

Le soutien social dans le cadre de la gestion d'un cancer du sein chez les immigrantes lusophones

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Le cancer du sein est l'un des cancers les plus fréquemment diagnostiqués chez les Canadiennes. De nombreuses recherches en sciences de la santé se sont penchées sur cette question. L'importance du soutien social formel et informel dans le cadre de la gestion d'un cancer du sein a fait l'objet d'une attention particulière, mais peu d'études ont été réalisées auprès des femmes immigrantes. Cet article présente les résultats d'une étude ethnographique appliquée menée à Toronto, au Canada, auprès de 12 femmes lusophones du Brésil, du Portugal et de l'Angola. L'étude se penche sur leur besoin d'un soutien social pour gérer le cancer du sein, ainsi que sur leur accès et leur recours à un tel soutien. Les principales conclusions portent sur les peurs et les stigmates liés au cancer qui entravent l'accès et le recours à ce type de soutien. Elles portent aussi sur la résilience des femmes dans un contexte où le soutien social informel et formel est limité. Les auteures font état des implications à l'endroit des fournisseurs de soins de santé, à une micro, méso et macro-échelle.

Mots clés : cancer du sein, Canada, immigrantes lusophones, résilience, soutien social

Social Support for Breast Cancer Management Among Portuguese-Speaking Immigrant Women

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Breast cancer is one of the most commonly diagnosed types of cancer among women in Canada. Much health sciences research has examined this topic. The importance of formal and informal social support in managing breast cancer has received particular attention, but research with immigrant women has been limited. This article presents the findings of an applied ethnographic study conducted in Toronto, Canada, with 12 Portuguese-speaking women from Brazil, Portugal, and Angola about their need for, access to, and use of social support in the management of breast cancer. The key findings pertain to cancer-related fears and stigma that restrict access to and use of informal social support, barriers to obtaining formal social support, and women's resilience in the context of limited informal and formal social support. Implications for health-care providers are presented at micro, meso, and macro levels.

Keywords: applied ethnographic method, breast cancer, Canada, informal and formal social networks, Portuguese-speaking immigrant women, resilience, social support.

Breast cancer is one of the most commonly diagnosed cancers among women in Canada (Canadian Cancer Society, 2010). The Canadian Cancer Society (2010) estimated that, in the year 2010, 8,900 women would be diagnosed with breast cancer and 2,100 would die from the disease. However, no comparable statistics are available for immigrant women, and only limited data are available on immigrant women's need for, access to, and use of formal and informal social support in the management of breast cancer. A substantial body of literature (Antonucci, 1994; Cohen & Syme, 1985; Hall & Havens, 2001; Reevy & Maslach, 2001; Simich, Mawani, Wu, & Noh, 2004) indicates that social support has a positive effect on physical and mental health, ability to cope with major illnesses, and health-risk behaviours. Social support is positively correlated to participation in social networks (Smith & Christakis, 2008). Social support from social contacts is especially important to women, who tend to rely on social networks for support, self-esteem, identity, and

perceptions of control (Antonucci, 1994; Cohen & Syme, 1985; Hall & Havens, 2001; Putland, 2000). Women tend to have larger and more diverse networks than men, and can more readily command support when in need (Antonucci, 1994; Belle, 1989; Kessler & McLeod, 1985). However, few studies have focused on the role of support derived from social networks among diverse immigrant communities, and no previous research has examined this topic among Portuguese-speaking women in Canada. This article draws from a study of social and cultural capital and readiness, intentions, and barriers to using social support among breast cancer survivors and general members of the Portuguese-speaking community in Toronto. It presents the study's key findings from the perspectives of Portuguese-speaking women on *their need for, access to, and use of* formal and informal social support in the management of breast cancer.

Literature Review

Social support can be informational, instrumental, emotional, or financial (Belsky & Rovine, 1984; House, 1981) and is usually provided by members of informal and formal social networks. Informal social networks include family, friends, and neighbours, whereas formal support may be provided by health professionals, social service workers, settlement workers, crisis hotline workers, police officers, and various other service providers (Guruge & Humphreys, 2009).

Social support from family members and close friends is of vital importance to women living with breast cancer (English, Wilson, & Olaman, 2008). Previous research has focused on how social support affects healing, rehabilitation, and survival among women with breast cancer. For example, community belonging and social involvement provide opportunities for contact with others, which is beneficial for physical and emotional healing (English et al., 2008). Perceived social support can act as a protective factor against anxiety, depression, and post-traumatic stress disorder in the context of rehabilitation following breast cancer care and treatment (Knobf, 2007), but its importance appears to vary among women of diverse ethnocultural origins (Gass, Weitzen, Clark, & Dizon, 2007). The influence of social support on survival is controversial (Falagas et al., 2007).

For women managing the "healthy-to-sick" transition, primary support often comes from their partner, who may have a profound effect on the transition process (Sawin, Laughon, Parker, & Steeves, 2009). During this process, spouses and other family members may require informational support regarding the provision of effective support for women with breast cancer (Makabe & Nomizu, 2007). Similarly, women who are living with a diagnosis of breast cancer may require information

on how to ask for and receive social support to better manage their illness. For example, some studies (e.g., Ashida, Palmquist, Basen-Engquist, Singletary, & Koehly, 2009; Yoo, Levine, Aviv, Ewing, & Au, 2010) report that older women diagnosed with breast cancer often feel that they do not want to be a burden on others but when they are able to accept their need for support, and are able to ask for it, family support can help them to deal with breast cancer. In other words, social support for patients and for family members is interlinked (Osborn, 2007).

Immigration usually results in the loss of informal social networks and support (Guruge & Humphreys, 2009; Simich, Beiser, Stewart, & Mwakarimba, 2005), the impact of which is compounded by language barriers, un/underemployment, unsafe living conditions, and racism and sexism in society at large (Guruge & Collins, 2008). Accessing health information can be a challenge, especially for newcomers (Caidi, 2008; Zanchetta & Poureslami, 2006). In addition, culturally and linguistically appropriate services specific to disease prevention and illness management are not often readily available in Canada (Guruge & Collins, 2008). All of these factors can impede successful access to and use of formal support by immigrants.

Purpose

The interest in this study came from a university-affiliated, hospital-based breast cancer survivorship program in Toronto. The staff there noticed that the Portuguese-speaking women who accessed their services tended to be living with advanced stages of breast cancer. Wondering why these women had not accessed breast cancer services earlier, they contacted the second and third authors of this article to conduct a study on the topic. The large-scale study examined social and cultural capital and readiness, intentions, and barriers with respect to the use of social support among breast cancer survivors and general members of the Portuguese-speaking community in Toronto. The study entailed individual as well as focus group interviews with both breast cancer survivors and general members of the Portuguese-speaking community. This article presents the findings in relation to the following research question: *From the perspective of Portuguese-speaking immigrant women diagnosed with breast cancer, what are their needs for, access to, and use of social supports in the context of breast cancer management?*

Method

The method used in this study was applied ethnography, which is “concerned with understanding sociocultural problems and using these understandings to bring about positive change in communities or

groups” (LeCompte & Schensul, 1999, p. 6). In general, ethnography helps to generate explanations for how members of a cultural group think, believe, and behave in a particular time and space (LeCompte & Schensul, 1999). The study and its method were negotiated with key community leaders and gatekeepers. The goal was to move beyond mere description of the topic from an outsider’s point of view to in-depth examination of the meanings, organizations, and interpretations of culture from an emic and etic perspective. This was achieved by including Portuguese-speaking co-investigators on the team (including one with 15 years of clinical experience in oncology nursing); by working closely with community members and agencies to ensure a cyclical, dynamic, and collaborative process; by engaging in lengthy involvement and data collection with and within the community; and by liaising with cultural insiders to locate and identify prospective participants as well as to immerse the research team in their cultural and social life in order to gather data on cultural values and beliefs and ways of living, interacting, and networking, with the aim of understanding how culturally based social networks support Portuguese-speaking women with breast cancer.

Potential participants had to meet five inclusion criteria: (a) be living in metropolitan Toronto; (b) be older than 18 years; (c) speak Portuguese as their first language; (d) self-identify as an immigrant to Canada; and (e) have undergone treatment for breast cancer. Women were recruited via postings at various community locations frequented by Portuguese-speaking immigrants to Toronto, a presentation on a Portuguese television network, a posting on the Web site of the Portuguese consulate, and flyers in clinics of family doctors offering services in Portuguese. Women who expressed an interest in the study were contacted by the second or third author, who described the study and answered any questions about participation. All prospective participants were given a week to think about the invitation, after which they received a follow-up phone call. Of the 13 women approached for the study, only one chose not to participate (due to concerns at the time about possible brain metastasis).

Following ethics approval from York and Ryerson universities, data were generated through individual interviews. Interviews were conducted by the second or third author (both oncology nurses) in English and Portuguese, respectively, during 2009 and 2010; each participant decided which language her interview would be conducted in. Interviews were generally held during evenings and weekends at locations convenient for participants, such as their home, researchers’ offices, or a public setting. All potential participants were informed, verbally and via a consent form, of their right to refuse to participate or to answer any questions or to terminate their participation at any time. All information sheets and consent forms were developed in English and translated into

Portuguese and tested for linguistic appropriateness by Brazilian- and Portuguese-born women. All refined documents were pilot-tested with two women, one from Brazil and one from Portugal (the latter was a cancer survivor). Participants also received a list of community-based resources.

Each participant was interviewed only once, because participants noted that they had said all they could about their perceptions and experiences related to the topic within the first interview. The interviews averaged 80 minutes in length and were audiorecorded and transcribed. The transcriptions were coded using ATLAS ti 6.0 software. Interviews conducted in Portuguese ($n = 10$) were coded in Portuguese by the third author and the two research assistants, all of whom were bicultural and bilingual native Portuguese speakers. The third author and the two research assistants independently drew up a list of 56 preliminary codes, which they then reviewed together for similarities and differences. The output of all coding processes was summarized per code by these three members of the research team. A general summary in English was then prepared by the third author. Interviews conducted in English ($n = 2$) were coded using the same procedure. The team then conducted a thematic analysis to see how the codes converged or diverged within and across interviews and grouped the codes into subcategories and categories for analysis. All authors collaborated on the interpretation of the findings.

Trustworthiness of the study was ensured through interviewer triangulation (interviews were conducted by two interviewers); data triangulation (data were collected in two languages); and member checking (with each participant during individual interviews and other participants during subsequent interviews) and prolonged engagement and debriefing (over a 1-year period) (LeCompte & Schensul, 1999; Lincoln & Guba, 1999). In addition, as per Creswell (1998) the results and interpretations were presented to other researchers, both within and outside of the community, to ascertain whether similar interpretations would be drawn.

Results

The final sample comprised 12 Portuguese-speaking breast cancer survivors. The participants were diverse in terms of country of origin (Brazil = 3, Portugal = 8, Angola = 1), age (27 to 60 years), education (less than elementary school to university), marital status (single, married, divorced/separated), length of residency in Canada (8 months to 37 years), and time since diagnosis (3 months to 27 years). Stage of cancer was not solicited from participants.

Three themes emerged from the data: *cancer-related fears and stigma that restrict access to and use of informal social support, barriers to obtaining formal social support, and resilience in the face of limited informal and formal social support.*

Cancer-Related Fears and Stigma That Restrict Access to and Use of Informal Social Support

Cancer-related fears and stigma shaped the type and quality of informal social support the participants were able to obtain as they lived with a diagnosis of breast cancer. Regardless of their country of origin, participants believed cancer was a taboo subject. Cancer was commonly perceived as a debilitating condition that leads to suffering and death, and participants believed that members of their community also held such views. These fears and stigma led most participants to believe that a diagnosis of cancer should be kept secret. Some of these ideas are captured below:

To our people, the word “cancer” means an incurable disease. When a person has cancer, she dies. (Portuguese, age 47, married)

My experience is with my mother and my aunts . . . I do not know about the new generation but I see a lot of taboo about cancer. People do not talk about cancer. People do not want to know about it. They prefer not to be tested or undergo examinations. (Brazilian, age 42, married)

My friends don't really want to know a lot about the disease . . . they are scared. In Angola, people are scared to enter the oncology centre because they think cancer is contagious. (Angolan, age 45, separated)

In the Portuguese community . . . there are people who are afraid to come near us or to talk to us. (Portuguese, age 48, married)

Some Portuguese participants expressed a fear of becoming a target of gossip within the community. Most said that they avoided chatting and mingling with community members to escape potentially embarrassing encounters — for example, in neighbourhood shops where someone might comment on their diagnosis. Participants noted that such a response was in stark contradiction to their “normal” day-to-day life in the community, whereby they chatted, shared information, and supported one another.

While most participants noted that they were not able to obtain support from members of their community at large, they reported considerable support from immediate and/or close family members and close friends. For those who were married, husbands and children were the main support providers. However, not all husbands were supportive:

Three weeks after my chemo, my husband started to drink and smoke. At the end of my treatment, my husband filed for divorce. (Portuguese, age 40, divorced)

Some participants reported that other immediate or close family members provided instrumental support (such as taking care of housework during treatment phases) and/or financial support:

I didn't have money for a wig that looks natural, so my stepmother gave me one as a gift. Even my friends collected almost \$3,000 and gave [it] as a gift. (Brazilian, age 37, single)

Immediate and close family members living nearby were the most frequent support providers for almost all participants, but some spoke of close relatives travelling to Toronto to care for them during and after treatments. Some participants also received emotional support from family and friends in their country of origin, who contacted them regularly via telephone and social networking Web sites.

The only Angolan participant spoke of difficulty sharing information about her diagnosis, even with her sister, with whom she was living, to keep her from worrying:

I went home crying. It was hard to tell my sister. When I told her what the doctors told me, she couldn't handle it and started crying as well. (Angolan, age 45, separated)

Consequently, this participant sought support from other Portuguese-speaking breast cancer survivors who had undergone treatments in Brazil, Portugal, or the United States. She also reported contacting close friends from Angola, who provided the emotional support she felt she needed to face the diagnosis and preparation for treatment. Interestingly, regardless of country of origin, almost no participants intended to share their diagnosis with or ask for help from extended family members.

The eight Portuguese participants noted that, apart from that provided by their husbands, children, and daughters-in-law, immediate support came from neighbours and co-workers:

My neighbour was so positive that I started to believe I would be able to deal with the chemo . . . every time I fell apart, I ran to her. She also had breast cancer. She was very optimistic and my best help . . . better than the help from my husband. (Portuguese, age 50, married)

My colleagues in the factory gave me a lot of support. When I cried they consoled me, saying that it would not be complicated. I felt some comfort in that. (Portuguese, age 40, married)

Those who were more educated, were fluent in English, or remained professionally active or employed during their treatment reported no significant contact with, or desire to seek support from, members of their communities. In general, they felt free to disclose their cancer status with friends and colleagues, regardless of their cultural background. In contrast, participants who were less educated, not fluent in English, and/or unemployed maintained contact with other Portuguese speakers when they were asymptomatic but during treatment generally limited their contact to other breast cancer survivors (whom they met in clinics or hospitals). Participants explained that they wanted to protect their family members in Canada and back home from any gossip generated by fear or stigma. Those who were able to connect with other breast cancer survivors from their own community felt supported by being able to disclose personal and emotional issues related to their struggles during breast cancer management.

Barriers to Obtaining Formal Social Support

Several barriers to obtaining formal social support emerged. Some of these were related to the women themselves. For example, most participants expressed psychological distress following their diagnosis and during and after treatment:

I lost all dreams in my life . . . Now I have no ambition of working, doing this or that. (Portuguese, age 56, married)

I loved singing while working. I do not have the same joy. I do not have the same voice. And I do not remember the lyrics either. (Portuguese, age 53, married)

However, they did not consider accessing psychological support because of a desire, for example, to preserve their reputation in the community as a mother and wife who leads a “normal” life. For some, being able to rely on oneself, self-sufficiency, and self-determination were important:

There were days I could not concentrate and I knew that it was due to treatment. Then I stopped and talked to myself: “Hey, I cannot stay like this! My psychological work I do myself. If I want to fight and win, I must do it myself. I must have strengths.” For this reason, I did not want a psychologist. I usually take a deep breath, I pray, and that’s it! The ball is rolling once more! (Brazilian, age 27, married)

For others, it was cancer-related fear and stigma, concerns about how their use of formal social support would affect their children and husbands, or a sense of futility that prevented them from accessing formal social support. For example, the Angolan participant said she did not

readily access formal social support because she believed that cancer is a deadly disease and that seeking care and treatment and additional support would be futile.

Other barriers to the use of formal social support were related to the support services available. First, participants noted a lack of age-appropriate services. For example, the youngest participant revealed that she could not find a self-help group to learn about issues of particular importance to younger women:

I was looking for groups or services [for] young women. I went to a few . . . but they only had older women. They said, "Sorry but we do not have material for young women." (Brazilian, age 27, married)

Lack of linguistically appropriate services was a key concern for many women, who could not find professional interpreters. In some cases, this led to confusion:

Through the help of my cousin, we asked the doctor what would be the best advice that he could give me, and he said, "The best we can do is to take out the nipple and clean up everything." After the doctor left, we asked the surgeon, who seemed to know a lot about the disease, what he thought about it. He said, "By my own experience, the best is to take off the breast." We did not know what to do. (Portuguese, age 58, married)

One participant highlighted the role played by her family members in the translation/interpretation of information:

With this disease I realize that I needed to learn English. Thanks to God and the Holy Spirit, my sons came to the hospital with me. Also thanks to Heavenly Father that my husband's cousin helps me a lot and a friend of mine that helps so much, much, much. (Portuguese, age 59, married)

Participants commented on a lack of information about breast cancer in terms of survival rates, treatment options, coping with the psychological impact of cancer, and managing or coping with concerns about body image:

She did not explain very well the benefits [of a breast implant]. She looked like she was doing some other business. I looked at my husband and I said to him, "I will think about it" . . . and I did not go back. (Portuguese, age 64, married)

Participants also mentioned a lack of information about available financial, instrumental, and other support and services. Some participants expressed interest in free physiotherapy services and lymphedema home-care services because most became unemployed or retired after their diagnosis, or could not afford the additional costs pertaining to such serv-

ices. Many were also unaware of a major cancer survivorship program in Toronto that works collaboratively with a Portuguese community centre:

For instance, when the hair starts to fall [out] it would be useful to know where to go to get a wig. In terms of medications, if I did not have private insurance, which type of aid could I have? (Brazilian, age 37, single)

Participants also identified a dearth of services for family members. Some of the Portuguese women, for example, expressed an interest in psychological support, not for themselves but for their husbands and children:

My dream is to find help for my children, help them face all the difficulties . . . there are many. I want to be able to help my son and my daughter to have strength and courage to move forward. (Portuguese, age 47, separated)

Since my husband learned that I had cancer, he was not able to sleep. He [did] not know what to do and where to go . . . he needed help. (Brazilian, age 42, married)

These barriers in the formal social support system limited participants' ability to cope with and manage their diagnosis, treatment, and care.

Resilience in the Face of Limited Informal and Formal Social Support

Despite the many challenges the participants faced in obtaining social support, both within their own community and in the larger society, they demonstrated remarkable resilience in coping and living with a diagnosis of breast cancer and engaging in care and treatment:

I was raised as a Catholic but I was never able to understand the power of believing in oneself, that we are not just a body, we're a soul too, and our spirit goes to get some strength and there is potential within us. [I have this understanding now.] (Portuguese, age 49, married)

After I had cancer, I perceived that my previous lifestyle was unhealthy and it did not help my health problem . . . Now I am able to face everything better because now I see things differently. I was able to free myself from negative energy. (Portuguese, age 47, separated)

My plans are to retire as soon as possible and then travel around the world. I do not have any long-term plan. I live today, and tomorrow I will see. I think about what happened to me and I am overcoming obstacles as they come to me. (Brazilian, age 42, married)

People were surprised with the way I reacted to the treatment; many of them passed by me and commented, "Strong woman!" (Portuguese, age 47, married)

For those who were employed, neither the diagnosis nor the treatment changed their motivation to work and plan for the future:

For my future I would like to be in a better professional and financial condition than what I have today. I plan to travel to Greece and also stay 2 weeks in New York. . . . All my plans are about travelling and evolving as a person. (Brazilian, age 37, single)

Some participants engaged in sports, outdoor activities, and/or religious or spiritual activities. Close bonds with other women increased their sense of personal strength, even if such connections were unrelated to surviving breast cancer. To increase their personal strength and to palliate for their non-access to support services, many participants learned about breast cancer by watching health-related programs on television, listening to radio programs about health issues, reading self-help books, obtaining information from relatives who browsed Web sites, and speaking with other breast cancer survivors. The Angolan participant said she relied on the Canadian Cancer Society's recommendations.

Discussion

The assumption that individuals can and do receive support from their informal social networks during stressful situations such as chronic illness has shaped the movement in Canada to relocate care from institutional settings to the home (Armstrong, 2007). Another common assumption is that support is available within ethnocultural communities for immigrant women (Guruge, 2007) who are diagnosed with an illness (Guruge & Collins, 2008; Guruge, Hunter, Barker, McNally, & Magalhães, 2010; Guruge, Lee, & Hagey, 2001). Our findings reveal that a diagnosis of breast cancer may evoke fear and stigma, significantly affecting the quantity and quality of women's support during breast cancer management. This finding supports previous research: Wilkinson (2007) reports that the women in her study were "often worried about other people's reactions to their breast cancer diagnosis and sometimes withheld the news for a considerable period of time from those close to them [and that] telling others was carefully managed" (p. 413). Other researchers (e.g., Clarke, 1985; Peters-Golden, 1982) report various negative responses from members of informal social networks after a diagnosis of breast cancer. Most of the participants in Peters-Golden's (1982) study reported that others appeared to fear and avoid them, even to the point of crossing the road. Over time, knowledge and attitudes about cancer have changed but

fear and stigma continue. Limited information is, however, available about these changes for immigrant communities.

Husbands, children, and other immediate family members were the primary informal support providers to most of our participants. English et al. (2008) also note the importance of social support from “household members” during recovery from breast cancer (p. 73). However, the quality and quantity of support provided by these household members might be insufficient for some women (Sawin et al., 2009), especially those who are single or divorced/separated. Armstrong (2007) notes that “women provide the overwhelming majority of both paid and unpaid care” (p. 529); when they become chronically ill, they might not receive quality care. Such situations leave immigrant women who are further socially isolated owing to immigration to a new country even more vulnerable.

Some of our participants were able to obtain instrumental, emotional, and financial support from immediate family members and close friends (whether they lived nearby or far away). However, regardless of their country of origin, participants were not eager to share their diagnosis or ask for help from extended family members or members of their community. Those who were employed in paid work and/or were well educated found some support from colleagues outside their community. Those who were not engaged in paid work sought support, comfort, and advice from close friends and family and from breast cancer survivors in their community; they felt a sense of support in being able to disclose personal issues about their struggles with breast cancer management. This finding supports the results of English et al. (2008), who report that (non-immigrant) participants spoke about “positive social support as important in contributing to healing and recovery from cancer for women” (p. 73); they note that engagement in a variety of activities (e.g., regular physical activity in community spaces) was an important way to obtain the social support that is vital to the physical and psychological healing process.

One of our key findings was two categories of barriers related to participants’ lack of or minimal use of formal support. Barriers originating with the women themselves included lack of acknowledgement of the need for external/formal social support; concerns about how the use of formal support might affect their immediate family; a sense of futility about care, treatment, and support; and a desire to project the image of a “normal” woman, wife, and mother. More pronounced barriers related to formal social support services — the dearth of (1) age-appropriate services, (2) linguistically appropriate services, (3) information about breast cancer, (4) information about services, and (5) services for family members. Studies with non-immigrant participants have highlighted similar problems with formal social support services. Wilkinson reports

that “support for partners and others living with, or close to, women with breast cancer has barely been addressed” (2007, p. 422). Arora, Finney Rutten, Gustafson, Moser, and Hawkins (2007) and Salminen, Vire, Poussa, and Knifund (2004) note that little is known about the range or evolution of the informational, decisional, and emotional support needs of people diagnosed with cancer over time as they move from initial diagnosis to treatment, care, and rehabilitation, and that services based on limited information are problematic. Our participants relied primarily on information from Portuguese-language newspapers, television shows, and radio programs, as well as from friends who accessed various Web sites and from other breast cancer survivors. This finding highlights the limitations of the traditional modes of information delivery commonly used by hospitals in Canada. A related concern was the lack of age- and language-appropriate services. Other researchers (e.g., Wilkinson, 2007) also question the extent to which generic organizations and support groups (i.e., a fit-all program for all types of cancer or all women) are sufficient to meet the diversity of women’s needs.

We observed remarkable resilience among our participants in coping and living with a diagnosis of breast cancer. Despite periods of psychological distress, the majority of participants relied on self-determination and self-control to become active self-carers and perceived survival as an opportunity to be reborn as a strong and independent woman. Studies with non-immigrant samples report similar findings: Clarke’s (1985) participants expressed a desire to do things they had never done before and were “developing a sense of adventure” (p. 107). Wilkinson’s (2007) participants claimed that uncertainty about the future made them appreciate and enjoy life. Our participants spoke of going on trips, engaging in activities they had always wanted to do, and taking better care of themselves.

Limitations

We used a small convenience sample. We chose to include Portuguese-speaking women from various countries to maximize the breadth of experiences, but, given the small samples from each country, we may have missed both similarities and differences between the diverse groups within this population. It is also possible that we lost some cultural nuances during the translation from Portuguese to English. Despite these limitations, a number of key implications can be drawn.

Implications

Implications are presented at micro, meso, and macro levels. At the micro level, health-care providers could work more closely with women living with breast cancer to help foster social connectedness and support to

ensure that they have the informational, psychological, instrumental, and financial support necessary to manage breast cancer. Information should be provided about prognosis, survival rates, treatment options, coping with the psychological impact of cancer, and coping with body image concerns. Health-care providers are also encouraged to screen all women for psychological distress at various times in their cancer trajectory and to offer linguistically appropriate information and services. Many of our participants indicated that, despite struggling with the fear and stigma associated with cancer, they did not seek psychological support because they wanted to be self-sufficient. It is critical, therefore, that practitioners present support for women (and their families) as complementary to self-sufficiency.

At the meso level, health-care providers must engage immigrant communities in raising awareness about breast cancer and must stress the importance of screening, early treatment, and involvement in cancer survivorship programs. Such work will require the support of key community leaders and the use of ethnocultural media. Health-care providers could collaborate with immigrant communities to build and maintain the social networks needed to support women with breast cancer, particularly to overcome the effects of social isolation resulting from the stigma of cancer (Vahabi, 2010, 2011; Working Women Community Centre, n.d.). Self-help and social-exchange groups (telephone, face-to-face, online) within and outside the community could be encouraged to provide informational, psychological, and instrumental support for husbands and children. Given their tendency to restrict social contact when diagnosed with breast cancer, Portuguese-speaking women might be more responsive to indirect approaches such as (a) telephone calls by trained community volunteers as an alternative to formal psychological counselling; (b) distribution of educational material in family doctors' offices; (c) creation of support groups for breast cancer survivors who speak the same language; (d) dissemination of critical information via language- or community-specific television programs; and (e) a network of community members providing domestic and instrumental support, especially for those who are single, separated, or divorced and who may have no family support in coping with the debilitating effects of chemotherapy and radiation therapy. The effectiveness of such approaches needs to be carefully evaluated.

At the macro level, it is important that health policies and formal social services reflect Canada's diverse demographics and offer an integrated and multi-tiered approach appropriate to the needs and interests of diverse groups of immigrant women (Vissandjee, Thurston, Apale, & Nahar, 2007, p. 233). It is also important that attention be paid to the

financial needs that arise from cancer care and treatment and/or illness-related loss of employment and income.

Conclusion

This is the first Canadian study to focus on the need for, access to, and use of social support in the management of breast cancer among Portuguese-speaking immigrant women, and the first to highlight the resilience of this group when faced with breast cancer. The study is an important first step in identifying implications for health-care providers when caring for immigrant women diagnosed with diseases such as cancer, when stigma and fear can diminish the informal social supports available to them, and in identifying the ongoing problems in the formal social support system for immigrant women with breast cancer. Further research is needed to clarify the similarities and differences within and between various immigrant communities in their need for, access to, and use of informal and formal social support in the management of breast cancer.

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