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Résumé

La recherche, le traitement et le partage de l'information sur le cancer du sein par les femmes souffrant de cette maladie

Carmen G. Loiselle, Sylvie D. Lambert et Andrea Cooke

La majorité des femmes auxquelles on a diagnostiqué un cancer du sein cherche à obtenir de l'information sur la santé pour faire face aux effets de la maladie. Cependant, peu d'études ont documenté la façon dont les femmes s'y prennent réellement pour chercher, traiter et partager l'information sur le cancer Cette étude qualitative explore le processus de gestion de l'information sur le cancer de la perspective de 12 femmes ayant le cancer du sein. Parmi les données, trois éléments principaux de la gestion de l'information (GI) ressortent : les déclencheurs d'information initiaux sur le cancer, les réactions émotionnelles et comportementales à l'information, et le sentiment de soulagement, d'espoir, de soutien ou de détresse résultant de la GI. Selon les participantes, la GI est un processus continu dans lequel le choix de continuer de partager l'information sur le cancer avec d'autres personnes dépend du soutien que cette information leur a apporté.

Mots clés : Gestion de l'information, besoins d'information, recherche d'information, révélation de soi, adaptation psychologique au cancer, cancer du sein

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The Searching, Processing, and Sharing of Breast Cancer Information by Women Diagnosed with the Illness

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Most women diagnosed with breast cancer seek health-related information to cope with the demands of the illness. However, few studies have documented how women actually seek, process, and share cancer-related information. This qualitative study explores the process of managing cancer-related information from the perspective of 12 women with breast cancer. Three core components of information management (IM) emerged from the data: initial cancer-related informational triggers, emotional and behavioural reactions to the information, and the IM outcomes of feeling relieved, hopeful, supported, or distressed. According to the participants, IM is an ongoing process in which the choice to continue sharing cancer-related information with individuals depends on women's perceptions of how supportive they have been.

Keywords: Information management, information needs, information-seeking behaviour, self-disclosure, psychosocial adjustment to cancer, breast cancer

Overview

Despite advances in detection and treatment, breast cancer remains one of the most common cancers in women around the world (Mills & Sullivan, 1999). Once diagnosed with breast cancer, women often find themselves in unfamiliar learning environments with little time to react to their diagnosis while being asked to consider various treatment options with their accompanying side effects. The potential spiral of negative events following diagnosis often represents a significant crisis in the lives of affected women and their families (Mills & Sullivan; Rees & Bath, 2000b; Stanton, Danoff-Burg, & Huggins, 2002).

Information-seeking is documented as a key coping strategy in the context of a challenging illness experience (Bilodeau & Degner, 1996; Hoskins & Haber, 2000; Jahraus, Sokolosky, Thurston, & Guo, 2002; Long, 2001; Rees, Bath, & Lloyd-Williams, 1998). The benefits of seeking timely cancer-related information are well documented. They include decreased anxiety and emotional distress (Beaver et al., 1996; Bilodeau & Degner; Chelf-Harper et al., 2001; Craddock, Adams, Usui, & Mitchell, 1999), increased sense of control (Long), enhanced coping (Edgar, Remmer, Rosberger, & Fournier, 2000), and more informed decision-making (Beaver et al.; Bilodeau & Degner). Research efforts have focused on examining how women with breast cancer seek cancer-related information, including the antecedents and circumstances of women's search for information (Boudioni et al., 2001; Rees & Bath, 2001), their discretionary actions when seeking the information (Jahraus et al.; Rees & Bath, 2001), and types and amounts of information sought (Jahraus et al.; Rees & Bath, 2001). This research has enhanced our understanding of women's information-seeking behaviours. However, there remains a need to specifically document how individuals manage the information once they have obtained it. Another important area of research is how information is managed with significant others and health-care providers and the differential consequences of information management (IM) strategies on health-related behaviour and outcomes (Brashers, Goldsmith, & Hsieh, 2002).

The purpose of the present study was to examine the process of IM from the perspective of women diagnosed with breast cancer, including women's interactions with others and the consequences of IM for adjustment outcomes. Women with a diagnosis of breast cancer were the target population for the study, as information-seeking is reported to be a key strategy in coping with this diagnosis (Hoskins & Haber, 2000; Jahraus et al., 2002; Long, 2001; Rees et al., 1998).

Background

The diagnosis of breast cancer often comes as a terrible shock, involving feelings of anxiety, uncertainty, denial, fear of dying, depression, and anger (Epping-Jordan et al., 1999; Hoskins & Haber, 2000; Lavery & Clarke, 1996; Schnoll, Harlow, Stolbach, & Brandt, 1998). The rapid succession of events following diagnosis, including complex decisions, arduous treatments, and possibly inadvertent life changes, places extraordinary demands on women's coping abilities (Hoskins & Haber; McCaul et al., 1999; Mills & Sullivan, 1999; Stanton et al., 2002). To better cope with the psychological and physiological demands imposed by a breast cancer diagnosis, women often actively seek illness-related information (Bilodeau & Degner, 1996; Hoskins & Haber; Jahraus et al., 2002; Long, 2001; Rees et al., 1998).

Several studies have examined the information-seeking behaviours of women diagnosed with breast cancer. Findings to date suggest that many of these women seek as much information as possible, particularly on the nature of the diagnosis, the likelihood of cure, treatment options and side effects, investigational tests, the stage of the disease, and the possibility of recurrence (Bilodeau & Degner, 1996; Degner et al., 1997; Harrison, Galloway, Graydon, Palmer-Wickham, & Rich-van der Bij, 1999; Rees & Bath, 2000a). Although most women report a desire to have illness-related information, there is considerable variability in the type and amount of information they prefer (Chelf-Harper et al., 2001; Harrison et al.; Leadbeater, 2001; Rees & Bath, 2000a, 2001). Some women report seeking cancer-related information that is perceived to be essential but avoid highly detailed information (Jahraus et al., 2002; James, James, Davies, Harvey, & Tweddle, 1999; Long, 2001), others seek the information they need to care for themselves and avoid other types of information (Jahraus et al.), and still others prefer to obtain information gradually as the illness experience unfolds to avoid being overwhelmed by such information (Shaw, Wilson, & O'Brien, 1994). Some women even report a need to avoid all illness-related information (Rees & Bath, 2001). Women diagnosed with breast cancer who shun illness-related information may do so to avoid associated distress (e.g., worry, fear) (Rees & Bath, 2001). The information-seeking behaviour of women diagnosed with breast cancer also may vary over time. For instance, a woman may avoid further information following an exhaustive information search (Rees & Bath, 2001) or may first seek information from health professionals and then turn to other sources (e.g., books, the Internet) (Johnson, 1997). In addition, women may have a stronger desire for information on prognosis at the onset of the illness or when they embark on therapeutic regimens (Mills & Sullivan, 1999; Rees & Bath, 2000a, 2001). Information about self-care and risk to other family members becomes more important later on (Rees & Bath, 2000a). In general, when seeking illness-related information, women diagnosed with breast cancer often control the type and amount of information that they attend to and use particular strategies to obtain the information they need (Jahraus et al.).

Brashers et al. (2002) use the term information management (IM) to capture all strategies or activities undertaken by individuals to seek, appraise or interpret, avoid, and provide selective information. They point to the need to understand if and how patients and family members coordinate IM strategies that may impact on their interactions and health outcomes. In the context of women with breast cancer, significant others also have been found to take on different roles related to IM (Chalmers, Thomson, & Degner, 1996; Kilpatrick, Kristjanson, Tataryn, & Fraser, 1998). Sometimes they are sources of cancer-related information for each other (Rees & Bath, 2000b). Sometimes family members collaborate with patients in gathering the desired information (Echlin & Rees, 2002) and in evaluating it (Chalmers et al., 1996; Echlin & Rees, 2002; Kilpatrick et al., 1998; Rees & Bath, 2000b). Significant others also may act as buffers against the incoming information (Chalmers et al.; Echlin & Rees; Kilpatrick et al.; Rees & Bath, 2000b). At times, IM strategies of patients and significant others are coordinated and information is shared unrestrictedly (Chalmers et al.; Rees & Bath, 2000b). At other times, their IM strategies are divergent, which, in turn, may result in different preferences for cancer-related information (e.g., a woman may wish to avoid information on breast cancer and yet have significant others provide her with such information) (Brashers et al.; Chalmers et al.; Kilpatrick et al.). Collaborative patterns of communicating cancer-related information between patients and significant others are reported to promote positive health outcomes, while mismatched preferences for communicating information are reported to contribute to negative health outcomes (Brashers et al.; Chalmers et al.).

Researchers have begun to examine how patients and significant others manage information related to breast cancer. However, no study reviewed to date documents IM processes from the perspective of women diagnosed with breast cancer, taking into consideration the role of significant others. In the present study, women were asked to describe: (1) how they obtained the cancer-related information they needed, (2) how they reacted to the information they obtained or received, (3) how they shared breast cancer information with significant others and how significant others reacted, (4) the consequences of seeking and sharing information with significant others, and (5) the factors that influenced their IM strategies. These questions contributed to the development of a conceptual model that depicts key characteristics of IM within this particular context.

Method

A qualitative multiple-case design (interpretative analysis) was used to examine how women diagnosed with breast cancer manage cancer-related information. Participants (n = 12) were interviewed by one of the authors in the course of receiving usual nursing care (n = 9) or prior to participating in a workshop on the role of information in psychosocial adjustment to cancer (n = 3). All participants were informed by the researchers about the study and its purpose and were assured of confidentiality. All participants provided either written or verbal consent to take part in the study prior to the first interview.

Participants

Purposive sampling was employed and participants were selected based on their diagnosis of cancer, time elapsed since diagnosis, presence of a significant other, and willingness and ability to discuss their experience. Most potential participants were approached by the researchers through an inpatient oncology unit or an outpatient chemotherapy clinic in a large urban teaching hospital. Women with major concurrent physical and/or psychological illnesses were excluded.

Twelve women agreed to participate in the study. They ranged in age from 43 to 88 years and were of various ethnic backgrounds (e.g., English Canadian, East Indian, French European, French Canadian, Polish, Scottish). The women were at various stages of breast cancer: stage 1 (*n* = 2), stage 2 (*n* = 3), advanced stage 4 (*n* = 4), and recurrence (*n* = 3). Three were single, four were married, three were separated or divorced, and two were widowed.

Data Collection

Data were drawn from in-depth, face-to-face semi-structured interviews with the 12 women diagnosed with breast cancer. Semi-structured interviewing was used as a way to ensure that issues related to IM were covered while allowing participants the flexibility to elaborate on topics important to them (Morse & Field, 1995). The interviews took place between January and May 2001 and lasted approximately 90 minutes. Each participant was interviewed individually. Participants were interviewed a second time if they showed fatigue during their first interview or if they expressed an interest in discussing the issues further. The interviews were conducted either in the patient's hospital room, in the outpatient chemotherapy clinic during treatment, during home visits, or in a discreet public area (e.g., restaurant), according to the preferences of participants.

At the beginning of each interview, the researcher described the study to the participant and time was provided to address the participant's concerns or questions. The participant was informed that her anonymity would be protected and assured of confidentiality. The interview consisted of a series of open-ended questions designed to elicit perceptions of the strategies and behaviours participants used when managing cancer-related information. The participants were asked the following general questions to ascertain their personal construction of IM: "Can you describe your experience with breast cancer information so far?" "Tell me about the ways you and your significant others together handle breast cancer information" "How is your family handling breast cancer information?" They were also asked about IM-related issues, such as general IM patterns, factors that influenced their search for cancer-related information, and their reactions to the management of cancer-related information by their significant others. Additional probes were used, as needed, to clarify and expand upon participants' comments (e.g., "What do you mean by that?" "Tell me more about that") (Krefting, 1991).

Four interviews were audiotaped and transcribed verbatim. For the remaining interviews, succinct notes were taken during the interview and completed immediately afterwards to ensure optimal recall and minimal bias. The notes included observations, explicit details of situations and interactions, assumptions about what was heard or observed, and the researchers' personal narratives: what they felt before, during, and after the encounter. Data were managed using Microsoft Word.

Analysis

Data analysis for this study draws on the interpretive tradition within qualitative research, whereby portions of data are placed in categories and the categories are linked together to form a coherent model for explaining the phenomenon of interest (Sandelowski & Barroso, 2003). Although no attempt was made to develop a substantive grounded theory about IM, analytic procedures were used to capture the process of IM from initiation to outcomes. Categories within the field notes were identified through latent content analysis (Field & Morse, 1985). First, the transcript and notes for each interview were read several times to gain a sense of the overall content of the interview. Then, these were reviewed line-by-line (microanalysis), and, through inductive reasoning, words, statements, and paragraphs describing IM and IM-related issues were extracted. Through this in-depth analysis, similar excerpts were identified using the same label or code (Holloway & Wheeler, 2002). Codes were identified in the margins of the transcripts or notes. During regular meetings, codes were compared and discussed until consensus was reached. Detailed analysis and interpretation of the codes resulted in the emergence of categories. A category was construed as a grouping of codes that were similar in concept or meaning (Holloway & Wheeler; Hutchinson & Wilson, 2001; Strauss & Corbin, 1998). Categories represented the triggers to IM, reactions to the information, and outcomes of IM. Each category was subsequently defined, a process of identifying subcategories, describing the overall meaning based on a review of all the transcripts, and identifying representative quotes. Possible relationships amongst the different categories and subcategories were then discussed and mapped. Participants were recruited until the categories and subcategories were sufficiently described and additional data became redundant. This resulted in a preliminary conceptual framework illustrating links among the various categories (Figure 1). This framework contains concepts that offer the most parsimonious representation of the data.

Evaluation of Rigour

The rigour of qualitative research can be evaluated using the criteria of credibility, confirmability, and transferability (Carnevale, 2002; Chiovitti & Piran, 2003; Sandelowski, 1986; Speziale & Carpenter, 2003). Table 1 describes the strategies used to enhance the methodological rigour of this study.

Figure 1 ***Information Management by Women Diagnosed with Breast Cancer***

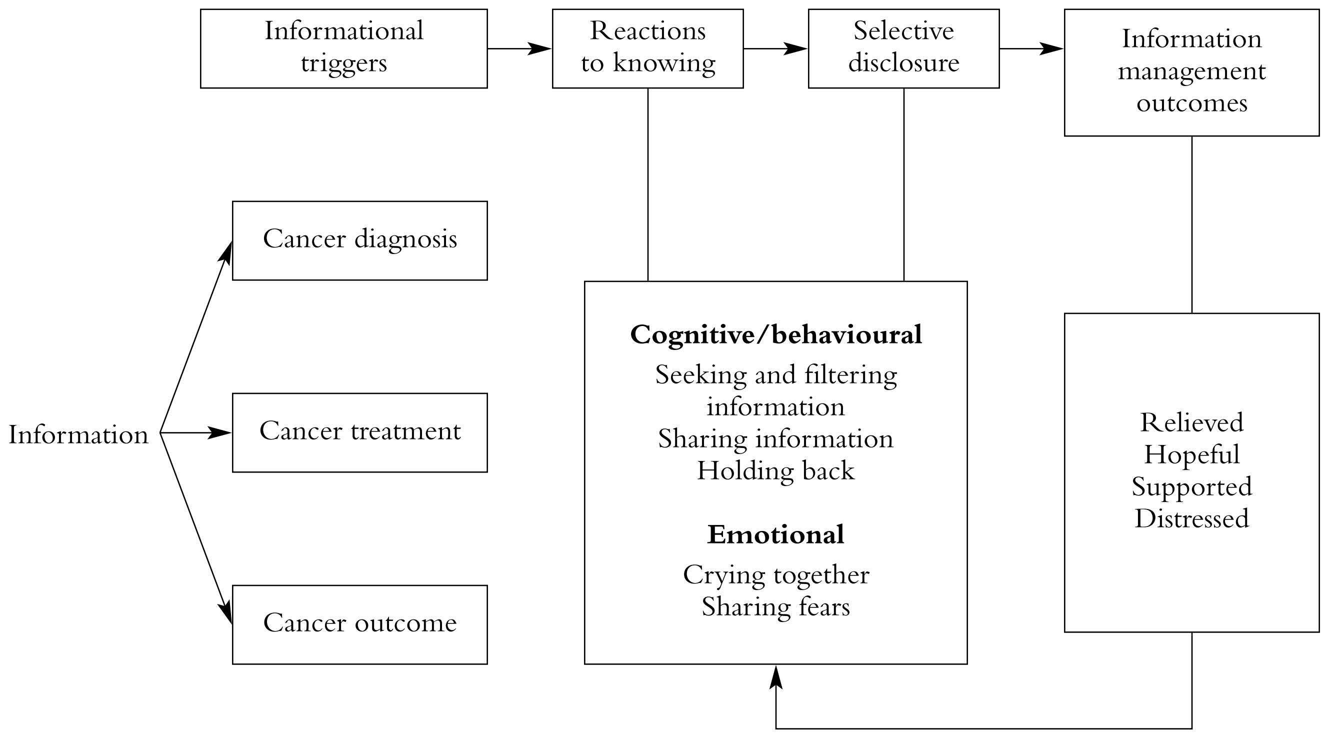

Table 1 *Evaluation of Rigour*

Criteria	**Strategies**
Credibility	Findings are discussed among the researchers for the purpose of reaching consensus (Carnevale, 2002). Prior knowledge of and experiences with the phenomenon are acknowledged; field notes are used in order to identify and document biases (Chiovitti & Piran, 2003; Sandelowski, 1986). The inquiry process is guided by participants; the point of view of participants is solicited during interviews (Chiovitti & Piran, 2003). Some labels used in the conceptual framework are the words of the participants (Chiovitti & Piran, 2003).
Confirmability	An audit trail is kept (Carnevale, 2002; Sandelowski, 1986): detailed records of data collection and analysis as well as personal notes documenting decisions made throughout the study.
Transferability	The phenomenon of IM is relevant to the target population (Chiovitti & Piran, 2003). The scope of the study, in terms of sample, setting, and proposed conceptual framework, is delineated (Chiovitti & Piran, 2003). The sample consists of individuals at different stages of the illness trajectory, so that the study will capture different experiences with IM (Sandelowski, 1986). Direct quotes are presented (Morrison-Breedy et al., 2001). The authors discuss how themes relate to the literature (Chiovitti & Piran, 2003).

Findings

Content analysis of the transcripts revealed that IM by women diagnosed with breast cancer can be conceptualized as a process consisting of four components. The first component, "informational triggers," refers to the women's initial exposure to breast cancer–related information and/or cancer-related events/situations that prompted them to react and to begin seeking or avoiding information. The second component, "reactions to knowing," can be defined as women's repertoire of emotional and behavioural responses in light of the perceived informational triggers. The participants' reactions included "information-seeking and filtering," "sharing information," "holding back," "crying together," and "sharing fears." The third component, "selective disclosure," refers to the process through which some of the women made decisions about the kinds of cancer-related information to be shared, when, and with whom. Through selective disclosure, some women readily assessed whether significant others were supportive and whether they would continue to exchange information with them. Last, four descriptors capture the range of IM outcomes reported by the women: "relieved," "hopeful," "supported," and "distressed." The IM strategies used within each dyad (i.e., woman/significant other) were found to influence the outcomes of IM and participants' reactions to further informational triggers. A conceptual framework (Figure 1) representing the findings was developed by the authors. Each category of the framework is described below.

Informational Triggers

In some instances, it was the information from health professionals that triggered participants to react and modify their behaviour regarding cancer-related information (e.g., whether to seek or avoid further cancer-related information). In other instances, informational triggers were cancer-related events or situations that incited the women to react and begin to seek or avoid information. Categories of informational triggers experienced by the women included cancer diagnosis, cancer treatment, and potential cancer-related outcomes.

Cancer diagnosis. Several participants said that their most significant emotion triggers included information they received from health professionals related to a possible (e.g., investigative test results) or actual diagnosis of breast cancer. Even though the time elapsed since diagnosis ranged from 6 months to 10 years, the moment when diagnostic information about breast cancer was provided to the women, and their reaction, stood out sharply in their memory. One woman spoke of her complete surprise when she learned of the diagnosis:

> *I went to the doctor for a check-up and she found a lump in my breast. My doctor said, "Oh, it's probably nothing, but we'll have it checked out." So even at the mammogram I was told that it looked like it was benign… So when it came time to get the biopsy results I was already convinced that I didn't have cancer.*

Another woman described seeking information about the nature of her cancer. She wanted to be more knowledgeable about her condition:

> *I did have some cancer in two of my lymph nodes, and I didn't know if this increased my chances of having a recurrence or not, if they managed to cure the cancer.*

Cancer treatment. Treatment modalities for breast cancer were important informational triggers. Several participants explained how objective information received from health professionals on the side effects of treatment incited them to react:

> *I received a sheet on side effects that I could have from the chemo. Some were serious — the chemo can damage your heart.*

Other participants were motivated to react after experiencing symptoms related to treatment (e.g., unpleasant side effects). Often, the subsequent search for information was related to management of side effects:

> *I've developed a really nasty side effect from the chemotherapy medication that I was taking most recently… [It] made me lose my taste as well as my appetite.*

Cancer outcomes. Some informational triggers were related to the outcome of having breast cancer, particularly in regard to prognosis and recurrence. For some participants, a constant concern was whether the disease was progressing and what the prognosis might be. Informational triggers often were related to physical symptoms interpreted as a sign that the disease was or was not progressing. An elderly woman had one particular question for her oncologist:

> *I wanted to know what was causing the pain. Was it because the cancer had spread? That was the question I wanted answered.*

Another participant was asked why she had been willing to share her experience of severe fatigue with women in the chemotherapy clinic but not with the oncologist:

> *Because I was scared. I was scared it was because the chemo wasn't working and the cancer was spreading.*

Several women experienced a recurrence of breast cancer. Similar to the period of diagnosis, the point at which they learned that the cancer had recurred stood out for them as a moment when they received informational triggers such as:

> *When I went to my doctor's appointment, he sent me for some tests.... He told me, "This is serious. Now the cancer has come back. We can treat it but we won't be able to cure it."*

Reactions to Knowing and Selective Disclosure

The women's range of reactions to the various informational triggers fell into two categories: cognitive/behavioural and emotional. Cognitive/behavioural reactions described by the participants included "information-seeking and filtering," "sharing information," and "holding back." Emotional reactions included "crying together" and "experiencing and sharing fears."

Cognitive/behavioural reactions

Information-seeking and filtering. Following the initial informational trigger, most participants were motivated to seek complete and objective information about breast cancer. To gain a better understanding of the illness and its treatment, these women sought information on the specific nature of their cancer and became more knowledgeable about their current status. One woman, for instance, was very inquisitive about breast cancer, stating that in addition to reading all she could about it, she prepared questions before meeting with health-care providers. Another woman said:

> *The day after my lumpectomy, I asked my husband to go to the bookstore and buy every single book that he could find on breast cancer. He came back with a half dozen, most of which were scientific and medically oriented.*

Two participants reported avoiding breast cancer information altogether. One woman had issues regarding additional information provided to her on the side effects of chemotherapy:

> *When I went for my first chemotherapy session, my nurse...handed me a four-page...document and told me to read it carefully. It contained a list of all the possible side effects I could get from chemotherapy. Without even glancing at the document, I handed it right back and told her that I didn't want to read it.*

Some women demonstrated selectivity in their search for cancer-related information. These participants did not seek all types of information but, rather, focused on information that they thought would be "positive" or comforting:

> *I was overwhelmed by fear… What I needed was "anti-fear" information — information that I could intellectually use, process, and combine, to counterbalance and reduce the fear. I needed information that would elicit hope and contribute to a positive attitude.*

Participants who sought positive information were often found to avoid the "cold, hard facts." One woman reported that she preferred to seek positive information and to avoid scientific and medical information, because "I understood too little of too vast a subject," and of what she did understand, only the negative appeared salient, causing her to be fearful.

Although information-seeking and filtering could be initiated by the woman herself, in some instances a significant other was involved in the search for and screening of information. One woman described the role her husband played in screening potentially threatening information and supplying her with more positive information:

> *I told my husband the things that I was ready to hear about breast cancer and the types of things I did not want to know…. He looked over all the pamphlets and other written documents that the nurse had given me and he told me only the things I was ready to hear. He was so helpful.*

Sharing information. Sharing information emerged as one of the most salient cognitive/behavioural reactions. All 12 women reported a desire to share cancer-related information with significant others. In the process of sharing information, they tended to disclose more information to individuals they perceived as supportive than to those they perceived as unsupportive or fragile. For example, one participant chose to discuss the potential side effects of chemotherapy with her daughter rather than with her husband:

> *I told her [about the potential side effects]. We're very close. I feel comfortable talking to her about anything. I feel she's strong and won't become depressed over hearing about what's happening to me.*

Some participants described situations in which significant others initiated information-sharing. One woman's son actively sought cancer-related information and then shared it with her:

> *It's so funny. Every time he comes home from Toronto he brings the latest piece of information that he got off the Web or from books. And we have a little family meeting, and he teaches us what he has learned.*

Significant others who had previous experience with cancer were identified as particularly important resources. One woman explained that the most recent chemotherapy drug she had taken had affected her appetite and her sense of taste. She talked to a friend who was receiving similar treatment for breast cancer at a different hospital:

> *My friend gave me some information that she had read in a pamphlet that her oncologist had given her… She also suggested that I start eating my food at room temperature or cold, and that has helped me taste it more.*

Holding back. Although seeking or avoiding information was a coping strategy used by all the participants in response to informational triggers, many reported that they withheld certain types of information from significant others, particularly if they thought it would upset or worry them. For example, after being given a pamphlet describing potential side effects of chemotherapy, one woman decided not to share the information with her husband:

> *I didn't tell him that, because I knew that then he would have double to worry about! He would worry about cancer and heart disease.*

Emotional reactions. Emotional reactions to cancer-related information included sharing and expressing emotions with significant others. The most common emotional reactions reported by the participants were crying together and experiencing and sharing fears.

Crying together. Two participants spoke of crying in the company of another person after learning about the progression of the disease. One woman spoke of calling a close friend immediately after discovering that her cancer had returned:

> *She's the first person that I called after I heard that I had cancer again. She came and picked me up at the hospital and brought me to a café, and we cried together.*

Another woman described a situation in which she cried in the chemotherapy clinic with a nurse present. This occurred after a long day at the hospital, where she had learned of a second bout of cancer in her lung:

> *I was sitting there in the chair and she asked me how I was and I just started to cry. I felt comfortable enough with her to cry with her.*

Experiencing and sharing fears. A salient emotion described by participants in reaction to cancer-related information was fear. One woman explained how the information she received induced fear:

> *The emotion of fear comes from within, from inside a person…we can readily ascertain that this fear is based on information that the patient has just been given.*

Several women spoke of the need to share their fears with people who "would understand" what they were experiencing. One participant felt comfortable talking to a friend about her fears because they were "close like sisters":

> *I talk to her about my fears, about my worries concerning who my daughter will live with… These are difficult issues that I don't necessarily want my daughter to worry about.*

Some women sought out significant others who had previous experience with cancer or who presently had breast cancer. One woman spoke of a group of four female friends who had breast cancer:

> *I don't have to explain anything to them. It's like we share the same fears, we've gone through the same things.*

Information Management Outcomes

Once they had reacted behaviourally and emotionally to cancer-related information, participants felt either "relieved," "hopeful," "supported," or "distressed." In some instances, they reported more than one IM outcome (i.e., a mixture of feelings).

Feeling relieved. Some women felt relieved when they shared information with significant others who were open to discussing issues related to breast cancer. One woman with a poor prognosis spoke to her 15-year-old daughter in order to prepare her for the eventual death. The girl was open to discussing the issue, to her mother's relief:

> *We have talked about [my death]. At first she would get upset…but recently she said to me, "You know, Mom, I am ready for the death" … I felt a sense of relief, because it means that she has been thinking about it.*

Feeling hopeful. Some women described feeling hopeful and encouraged after receiving cancer-related information from significant others or sharing it with them. Several participants felt hopeful as the "filtered" information they received from family members was "promising." One woman spoke of feeling hopeful after receiving information as a result of her son's Internet searches:

> *I'm always left with a strong feeling of hope, a feeling that I know that I am going to get better and survive this. I know I am. The information he gets is always promising. It's always positive in some way.*

Feeling supported. Participants often spoke of feeling supported by their significant others after sharing information with them. One woman described how she felt after telling a significant other about the information gathered during appointments with the oncologist:

> *The fact that she cares for me and is truly concerned about how I'm doing is so important to me. It makes me feel so supported and that I am not alone.*

Another woman described her relationship with her sister, whose husband had died of cancer the year before:

> *She would listen to me, and then convey to me that she understood what I was going through. That was reassuring. It was comforting.*

Feeling distressed. When information was disclosed to significant others who were not open to discussing issues about breast cancer, the encounter often was viewed as unhelpful and distressing:

> *When I told my husband that the cancer had come back, he didn't believe me… When I was so sick the first time, he would never acknowledge that I was sick. He would just ignore it and pretend like everything was normal.*

When asked if this relationship had helped her adjust to cancer, the woman said it had not and she had asked her husband to leave:

> *I couldn't take him any more. He was causing me more stress than anything else in my life. He could never show me any sympathy, and he was of no help.*

Subsequent to the negative interactions with her husband, this participant chose to share information about breast cancer with significant others whom she considered supportive.

Another woman was distressed by the inability of her two daughters to openly discuss cancer-related issues with her. She was obliged to "hold back" some information:

> *I've tried, trust me, but they will not talk about that. They always change the subject, as if I didn't say a thing… I think it's important to be able to talk about these things with family members. I'm not going to live forever, that's for sure.*

Discussion

The purpose of this study was to explore the experience of information management (IM) among women diagnosed with breast cancer. IM began as soon as the participants received cancer-related information, most often from health professionals at the time of diagnosis or later when they undertook treatment. These events triggered the women to react behaviourally and emotionally. Some participants focused on seeking further information, whereas others preferred to avoid or ignore subsequent information. Some reacted emotionally, such as by crying. Women's reactions and how these were subsequently managed together with significant others influenced their feelings about their situation, themselves, and others. "Informational triggers" is a term akin to "stimulus" proposed by Freimuth, Stein, and Kean (1989) and Lenz (1984). According to these authors, a discrepancy between the amount of information one possesses and the amount needed acts as a stimulus for future behaviours. In the present study, similarly, the informational triggers were found to be either internal (e.g., linked to symptoms) or external (e.g., linked to cancer information provided). Freimuth et al. and Lenz discuss two potential outcomes of triggers (information search or avoidance). The present study describes a wider range of possible reactions to informational triggers. Participants' reactions to triggers revealed nuanced patterns of information-seeking (i.e., selective information-seeking).

Most participants sought as much cancer-related information as possible, just as documented elsewhere (Jahraus et al., 2002; Rees & Bath, 2001), and a few participants avoided information altogether. Participants who gathered all available information were mainly interested in what Loiselle (1995) refers to as the "diagnosticity" of the information — that is, they were interested in information that would significantly reduce the ambiguity or uncertainty of some aspect of their situation. Interestingly, some women reported a preference for "positive" cancer-related information. This type of selectivity has not been reported elsewhere for this population, although recent studies document a positive orientation of women towards "benefit finding" pertaining to their cancer (Tomich & Helgeson, 2004). Selectivity in seeking positive information about oneself has been termed "self-enhancement," primarily in the social psychology literature (Gaertner, Sedikides, & Graetz, 1999; Sedikides, 1993; Taylor, Lerner, Sherman, Sage, & McDowell, 2003). Self-enhancement is described as a desire to promote, maintain, and defend a positive view of the self (Loiselle; Sedikides; Taylor et al.). In the present study, other participants also sought to protect themselves from aversive information about their cancer in an attempt to maintain hope or a positive outlook.

Findings from this study support the notion that women with breast cancer and their significant others are intricately involved in IM activities (see also Brashers et al., 2002; Chalmers et al., 1996; Kilpatrick et al., 1998). Participants and significant others were important sources of cancer-related information for each other. In the process of sharing information, the women were sensitive to how the disclosure of information would affect significant others, which led to selective disclosure of cancer-related information. Participants were more likely to share information unrestrictedly if they thought their significant others would be "strong enough to take it." Selective disclosure often led to decisions regarding which type of information to share, with whom, and when. Participants also were found to act as gatekeepers of cancer-related information (see also Chalmers et al.; Rees & Bath, 2000b). Some women selectively disclosed information to or withheld it from significant others because they thought it would be too upsetting or worrisome for their loved one. Such protectiveness of significant others by patients has been documented elsewhere (Hilton, 1994; Rees & Bath, 2000b). Hilton found that when sharing cancer-related issues, women diagnosed with breast cancer and their significant others were more satisfied with sensitive communication than with indiscriminate sharing.

In addition to sharing information, some participants reported sharing feelings with others in reaction to cancer-related information received or sought. Emotional reactions to breast cancer information have received less research attention than cognitive/behavioural reactions. Hilton (1994) refers to communication about fears, doubts, and emotional issues among women diagnosed with breast cancer and their significant others as "sharing meaning," an important strategy used by couples in managing illness and enhancing psychosocial adjustment.

In the present study, the experience of cancer-related IM resulted in one of four outcomes for the participants: feeling relieved, feeling hopeful, feeling supported, or feeling distressed. It became clear that the congruence (or lack thereof) between the IM strategies of participants and their significant others influenced the reported outcomes of IM. Participants were more likely to report a positive outcome (e.g., relief, support, encouragement) when significant others had similar preferences regarding the sharing of cancer-related information. Participants reported that information-sharing had little benefit or was distressing when their need for disclosure was not shared by significant others. In these instances, significant others were often seen as unsupportive. The importance of open communication about cancer among affected individuals for optimal health-related outcomes also has been discussed elsewhere. Chalmers et al. (1996) found that restricted communication about breast cancer between patients and significant others contributed to negative adjustment outcomes for significant others; however, they did not report on the consequences of different communication styles strictly from the perspective of women diagnosed with breast cancer. Hilton (1994) found that the single most critical factor in couples' adjustment to breast cancer was that they share similar views on the importance of talking about cancer-related issues. The present study supports such observations and documents the various outcomes pertaining to communication patterns from the perspective of the women themselves.

As a consequence of their interactions with significant others, the participants quickly learned whom they could share cancer-related information with and who would be most helpful in securing any required information. Participants' learning appeared to take place both during and after information-sharing. When they felt supported, the women would continue to disclose information to significant others. However, when they shared information and felt unsupported, they chose not to disclose new information and to hold back associated emotions. These findings are supported by previous research suggesting that individuals with dissimilar communication patterns disclose little information (Rees & Bath, 2000b; Rees et al., 1998). They also corroborate the theoretical proposition that IM is a process of self-regulation whereby one's IM strategies evolve and are modified until the satisfactory level of disclosure to a "coordinated" significant other is achieved (Loiselle, 1995).

Implications for Practice

The present findings highlight the need for health-care providers to more systematically assess the social networks of women with breast cancer to identify the potential IM strategies used and to address how reliance on these strategies may affect health-related outcomes. Such assessment would guide health-care providers in supporting women as they engage in IM with significant others. The findings also suggest that information provided by health professionals acts as triggers to patients, which, in turn, impact on subsequent IM strategies and outcomes.

Limitations

Findings from this study may be considered preliminary, as the sample was relatively small and homogeneous in terms of being mostly Caucasian. Additional sociodemographic data would also have been helpful in qualifying our analysis (e.g., education, number of children, family income). In addition, the audiotaping of all interviews instead of just four might have added details to certain of the comments by participants.

Conclusion

The purpose of this study was to investigate women's experience in managing cancer-related information together with significant others. A qualitative approach revealed that the process of information management (IM) is very real for this sample and includes four main components: informational triggers, ensuing behavioural and emotional reactions to knowing, selective disclosure of breast cancer information, and outcomes related to the overall IM process. The findings also highlight the importance of IM in the context of breast cancer and underscore the intricate ways that such information is managed with significant others.

To our knowledge, this is the first study on IM among women with breast cancer. Further research is needed to study potential shifts in IM strategies and behaviours as the illness experience unfolds. This would allow for comparison of IM patterns at different points on the illness trajectory. Also, the exploration of cultural and sex differences in the management of illness-related information is a promising avenue for research.

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