussed the following expectations of patients:

- Recognize their own financial need
- Be able to afford transportation costs associated with treatment
- Be able to make the time to transport themselves to and from the treatment centre sometimes several times per week
- Be aware of the services that exist (like transportation) and then organize it and do not complain if they need to wait for other patients to finish their appointments.
- Use tokens provided to them to assist with transportation costs to and from the treatment centre
- Accept and use the referred home care service instead of declining the service after one visit
- Expediently submit completed insurance or Trillium Drug Program forms to the social worker, or pharmacist, or the insurance company.
- Pay dispensing fee at the hospital pharmacy to understand that the service has value.

Finally, health professionals in cancer institutions expect that they will be able to offer particular services. However, for example, those cancer patients in need of transportation and also receiving social assistance are not eligible for the free transportation services provided by the Canadian Cancer Society.

"everyone relies on the Cancer Society (for transportation) and rightly or wrongly that's just not happening." (Social Worker)

Though many health professionals in the cancer system believe that the social workers will facilitate access to the necessary financial help for patients in need, the social workers felt the lack of ability to do anything at all for some cancer patients.

"so I think sometimes the people are sent to us with the idea that we can somehow make things happen...that we have access to money...and because it's a social worker calling another social worker, it's (access to resources) going to happen" (Social Worker)

Social workers felt that it was especially difficult to tell those patients who do not qualify for income security programs (such as those who are self-employed or the working poor) that there were no other programs to assist them.

"I think that's one of the hardest parts of the job is to have to tell someone that based on their situation there (is) no government support. I don't know of any support." (Social Worker)

"I think for me it's just a feeling of being impotent in a sense of you recognized there's a problem and...many times there's nothing you can do about it and so...people look at you, people come to you for help and the only thing you can say is 'sorry'." (Social Worker)

Access Strategies

Once financial need has been identified, patients with breast cancer can and do access the following small offering of services and support from professionals in community-based cancer organizations and cancer treatment centres.

Community-based Resources

Staff from community-based cancer organizations mentioned the existence of programs specifically focused on providing resources to those with cancer with financial need. These programs include (but are not limited to):

- the Canadian Cancer Society's (Ontario Division) Volunteer transportation program;

- the Good Food at Home pilot program (offering weekly home delivery of fruits and vegetables) offered by FoodShare (pilot program, funding limited);
- the Leveling the Playing Field - Personal Coach Program program offered by the University Health Network (pilot program, funding limited);
- financial consulting services provided in the past by Willow Breast Cancer Support and Resource Services;
- emotional support services offered by Wellspring: A Network of Support Centres for People with Cancer and their Loved Ones; and,
- a small amount of money available through United Way for homemaking services when an individual is sick.

These programs address barriers frequently encountered by those with financial need by offering their services for free (all), in the individual's home (transportation program, Good Food at Home and the Personal Coach program), and close to public transit and in low-income neighbourhoods (Willow, Wellspring).

Though no longer in existence, health professionals wondered aloud at the possibility of reinstating the instrumental support programs (child care and house cleaning) once offered by the Canadian Cancer Society, Ontario Division. One community organization professional suggested that fewer emotional support programs should exist for women with cancer in favour of instrumental support programs such as food, housekeeping and childcare services.

During focus groups and interviews, participants mentioned educational services provided by community-based organizations for women with breast cancer who experience financial stress. These resources include:

- the resource booklet “Coping with your financial concerns” and national phone-in support service (Willow Breast Cancer Support and Resource Services)
- informational sheets entitled “Where will my money come from” (Canadian Cancer Society, Ontario Division)
- Oncology nurses in the home to provide information (i.e., Interlink Community Cancer Nurses - a non-profit community nursing program providing children, adults and families experiencing cancer, access to care and support.)
- a phone-in support service (Cancer Information Service) that provides access to the community services directory (Blue Book)
- website offerings with financial information on government programs and tax credits (Canadian Cancer Society, Ontario Division; Willow Breast Cancer Support and Resource Services)

“...so if they call us and say they’re concerned about the financial situation it’s not as embarrassing as having to say it face to face and they can also e-mail us and I think also putting the information on the website has broadened access and made it easier for people to connect with us” (Community Organization Professional)

Institutional Resources

In the cancer treatment centres health professionals arrange information sessions about issues related to treatment and aftercare, organize and refer patients to compassionate-use prescription programs, refer breast cancer patients to community-based services, and provide individualized service to assuage patients’ financial concerns. Each resource is discussed next.

Information sessions.

Information sessions are organized for new patients. The issue of the financial costs of cancer is discussed during those sessions. Unfortunately, the sessions do not tend to draw many patients.

“I mean they have been really trying...you have little pamphlets everywhere...it’s in the elevator, it’s at the door, it’s outside...I mean you can always miss it but it’s pretty obvious.” (Oncologist)

Compassionate-use programs.

If a patient is identified as having financial issues and has no private insurance coverage for prescription medication or is awaiting confirmation to participate in a government drug assistance program then she will be considered for inclusion in a compassionate-use prescription program.

“Our way around (cost-shifting) is through the compassionate supply, so no one who needs that drug goes without it.” (Pharmacist)

There are several ways that compassionate-use programs are organized within the cancer system. These pathways include setting up a program directly between the oncologist, the pharmacy and the pharmaceutical companies; between the pharmacy and pharmaceutical company (initiated by either); between the pharmacist and the social workers; or between a company at arms’ length to the pharmaceutical company and the patient, oncologist and pharmacist. Prescription medications accessed from compassionate-use programs include supportive care drugs, such as anti-nausea medication.

“...we find (the anti-nausea medication) for them for free...the pharmacist has it or we’ll find out. I’ll call the drug company sometimes and say, ‘Can you give us more drugs?’ And they do.” (Oncologist)

“...so there are some compassionate-use programs where you have to fill out forms and it involves me filling a form, a pretty easy one, every three months and they’ll ship a three month supply” (Oncologist)

“...we have a compassionate supply from the company. And social work says ‘this patient requires compassionate supply of Zophran for the full duration of their treatment’ or ‘until their Trillium application can be processed’ which might take 6-8 weeks. So...uncommonly (the patient receives the drug) for the full duration of their treatment.” (Pharmacist)

Sometimes compassionate-use programs are initiated when a new drug becomes available on the market. While these programs directly benefit the patient in need of prescription medication, they are also in the best interests of the pharmaceutical companies. These companies offer their drug for free and by doing so achieve name-brand recognition amongst oncologists and pharmacists.

“...(the pharmaceutical companies) have fairly elaborate compassionate programs put in place.” (Pharmacist)

The pharmaceutical companies can also discontinue the compassionate-use program at will. Some health professionals expressed concern that oncologists not access compassionate-use drugs directly from the pharmaceutical company lest, due to overutilization, the company decides to close-down the program.

Referrals to community resources.

Health professionals within the cancer centres have devised a number of strategies to connect financially-strapped breast cancer patients to community resources. For example, social workers, nurses refer patients to home care or to community-based programs (e.g. the Good Food at Home program); or oncologists, nurses or social workers refer patients to the volunteer transportation program provided by the Canadian Cancer Society, Ontario Division.

Individualized service.

In order to decrease transportation costs or time away from work, nurses will try to batch appointments on the same day.

“We are running a business but I think with some of the families we have to realize that...if they’re taking a day off work and the spouse ...has taken the day off with them then to take another day off that week or the following week is just not possible for some people.” (Nurse)

Nurses also described efforts to organize or arrange the batching of prescriptions so patients need only pay one dispensing fee. Pharmacists attempt to charge the private insurance company directly for prescription costs, they suggest to patients that they apply to the “under-utilized” (Pharmacists) Trillium Drug Program, and they will also work out the deductibles for patients who decide to apply to Trillium. The social workers will assist patients to complete all Trillium Drug Program forms (along with myriad forms associated with private and public assistance programs) and offer practical financial counseling and emotional support to those requesting guidance.

“Finances are very individual, very subjective...and there is a whole piece of it that needs to look at the assets...it’s a whole piece to understand that ‘well, it’s a rainy day’ ...It’s more effective and appropriate to do it on a personal level only because money is very subjective.” (Social Worker)

When oncologists know that a patient has no drug coverage, they will talk to her about completing a Trillium application especially in the following circumstance.

“...if we know they’re going to have an extensive therapy or might be offering them a clinical trial with an expensive therapy.” (Oncologist)

Oncologists relayed other methods of ‘going to bat’ for their patients including,

- Suggest to patients that they receive their treatment from an institution closer to home (if patients do not require radiation);

- Encourage patients to talk to their workplace Human Resource Department about available benefits should they need to leave work for a period of time;
- Connect patients who are experiencing similar financial and supportive care concerns;
- Create a system for patient information to travel with the patient (this information would include an indication of drug coverage, the amount of coverage, and whether or not they have applied for the Trillium Drug Program); and,
- Provide patients with information about the free accommodations offered by some hospitals.

Stop Gaps

Health professionals spoke about the many ways they or their patients applied stop gaps to remedy difficult situations. These acts or peer-based strategies were viewed by health professionals as potentially harmful to financially-stressed women with breast cancer or to the health professionals attempting to assist them.

First, oncologists and nurses felt that they lacked the necessary knowledge to counsel individuals about financial resources. To attempt to address patient's financial concerns, health professionals found themselves employing the following strategies:

- Relaying eligibility criteria of particular government programs

"We do it because there's no one doing it and that's not to say we do it well, it could be done a lot better." (Oncologist)

- Completing Trillium Drug Program application forms
- Making treatment decisions based on patient's perceived financial need

"I know that from my own practice, if a patient doesn't have a drug plan it does sometimes affect the...therapy I give." (Oncologist)

- Accessing one-off compassionate supply for a financially-stressed patient (which could be perceived as unfair practice since a standardized system for determining need does not exist).

Second, nurses also expressed concern about patients having to purchase large quantities of medication before their cancer care team has determined whether or not the patients will respond positively to that drug. When patients respond negatively, the remaining portion of the prescription goes to waste.

“...the problem with the metastatic setting is if you’re giving them a new hormone you don’t want to give them 6 months supply of it because...it might not work for them...and then they’ve paid for six months and they actually only need four weeks of it (Nurse)

Finally, to financially assist some patients, oncologists mentioned that some of their colleagues purchased after-treatment products for patients who could not afford the product.

Health professionals also noticed that their patients, who were unable to pay for their treatment or supportive care medication, would decline to purchase this medication.

“I have patients who avoid having anti-sickness drugs because of expense, yes I do...they retain some control over the situation by not taking the anti-sickness drug.” (Oncologist)

Nurses observed that patients or their family members would talk to each other in the waiting rooms about the possibility of sharing leftover prescription medications or unused bandages.

“families that have had a loved one who have gone through the process and even though it hasn’t worked for them they want to share, they want to give something back and I think they just see it as being so wasteful just to...throw them (medications) out...there must be somebody that can use these.” (Nurse)

Participants' Recommendations

Practical, Professional Services

Financial/resource manager.

Health and community organization professionals from across disciplines suggested the creation of a financial manager position to provide practical support to individuals who were having financial concerns while dealing with their diagnosis.

*“there’s so many things that you have to be considering, it would be nice if there was someone who actually...had the financial responsibility of the patient ...if you had a navigator through the cancer system you would have someone to do that.”
(Oncologist)*

“having somebody who can help you navigate the system is a really helpful thing because there’s so much information and so much to think about and if you’re not linked up...you’re just kind of lost, right?”(Community Organization Professional)

The respondents thought that a navigator or financial case management model might have greater appeal to patients than educational materials or information sessions, given the personal, unique and subjective nature of discussing finances and financial information. Participants recommended that the individual in the financial manager role could:

- Supplement the work of the social workers;
- Follow-up on applications to income security or drug benefit programs;
- Discuss the financial costs with patients at intake and throughout the treatment trajectory to ascertain financial need;
- Provide financial counseling to assess how patients might get back on their feet financially following treatment; and,

- Provide information about community and institutional services e.g., transportation services, child care, home care, etc.

Recognizing that greater numbers of individuals are diagnosed with breast cancer as compared to HIV/AIDs, one community-based professional enthusiastically supported the creation of a cancer financial navigator position citing her knowledge of a similar position in the HIV/AIDS community.

“...the clients...show up and say “I need housing, I need a drug card, I need money, I want to cash in my life insurance policy, I want to talk to my family, I want to plan my funeral, help me with all of this” and it gets done...”.

Finally, several community professionals suggested that the financial manager be based in the community and liaise with professionals inside the cancer centre.

Fine-tune Institutional Resources

Screening procedures: revisiting the identification of financial need.

Both the nurses and the social workers called for a more sensitive or high risk screening instrument to identify those individuals requiring financial assistance over the course of the cancer trajectory. A pharmacist added that this centre-wide screening tool should include information concerning the patient’s chemotherapy regimen and the likely cost of medication. If the patient lacked private insurance coverage then an appointment could be arranged with a pharmacist and either a primary nurse or a social worker to discuss necessary next steps. This pharmacist felt that if this proactive system were implemented then those in need of drug coverage would be assisted immediately and delays in treatment, due to delays in public or private insurance support approval, could be avoided.

“What are they facing?... What are their prescription needs going to be? And what does that mean for them and how can (we identify) some gaps in their

coverage (so) that we could start addressing now before we run into a problem?...It would make more sense ...(to) have the insurance pieces covered at the outset.” (Pharmacist)

Finally, most health professional participants identified that the only formal mechanism designed to inquire about financial need was presented to patients at the wrong time. Many recommended that the question about financial need be asked several times, and over the course of treatment.

“there almost needs to be a system in place that they’re actually followed up with that question while they’re on treatment.” (Nurse)

Health professionals suggested meaningful opportunities for these discussions over the treatment trajectory, as well as ‘significant windows’ of time including,

- after the patient is aware of her treatment plan (i.e., chemotherapy or radiation)
- when patients are in the waiting room prior to receiving chemotherapy, and
- during radiation review

“...when they’re on their radiation treatments ...once a week, they’re visited by the physician and the nurse or if the physician’s away it’s just the nurse...and that’s when...we assess their skin, we assess any problems that they might be incurring along the way and just a general ‘hi, how are you? We’re still here.’” (Nurse)

Advertise that cancer costs.

Many health professionals with whom we spoke put forth that all women (and men), regardless of socioeconomic status and with a diagnosis of cancer should be directly informed that cancer will cost them out of pocket. Many health professionals emphasized that the working poor, young (single) women, and the self-employed were particularly vulnerable to financial hardship following a cancer diagnosis.

"patients that are sort of in the middle category, like not the very poorest cause they have coverage usually, but somewhere there's that sort of intermediate group where... they can't even pay for anti-nauseate so that group you identify up front" (Oncologist)

They added that if all patients were informed that cancer costs, then patients could reflect on their financial circumstances in this new light, without feeling stigmatized. Patients might more readily come forward as requiring assistance and might more often than currently occurs, gain access to resources.

Information sessions.

Most focus group participants and interviewees were adamant that neither patients nor the cancer system needed another pamphlet to address the concerns of low-income women with breast cancer.

“A pamphlet isn’t going to...get them anywhere.” (Social Worker)

“...instead of making new pamphlet, use Willow’s. “If we could even get their permission just to copy it and do it again...to be able to provide to any new patient this brochure (is) to open the door for their understanding.” (Social Worker)

If hiring financial case managers was not possible then many health professionals suggested that the cancer centres host group information sessions about the financial costs of cancer treatment. To increase participation in these information sessions, the cancer centre must include these sessions as part of the treatment care path and not as extraneous to treatment. In addition, social workers could send an invitation to each patient explaining that cancer treatment costs and encourage her to attend an information session. During these information sessions, social workers could discuss the costs associated with cancer treatment and aftercare, and could introduce cancer patients to the public insurance application processes. Additionally, community organization staff could be invited to speak about community services.

Increase complement of social workers.

The social workers gravely expressed that if a high-risk screening tool were developed to flag those with breast cancer with financial need, there would not be enough staff to meet this need. To address this shortage, nurses and oncologists recommended that more social workers be hired into breast cancer treatment teams.

Advocacy

Community health professionals suggested that one way to make change to the cancer system was to expand into the advocacy arena. They felt that the first step in advocating for changes to the financial experience of lower-income women with breast cancer was to document their issue of financial need. Professionals from community-based cancer organizations felt that the production and distribution of studies that underscore the financial need of cancer patients is imperative to “*effect some kind of change to the system*” (*Community Organization Professional*) and to assist health and income security professionals to understand that many individuals with cancer will also suffer financially. The Canadian Cancer Society, Ontario Division needs assessment (introduced at the beginning of this report) has the potential to motivate cancer organizations to develop standard approaches to tackle this financial issue within cancer centres.

Actions to affect provincial or federal policy change requires mobilization of a greater scope. Health professionals from community-based organizations expressed great concern that the cancer care system, in general, lacked the ability to mobilize advocacy efforts. They explained that difficulty lies with the fact that there are so many different

cancers and hence different organizations representing diverse cancers and diverse cancer needs. One cancer professional explains:

"I think this is sometimes the problem to get people to see that their experiences go beyond their particular cancer and can...involve all people with all types of cancer and to try and work together around that." (Community Organization Professional)

Still, some members of the cancer community are interested in moving forward with an advocacy agenda. One recently created position at a provincial cancer organization is focused on drawing together interested agencies and groups to understand the issues regarding drug coverage for cancer patients. In particular, this agency would like to better understand how prescription drugs come to be included on the Ontario Drug Benefit Program's general formulary and to ensure that the process is more transparent to cancer patients. In addition, community members are interested in encouraging the development of clinical practice guidelines to assist the patient to access a particular drug.

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