Practical support for women with breast cancer

By Sally Thorne,
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Abstract

Although emotional, social and informational support are well recognized needs among women with breast cancer, practical support has not attracted serious research attention. However, consumer advocates and researchers studying the subjective experience of breast cancer note that practical support may be a particular concern for some women. In order to document some aspects of the practical support issue and begin to render this element of the experience visible, a community-based consumer group conducted a preliminary survey of practical support needs of women who were living with or had experienced breast cancer. Among the 100 women who responded to this survey, there was considerable evidence that practical support may well remain an unmet need in the current health care climate.

The relevance of emotional and informational support for women with breast cancer has been well documented. It is generally accepted that strategies to meet women's needs in these areas represent an essential component of an integrated breast cancer care program (Health Canada, 1994; Olivotto, Gelmon & Kuusk, 1996; Williams, O'Sullivan, Snodgrass & Love, 1995). In contrast, practical support is rarely addressed in the literature and is often invisible in health care programming. However, consumer advocates in breast cancer have noted that practical support may well be a critical unmet need for a significant number of women (Batt, 1994; Health Canada, 1994).

A literature review confirms the prominence of information and emotional support as issues attracting the attention of researchers. Research using qualitative or descriptive approaches to generate knowledge from the perspective of the women themselves typically documents the importance women place on having their emotional concerns attended to and their information needs addressed. While brief mention is made of practical or physical support as an additional issue, rarely has it been explored in any detail. The reason for this is unclear. It may have to do with general assumptions that practical support is a family matter rather than a basic concern of the health care system. Or it may be that information and emotional support are normalized as acceptable while practical support needs are rendered invisible or unimportant in the general discourse about breast cancer.

This study represents the efforts of a "grass roots" community group to begin to grapple with the problem of practical support in breast cancer. Recognizing that practical support had been a serious

challenge in their own experiences with breast cancer, members of the Life Quilt Project for Breast Cancer in Vancouver, BC decided to try to document the nature of the need so as to develop a better understanding of possible gaps within the existing health services and resources. This paper reports the findings of a preliminary survey of practical support needs from the perspective of women who have had firsthand experience coping with the complex challenges imposed by breast cancer.

Background literature

There is considerable recognition within the available literature for the complexity of psychosocial issues in breast cancer (Carlsson & Hamrin, 1994; Glanz & Lerman, 1992). In keeping with this understanding of breast cancer as an event associated with profound psychosocial sequelae, there has been substantial research activity in relation to the support needs of these women. In particular, informational and social support have received considerable attention.

There is a significant body of research into the information needs of women with breast cancer, particularly at critical points such as the time of diagnosis and treatment decision-making (Bilodeau & Degner, 1996; Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, Mueller, 1997). In addition, it is commonly recognized that women with breast cancer require considerable social and emotional support, especially during certain phases of their illness experience (Payne, Sullivan, & Massie, 1996; Suominen, Leino-Kilpi, & Laippala, 1995). Longitudinal and retrospective research has revealed that adverse effects on quality of life as a result of breast cancer illness and treatment can be documented in many women well into the survivorship phase (Ferrans, 1994; Fredette, 1995; Northouse, 1990).

Studies focusing specifically on social support reveal that it plays a significant role in managing threats to identity and regaining normalcy throughout the trajectory of breast cancer (Colyer, 1996; Lugton, 1997). Because of this, it is typically considered a primary indicator of adjustment in breast cancer (Hoskins, Baker, Sherman et al., 1996). The disruption that breast cancer can invoke in family life

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has also been well documented (Hilton, 1996). Thus a variety of intervention strategies to maximize effective social and informational support have been implemented and evaluated (Cope, 1995; Pålsson, & Norberg, 1995; Samarel & Fawcett, 1992). Despite widespread efforts to intensify emotional support and implement such interventions as support groups, women continue to report gaps in meeting their need for support (Smyth, McCaughan, & Harrisson, 1995).

While the notion of practical support appears as a subtext in many of the research reports, it has not emerged in its own right as an important element of investigation findings (Health Canada, 1994). Recent research into the notion of fatigue, however, documents the profound effect that breast cancer illness and treatment can have on the energy level of these women (Cimprich, 1998; Irvine, Vincent, Graydon & Bubela, 1998; Mast, 1998). Although the specific relationship between fatigue in breast cancer and practical support requirements has not been the focus of systematic investigation, the negative implications of fatigue on quality of life, symptom distress, and ability to maintain normal activities of daily living have been well documented within the general cancer population (Ferrell, Grant, Dean, Funk & Ly, 1996; Winningham, Nail, Burke et. al., 1994). Thus, despite the absence of a strong research foundation, there is considerable basis for the suspicion that, for many women with breast cancer, practical support may well be as critical as social and informational support.

Method

To document the practical support needs of a group of women with breast cancer, a preliminary survey was developed by members of the Life Quilt Project for Breast Cancer in Vancouver, BC, a community based grass roots organization of women with breast cancer. This survey was comprised of five central questions designed to provide a snapshot of the practical support received and needed by women living with breast cancer. In recognition of the complexities inherent in women's understandings with regard to the chronicity of breast cancer, women who self-identified as "having" breast cancer as well as those who self-identified as "having had" breast cancer were included in the survey. Women were asked about the types of practical support they received during their experience with breast cancer and what types of practical support they would have liked to receive but did not. Likert-type scales were used to assess how helpful the support was (i.e., not helpful, somewhat helpful, very helpful) and how necessary they perceived the support to be (i.e., not necessary, somewhat necessary, very necessary). The specific types of practical support assessed included child care, transportation, help with household chores, and assistance with meal preparation and shopping. Open-ended questions were also used to explore and describe the additional kinds of practical support received by

women, what other kinds of support would be helpful, and at what point during the breast cancer experience were certain practical supports found to be the most helpful.

To recruit a convenience sample of women living with breast cancer and women who have had breast cancer, the survey was included in a mail-out of the BC and Yukon Breast Cancer Information Project quarterly newsletter, "Abreast in the Nineties." The individual subscriber group, numbering about 2000, is comprised of women with breast cancer, individuals affected by breast cancer, health care professionals, and community services. Women currently living with breast cancer and women who have had breast cancer were invited to complete and return the survey. In total, 100 women completed and returned the short questionnaire, although some respondents answered questions selectively. In several instances, women omitted the numeric responses and instead wrote their comments in marginal notes. In keeping with the preliminary nature of the survey, demographic data was not requested. Data analysis involved descriptive statistics of quantitative data and thematic content analysis of qualitative responses.

Findings

Practical support received and perceived usefulness

Seventy-four per cent of participants reported that they had received at least one of the listed practical supports, including child care, transportation, homemaker service, and/or meal preparation/shopping. As shown in Table One, the most frequently reported practical support received by women with breast cancer was assistance with transportation (56.5%), followed by help with preparing meals and shopping (54.5%), help with household chores (50.0%), and child care (15.1%). No significant difference in practical support received was found between women who identified themselves as living with breast cancer and those women who saw themselves as having had breast cancer.

Interestingly, not all the women who received practical support perceived the support as being useful to them or to their loved ones during their experience with breast cancer. For example, of the 52 women who received practical support in the form of transportation, only 75.5% perceived that support to be somewhat helpful or very helpful. Despite the discrepancies between received practical support and perceived usefulness, the majority of women found the practical support and help they received to be useful to them (Table One).

The open-ended questions solicited additional information as to other forms of practical support women had received and had found to be particularly beneficial. As might be predicted, women's needs varied considerably and depended on their course of treatment, stage of life, living situation, and social network. What became apparent through the qualitative analysis was that women with breast cancer hold a broad conceptualization of what is encompassed by practical support. For many women, resources such as alternative and complementary therapies, counseling, and other forms of supportive care were identified as practical support. Women considered assistance with coping to be a practical matter rather than simply a matter of social or emotional support. Participants also identified kindness from others as being a very important aspect of practical support in their cancer experience. This form of support included such acts of kindness as sending greeting cards, bringing meals, books, tapes or flowers, offering prayers, visiting or volunteering to take them for outings. Clearly, the acknowledgement that these kindnesses signified illustrates an important aspect of feeling supported.

Table One: Received practical support and perceived usefulness

Type of support	Received (%)	Perceived usefulness (%)			
		Not helpful (%)	Somewhat helpful (%)	Very helpful (%)	Not applicable (%)
Child care (n=93)	14 (15.1)	2 (2.2)	6 (6.5)	6 (6.5)	79 (84.9)
Transportation (n=98)	52 (56.5)	7 (7.6)	11 (12.0)	34 (37.0)	39 (42.4)
Help with household chores (n=98)	46 (50.0)	14 (15.2)	12 (13.0)	30 (32.6)	36 (39.1)
Help with meal preparation/shopping (n=92)	49 (54.5)	12 (13.3)	10 (11.1)	27 (30.0)	41 (45.6)

In addition to these supportive forms of caring, women also identified specific kinds of practical support which they believed to be critical to their ability to manage their cancer experience. Some women mentioned the importance of home care services and regular monitoring through phone calls. This form of support extended beyond attention to the women's physical condition and involved assistance with problem-solving related to practical, everyday issues they had to confront. While child care was explicitly included in the survey, the open-ended responses highlighted the many other forms of caregiving that women may need assistance with when they have breast cancer. Several women required help in caring for a disabled or elderly family member. Others reported the need for help in monitoring adolescents, transporting younger children to their activities, or helping their family members cope with their own emotional needs and shifted functional responsibilities in the family. Several women, especially those who lived alone or had busy families, identified the importance of having a quiet place to recuperate after treatment.

Other forms of practical support identified as being important to the successful management of the breast cancer experience were those related to financial and occupational support. For those women on a restricted budget, the additional money needed to purchase anti-emetic drugs or foods that they could tolerate during chemotherapy treatment was a significant burden. Several women reported extreme anxiety related to accessing sick leave or disability benefits without jeopardizing the security of their jobs. Still others identified the need for career guidance in relation to the current and long-term implications of the breast cancer illness.

Practical support required

When asked about what types of practical support would have been helpful during their cancer experience that they did not receive, many women indicated that help with household responsibilities (56.6%), assistance with meal preparation and shopping (57.5%), and transportation (55.1%) would have been supportive (Table Two). Only 12.8 percent of women responded that assistance with child care would have been helpful, possibly reflecting the life stage of the majority of women who have breast cancer.

Closer examination of the data reveals that over 31 per cent of women identified help with meals and shopping activities as being very necessary in assisting them in managing their cancer experience. With regards to transportation needs and help with household chores, 26.1 percent and 25 percent of women respectively felt that assistance in these areas of practical support was very necessary. These findings are indicative of the importance of practical support in the lives of women coping with breast cancer and related experiences.

The open-ended responses specific to the practical support needs of women with breast cancer revealed a range of issues reflecting a diversity of living and illness situations within the sample. Some women expressed their inability to attend to such practical matters as laundry, gardening, meal preparation, shopping, housework or pet care. For them, specific assistance with the things they could no longer manage independently was of great importance. Another form of practical support had to do with personal assistance in hygiene and grooming. Some women mentioned the difficulties they experienced with washing their hair, or putting on certain articles of clothing. Much of these concerns were related to lymphedema following surgery. For others, assistance with wigs and prostheses was an important issue associated with practical support.

In addition, several of the women reiterated the explicit significance of

transportation and accompaniment as a form of practical support during their cancer experience. While assistance with travel to and from clinic appointments and office visits was most often mentioned, many women indicated the general importance of being accompanied by supportive friends. Many women found that company during waiting periods, another ear to hear the advice they were given, and someone who knows what they were going through was an invaluable form of support.

Finally, the open-ended questions solicited women's response about the occasions during their cancer experience when practical support had been most necessary. Many women identified the time of diagnosis as the point most critical for informational support and the time of surgery as the most important in relation to emotional support. For many of the participants, the period after surgery, or during chemotherapy and radiotherapy, became the time during which many of the practical support needs became most apparent, while the necessary people and resources became less accessible. Some wrote of feeling abandoned during this time, in contrast to feeling supported in the initial phases of diagnosis and surgery. Thus, it appeared that when women most needed practical support in their illness experience, the necessary supports were inaccessible, leaving women to manage on their own.

Discussion

From the findings of this preliminary survey, it is possible to draw some tentative inferences that may have implications for further work in this area. Clearly, practical support was a specific cancer-related need for many of the women, and the women identified a range of activities and functions for which they might require such support. Women responding to this survey did seem to contrast support that was simply "practical" with support that contained an emotional or informational element. Discrepancies were noted between the support received and that which was considered useful, suggesting that there may well be significant unmet needs despite increasing attention to some elements of support within the formal caregiving systems. Thus these findings lend support to the argument that support is indeed a complex and multifaceted phenomenon in an illness such as breast cancer (Health Canada, 1994; Smyth, McCaughan & Harrison, 1995).

While the results of this survey are inherently limited, they suggest the value of continued inquiry into the area of practical support as an unmet need in breast cancer. In particular, they suggest that fatigue and other symptoms may well influence a woman's ability to maintain her usual activities and responsibilities well beyond the time during which she is actively involved in the treatment phase. Thus, supportive services that are explicitly linked to treatment centres may address only one aspect of the problem, and there would seem to be a strong indication for the continued development of community based supportive services that are geographically accessible and adaptable to the changing demands of the breast cancer illness trajectory.

The gap between the practical support received by the women and

Table Two: Perceived practical support needs

Type of support	Not necessary (%)	Somewhat necessary (%)	Very necessary (%)	Total support necessary (%)
Child care (n=78)	68 (87.2)	3 (3.8)	7 (9.0)	10 (12.8)
Transportation (n=69)	31 (44.9)	20 (29.0)	18 (26.1)	38 (55.1)
Help with household chores (n=76)	33 (43.4)	24 (31.6)	19 (25.0)	43 (56.6)
Help with meal preparation/shopping (n=73)	31 (42.5)	19 (26.0)	23 (31.5)	42 (57.5)

their unmet needs suggests that practical support is an issue that transcends the family and may require formal intervention. Further, it must be recognized that practical support needs will inevitably vary according to the unique social circumstances of each woman. For example, while the total number of breast cancer patients requiring child care support may not be large, the significance of that unmet need may be profound for those women affected.

The available qualitative research strongly confirms the intense desire of most women with breast cancer to return to normal activities and responsibilities as soon as possible (Hilton, 1996; Lugton, 1997). However, breast cancer treatment consequences such as arm immobility, nausea, difficulty concentrating and especially fatigue seem to have a powerful and sustained negative impact on the quality of life of many women (Ferrans, 1994; Ferrell et al., 1996). While breast cancer undoubtedly represents a profoundly emotional experience (Carlsson & Hamrin, 1994; Payne, Sullivan & Massie, 1996), the focus on psychological and emotional support may well have eclipsed the practical aspects of the experience that are also deserving of attention and support. We conclude, therefore, that an expanded conceptualization of support in breast cancer to explicitly include practical aspects should be considered a clinical and research imperative.

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