

Understanding the role of cancer informational support in relation to health care service use among newly diagnosed individuals

by Sylvie Dubois and Carmen Loisel

Abstract

A qualitative study was undertaken to explore the role of informational support in relation to health care service use among individuals with cancer. In-depth interviews were conducted with participants (N=20) newly diagnosed with either breast or prostate cancer receiving radiotherapy from an oncology clinic in Montreal, Quebec. Content analysis revealed that participants' perceptions about their experience with cancer informational support in relation to health care services varied along the following dimensions: (1) Cancer informational support was tangible, which enabled, confirmed, normalized, and directed their decisions about reliance on health services; (2) Cancer informational support was somewhat paralyzing, which led to distress, conflict, reduced confidence in the health care system and, at times, misuse of health care services; and (3) Cancer informational support was limiting, with perceptions of having received both helpful and unhelpful cancer information which, in turn, although tolerated, offered little guidance in terms of reliance on the most appropriate services. Knowledge about how and when informational support may be most timely may optimize individuals' well being and further guide their use of cancer-related services.

Background

With advances in treatment, individuals with cancer now live longer, increasing the need for various services such as psychosocial support and cancer control (Rosenbaum & Rosenbaum, 2005; Rutgers, 2004). Part of psychosocial support, informational support is now known to contribute to knowledge acquisition, decision-making, self-care abilities, and adherence to treatment recommendations. It may also decrease fear and anxiety, and increase hope and empowerment (Gornick, Eggers, & Riley, 2004; Lambert & Loisel, 2007). When information needs are not fulfilled, individuals with cancer may be more likely to over-use health services such as community and emergency facilities (Carlson & Bultz, 2004).

Even though a literature review suggests that informational support may lead to more reliance on cancer screening services (Finney Rutten, Arora, Bakos, Aziz, & Rowland, 2005) and that, overall,

women are more likely to use health services than men (Green & Pope, 1999; Vasiliadis, Lesage, Adair, Wang, & Kessler, 2007), few studies have explored the role of informational support in relation to health care service use. Studies on health care services have mostly focused on factors that predict the use of services (e.g., treatment modalities, comorbidity, physical function, pain, sociodemographic variables) often with one main goal of reducing costs (Andersen, 1995). For instance, one study conducted among women diagnosed with breast cancer (N=123) reported fewer visits to the cancer centre after receiving an educational intervention (Simpson, Carlson, & Trew, 2001). This study was the first to demonstrate that women who participated in an intervention group reported a reduction of visits to clinics and a better quality of life than those in the usual care condition. More recently, a study was conducted with veterans (predominantly men) diagnosed with cancer (N=125; all cancer types) to compare a telehome health care program (i.e., using technology for informational support, including professional follow-up during chemotherapy treatment), with usual care relative to the use of health care services (Chumbler et al., 2007). Results showed fewer visits to clinics and fewer hospital stays in the experimental group. However, this study focused on coordination of care for symptom management that included informational support, which was not separately measured. Moreover, the role of cancer informational support in guiding their use of services from the participants' point of view has not been reported.

The present study was conducted to further explore the perceived role of informational support in relation to the use of health care services among women and men newly diagnosed with cancer. Several questions guided the inquiry such as: What is it like for individuals newly diagnosed with cancer to be provided with or to have to seek cancer-related information? What is it like to negotiate health care services when one has just learned that they have cancer? To what extent is cancer-related informational support (both formal and informal) helpful or unhelpful in guiding reliance on cancer-related services? We also explored whether sex differences were emerging from the data. Breast and prostate cancers were chosen as they involved different sexes and are the most frequently diagnosed cancers in both Canada and the United States (American Cancer Society, 2008; National Cancer Institute of Canada, 2008).

Method

This descriptive qualitative study used a purposive sampling strategy to recruit participants who showed an interest in communicating their experience with cancer information in relation to health care service use. Inclusion criteria also included a primary diagnosis of breast or prostate cancer (within a year of diagnosis), reliance so far on at least two distinct cancer services (e.g., outpatient clinics, emergency rooms, group support, community health centres) to allow enough richness in accounts. In addition, individuals had to have a good understanding of English or French, and be cognitively and physically capable of participating in a two-hour

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face-to-face interview. Individuals with major comorbidity were excluded, as this would have confounded reports of health care services utilization. Following ethical review and approval by the relevant ethics committees (hospital and university), data were collected over a four-month period (between the months of May and September in 2006) in a large urban teaching hospital in Montreal, Quebec.

Initially, potential participants were identified by staff nurses or radiation technologists and initial agreement to be approached by the researcher was obtained. The researcher then met interested patients in a private clinic room, the study was described, eligibility criteria were assessed, and ethical considerations were discussed. Written consent was obtained from patients who agreed to participate, and they completed the sociodemographic sheet. Next, an appointment was scheduled to conduct the individual interview. Participants were interviewed in a location of their choice (either at the participant's home or in a private room in the hospital). The interview was either conducted in French or English according to the wish of participants.

All individual interviews, conducted by the first author, lasted between 55 and 150 minutes and were digitally recorded. The open-ended interview questions asked the participants to describe sources of information used since they received their cancer diagnosis, types of services used and issues related to information and services such as accessibility of services, barriers or frustrations, potential links between the cancer information received and subsequent use of health care services, and satisfaction with these services. Specific probes were used to develop further the recounting of events surrounding their experience with cancer (e.g., diagnosis, treatment). The inter-

views ended with a summary of the discussion, and verification of the accuracy of the main points made by participants. Detailed field notes with comments, and personal impressions were compiled during and immediately after each interview. Compensation (\$20) was offered before the interview to participants to acknowledge their time spent with the interviewer.

An initial sample size of 20 participants was planned with an overarching goal of continued recruitment until the research questions were sufficiently documented and additional data became redundant. Sample characteristics of participants (women with breast cancer, $n=10$; men with prostate cancer, $n=10$) are described in Table One.

Data analysis

Field notes and digital interviews were transcribed verbatim and a content analysis was undertaken (Miles & Huberman, 1994). Transcriptions were checked by the first author for accuracy. They were then transferred into NVivo 7.0 (QSR International). To easily search, retrieve, code and analyse the data collected, a unique marker was attributed to each participant (i.e., W1 to W10 for women, and M11 to M20 for men). The lead author (SD) undertook coding of the content.

The analysis began concurrently with data collection starting with the first interview. As data collection progressed, categories were identified through content analysis, which involves three stages of analysis (Miles & Huberman, 1994). First, data that appeared in field notes and transcriptions for each participant were sorted and organized with respect to the questions being addressed. Second, information was organized with narrative text; then a

Table One. Sample characteristics of newly diagnosed (< 1 year) individuals (N=20) that includes women with breast cancer (n=10) and men with prostate cancer (n=10)

	Age	Ethnic Background	Marital Status	Live Alone	Work Status	Income	Level of education
W_P1	47	French Canadian	Married	No	Full time	>\$30,000	High school
W_P2	58	English Canadian	Married	No	Unemployed	>\$30,000	High school
W_P3	59	English Canadian	Single	No	Full time	<\$29,999	High school
W_P4	68	French Canadian	Married	No	Retired	>\$30,000	High school
W_P5	68	Haitian	Divorced	Yes	Retired	<\$29,999	High school
W_P6	79	French Canadian	Widowed	Yes	Retired	>\$30,000	High school
W_P7	63	Italian	Married	No	Full time	<\$29,999	Elementary
W_P8	36	English Canadian	Married	No	Full time	>\$30,000	Elementary
W_P9	29	Tunisian	Married	No	Full time	>\$30,000	University
W_P10	40	Libyan	Married	No	Unemployed	<\$29,999	CEGEP
M_P11	78	English Canadian	Married	No	Retired	>\$30,000	High school
M_P12	75	French Canadian	Married	No	Retired	<\$29,999	Elementary
M_P13	65	British	Married	No	Full time	>\$30,000	University
M_P14	59	English Canadian	Married	No	Full time	>\$30,000	University
M_P15	70	Belgian	Widowed	Yes	Retired	<\$29,999	High school
M_P16	69	Asian	Married	No	Retired	>\$30,000	University
M_P17	69	French Canadian	Married	No	Part time	>\$30,000	University
M_P18	74	French Canadian	Married	No	Retired	<\$29,999	Elementary
M_P19	64	French Canadian	Married	No	Full time	>\$30,000	University
M_P20	58	French Canadian	Married	No	Full time	>\$30,000	Elementary

matrix presentation was developed to classify data into categories. This allowed the identification of preliminary themes and potential connections between informational support and health care service use. Third, data were explicitly connected to themes, and revised several times with the second author to crosscheck and verify emerging recurrent, converging and contradictory findings. Pertinent literature was also used to identify and describe the emerging themes. All categories and themes were reviewed by the second author through discussing and re-examining discrepancies to ensure that they reflected the content. In addition, decisions and events related to the study were documented in an audit trail. In terms of methodological rigour (Loiselle, Profetto-McGrath, Polit, & Beck, 2007), credibility was enhanced by feedback from participants in terms of the adequacy of the summary of findings and detailed field notes were kept. Direct quotes and summary of findings were also reviewed and discussed among our research team and additional nurse researchers involved in qualitative research.

Findings

Following in-depth content analysis, three main experiences emerged with respect to cancer informational support and health care service use. These included: (1) a positive experience with informational support to guide service use—*i.e.*, *Cancer informational support as tangible in guiding participants' use of health care services*, (2) an unsupportive experience with informational support to guide service use—*i.e.*, *Cancer informational support perceived as paralyzing, precluding participants from using certain health care services*, and (3) a mixed experience with informational support although tolerated, was less than optimal in guiding service use—*i.e.*, *Cancer informational support experienced as limited in terms of guiding participants to the most appropriate services*. In addition, gender or sex differences emerged according to both concepts of interests. These findings are reviewed in turn with relevant quotes from participants.

Cancer information as tangible support in guiding health care service use

The first category of informational support refers to its positive role as a tangible support in guiding participants' use of services through several distinct processes that were either *enabling*, *confirming*, *normalizing*, or *directing* services use.

The process of *enabling* refers to cancer informational support as assisting individuals in self-care and facilitating informed use of relevant health services (e.g., using phone calls as opposed to visits to health care providers). With enabling support, participants felt better prepared for appointments with health care professionals such as their oncologist; they reported taking part in decision making and progressing more smoothly through the illness trajectory. Participants also reported that the services sought seemed appropriate and helpful and that they gained confidence in these services in terms of having additional information related to their cancer experience. For a few, satisfaction with information meant that they used these services on several occasions. One woman recalled:

I called Info-cancer [Société québécoise du cancer] to have information before my surgery [breast cancer]. A nurse returned my call. He answered clearly my questions and I knew what to do [mainly with wound and persistent pain]. I called the service at least seven times. That really helped me. (W_P9)

The internet was also reported as enabling, particularly at the time of diagnosis, as such information was readily accessible, presented in simple language, and often used to guide subsequent exchanges with health professionals. This was particularly salient for four participants (two women and two men). For instance, one man explained:

After being told of my diagnosis [prostate cancer]... the internet was the way to have easy information about my disease... And the more I learn, the more I know what I have to do... and what to ask the doctors [about treatment, side effects and fatigue]... (M_P14)

A second process, that of *confirming*, captures the process of validation of cancer information accessed through subsequent formal or informal means (e.g., through consultations with oncologists, radiation oncologists, nurses, support groups or lay individuals). Cancer information, particularly pertaining to types of treatments or side effects was sought to be confirmed before choosing to act on such information. One man recounted:

I told the doctor [the urologist] who advised me... I wasn't sure I wanted this treatment. ... my wife and I [went] to a support group, and by listening to the others... we were sure about our decision to go further [in searching for other treatment choices]... We went to a conference and had a discussion with the keynote speaker, a radio-oncologist... he confirmed the treatment option... (M_P16)

The third process, *normalizing*, refers to informational support that serves to reassure or place into context various pieces of cancer information that can then be used to decide which health care services to rely on (i.e., agreement with their own perceptions about cancer information received). In this study, we observed that men particularly tended to normalize their cancer situation through reliance on literature provided routinely by staff. Their decision to subsequently consult health care professionals or not was based on what they learned. One man explains:

I refer to the information that the nurses gave me [brochures and booklets]. For example, if I have cramps, I will see the side effects and I see that it is normal, and then fine, everything is normal... I do not need to call the hospital for that. I do not ask for more... (M_P19)

Interestingly, women tended to report that they preferred personal contact (e.g., phone calls or visits) as opposed to written materials, as they felt that the information was more personalized. For instance, one said:

Even though I had read the booklet, I called the nurse three times and asked questions about side effects I experienced... (W_P7)

The fourth process, information as *directing* use of health care services, refers to informational support that guides participants' decision to rely on particular services. Informational support from health care providers, particularly from oncology nurses, was reported by most of participants as an important source of information, often helping them in deciding which service to use and when (e.g., when to rely on emergency services as opposed to the walk-in clinic). One woman recalled:

When I had chemotherapy, the nurses informed me that if I had a fever or difficulty breathing to come immediately to the emergency. So, when I felt so badly and that I did not know what to do, I came automatically to the emergency. When I needed to ask questions, but it was outside business hours or working days, I phoned them [nurses at the oncology clinic]. (W_P1)

One participant reported using informal channels to obtain information and services that he felt he needed:

I spoke with my sister-in-law about my cancer [prostate]; her brother had the same cancer as I did... I really didn't like the oncologist I had consulted... My sister-in-law... found me another oncologist. (M_P20)

When using cancer services, tangible informational support was experienced positively by participants. This support was perceived as helpful and satisfying for their search and use of services. In addition, most participants reported experiencing a blend of processes. As indi-

cated in Table Two, *enabling* and *directing* were experienced more frequently by participants (women and men) whereas *normalizing* was least frequent. Participants' capacity for involvement in decisions pertaining to service use may have been enhanced by the type of informational support provided.

Cancer information as paralyzing participants' potential reliance on health care services

The second category of informational support refers to its perceived unsupportive role in guiding participants' use of services. Four distinct processes were found within this category. Informational support perceived as *distressing*, *conflicting*, or *misguiding* service use. Last, unsupportive information also could lead to a process of no longer trusting the health care system.

Informational support construed as *distressing* refers to information provided by health care professionals that participants experienced as stressful, especially pertaining to wait times. Participants often felt that they had waited more than they should have to obtain the services they needed (e.g., test results, follow-up appointments, consultations with health care professionals). They also often felt they had to persevere to get the needed services (e.g., making repeated phone calls to get through). As expressed by this woman:

After the surgery [breast cancer], it had been several days since I had any information [about the next step in treatment]. I called [in radiation therapy] and the nurse told me, "We will call you, don't you worry". And I waited. I called twice a week and she [the secretary] told me, "I'm overbooked; there are people from January who are still on standby." We were in March. Then I came that close to not wanting treatment [radiation therapy] anymore. (W_P4)

In addition, when participants received information they had not expected or did not understand, they experienced anxiety and felt unsure about further service utilization. For one man, such ambivalence was related to treatment options and his wish to consult more than one oncologist. He reported, "I did not see more options than surgery with this oncologist" (M_P17).

For one participant (W_P7), the physician's minimization of her pain at her first visit led her to question whether she should consult again. She recounted him stating that: "All women above 60 (years) have some physical problems." She waited several weeks before deciding to see the physician again.

The second process, *conflicting*, refers to informational support that places participants in a quandary as to what to do or what services to use next. Some participants reported that they had received contradictory information from health care professionals at different

Table Two. Summary of experiences with informational support and related processes used by participants (N=20)

Informational Support and Related Processes									
Participants	Tangible Support			Paralyzing Support				Mixed Support	
	Enabling	Confirming	Normalizing	Directing	Distressing	Conflicting	Misguiding	Mistrust	Tolerating
W_P1		X		X		X		X	
W_P2			X						
W_P3				X	X	X	X	X	
W_P4					X				
W_P5				X					
W_P6	X								
W_P7			X		X				
W_P8	X			X	X				
W_P9	X	X					X		X
W_P10	X	X							
M_P11		X	X	X					
M_P12					X				X
M_P13	X	X							
M_P14	X				X				
M_P15							X		
M_P16		X				X			X
M_P17					X				
M_P18									X
M_P19	X		X	X					
M_P20				X				X	

Note. N (20) = Women with breast cancer (n = 10) and men with prostate cancer (n = 10)

stages of their experience with cancer (e.g., at their first consultation with the oncologist, post-surgery, etc.) or from informal sources (e.g., lay individuals) that left them confused as to what to do. One participant recounted:

The oncologist was not happy to learn I was taking a drug, Paxil (to decrease dysphoria prior to menses). My gynecologist had prescribed it to me... because of my pre-menopause... Then one of them says, "I want you to stop taking this drug," and the other one, "I want you to stick to it..." Do I have to see my family doctor to talk about it?... [She did not know] (W_P1)

The third process, *misguiding*, refers to informational support that led to erroneous or incorrect perceptions of the health situation based on the information received (or lack thereof). This particularly seemed to happen at the time of diagnosis. As reported by this participant:

Then, I never had news from them [professionals at the private clinic for the results of the breast biopsy]. The doctor told me, 'Within 15 days you will have the results.' I did not worry too much. But I did not have news... I phoned them to have the results. I was told that if they did not call back it meant that the results were good... However... later, the doctor told me: 'We found malignant cells...' (W_P9)

Mistrust of the health care system refers to how unsupportive or inadequate informational support leads to reduced participant confidence in relying on health care services. One participant explained that receiving "generic" information from health professionals that did not apply to her made her reluctant to seek further assistance (e.g., through phone calls or visits). She recalled:

The nurse gave me all the training on the drain [before my breast surgery]... I tried to remember it all, but I [ended up] not having a drain... I didn't want to receive any more information... because when I receive information I don't need, I don't want to ask questions or use subsequent services like the emergency or the oncology clinic... they [professionals] gave me information that was not for me... I would like to be more confident, but ... (W_P1)

In this study, more than half of the participants (both women and men) experienced at least one episode that was reported to be found unsupportive in terms of directing them to cancer services (Table Two). Of those, most related to the experience as a *distressing* rather than *conflicting*, *misguiding* or leading to *mistrust*. This highlights that a distressing experience with informational support perceived as unhelpful could stimulate over-utilization of health care resources (Roy-Byrne & Katon, 1997; Saares & Suominen, 2005). In this study, only one participant (W_P3) reported all four unsupportive processes to have been present at some point of her illness trajectory, which ended up undermining her overall confidence in the health system.

Cancer information as limiting support in guiding health care service use

The third category refers to a mixed experience with informational support leading to both positive and negative feelings pertaining to participants' use of health care services. Within this category, the process of *tolerating* less than optimal informational support often led participants to limit their subsequent use of cancer-related services.

Within this category, even though cancer information provided by health care professionals was perceived by participants as minimal or insufficient, they provided excuses to account for such limitation while acknowledging that this impacted on their use of relevant care services. Participants often reported that they felt they had to accept the situation; they did not wish to complain or to be more proactive in searching or using services. One woman and three men referred to this situation (Table Two). As one woman recalled:

The surgeon removed the mass [breast cancer]... yes, I had three surgeries within the last five months to remove all of the malignant cells; I knew I had cancer, but I did not know more about it... What can I do?... It took a long time to get the first appointment, to have surgery, to get results... I did not want to complain and lose my turn, search for another specialist and not find one, or have other kinds of problems... (W_P9)

The types of excuses made by participants included rushed consultations because of limited professional time and overbooking of appointments (particularly among physicians). However, participants seemed resigned to accept the situation. One man reported:

The doctor's waiting room [family practitioner or oncologist] is always filled and, as time goes by, the more I see that time he takes with patients decreases; instead of 15 minutes, it is 10 minutes and even five minutes. He is so overflowed and in a rush... with each visit, it is always the same thing. (M_P16)

In addition, one man said that it was the patients' own fault if they did not get sufficient information from health care professionals because "the nurse and the doctor gave information; each of them is set out to help us. We only have to ask." (M_P15)

Discussion

To date, little is known about how and when the receipt of cancer information from health care professionals may impact on the subsequent use of health care services by patients. The present qualitative study provides new insights about the role of informational support (formal and informal) among women and men newly diagnosed with cancer differentially guiding their use of health care services.

Findings revealed various experiences with cancer informational support provided and several related processes that subsequently guided (or misguided) health care service use. Participants either perceived informational support as positive, unsupportive or having a mixed impact on their subsequent search and use of health care services. To our knowledge, these processes have not been reported elsewhere.

In the present inquiry, participants experienced at least one type of informational support (e.g., positive, unsupportive, or mixed), as well as several processes (e.g., enabling, distressing, conflicting) underlying health service use. Moreover, the relationship between informational support and use of health care services was found to be more complex than initially thought. Participants who experienced positive informational support (e.g., that met their needs for cancer information) also reported being satisfied with the services sought. Whereas, the "need factor" is reported to be the most significant predictor of actual health care service use (de Boer, Wijker, & de Haes, 1997; Vasiliadis et al., 2007), the relationship between enhanced informational support and more or less health care service use still remains unclear.

For participants who reported negative experiences, the findings were in line with those described by individuals with cancer (Bowes, 1993; Kearney, Miller, Paul, Smith, & Rice, 2003). Individuals were less likely to ask questions, come back to the health care system or seek appropriate services when they received what they considered inadequate cancer information or when they experienced ineffective communication with health care providers. These observations suggest that several challenges and issues still exist with our health care system across the illness continuum.

Although anecdotal and in need of further study, some gender/sex differences, particularly pertaining to modes of communication about cancer, emerged (e.g., preferences for verbal as opposed to written advice). More men relied on written information and more women relied on personalized exchanges with professionals. Similarly, Seale, Ziebland and Charteris-Black (2006) found that men with cancer tended to prefer written information and the internet, whereas women generally preferred direct communication.

Several limitations are linked to the present study. All interviews were conducted with participants receiving active radiotherapy treatments for their cancer, which often dictates reliance on particular health care services. Interview questions relied on participants' memory of events and bias in recall may have been introduced. In addition, men in this sample were more educated than the women (five held university degrees, as opposed to one woman). This may have also qualified the findings in terms of eagerness to seek cancer information and accessing more services—a finding reported elsewhere (Gray et al., 2000; Steginga et al., 2008).

Implications for practice and research

The present findings highlight the need for health care professionals to more explicitly address how patients' perceptions of informational support may affect their subsequent use of health care services and possibly their health outcomes.

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