

Sylvie D. Lambert, N, PhD(c)

Carmen G. Loiselle, N, PhD

Mary Ellen Macdonald, PhD

An In-depth Exploration of Information-Seeking Behavior Among Individuals With Cancer

Part 1: Understanding Differential Patterns of Active Information Seeking

KEY WORDS

Cancer

Focus Groups

Grounded theory

Information-seeking behavior

Information needs

Qualitative studies

Semistructured interviews

The purpose of this 2-part paper was to describe individuals' health information-seeking behavior (HISB) patterns that emerged from our grounded theory study. Thirty individual interviews and 8 focus groups were conducted with individuals diagnosed with cancer. Analysis was characterized by constant comparison diagram, an evolving coding scheme, and ultimately the generation of a grounded theory of HISB patterns. Five HISB patterns were identified: (1) intense information seeking—a keen interest in detailed cancer information; (2) complementary information seeking—the process of getting “good enough” cancer information; (3) fortuitous information seeking—the search for cancer information mainly from others diagnosed with cancer; (4) minimal information seeking—a limited interest for cancer information; and (5) guarded information seeking—the avoidance of some cancer information. Part 1 focuses on describing the first 3 HISB patterns considered to illustrate variations in active information seeking. Each pattern is explained, including the type, amount, and sources of

Authors' Affiliations: School of Nursing (Ms Lambert and Drs Loiselle and Macdonald), Department of Oncology (Dr Macdonald), McGill University, Montreal, Quebec, Canada; Centre for Nursing Research, SMBD Jewish General Hospital, Montreal, Quebec, Canada (Dr Loiselle); and Montreal Children's Hospital, Quebec, Canada (Dr Macdonald).

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Corresponding author: Sylvie D. Lambert, N, PhD(c), School of Nursing, McGill University, 3506 University Street, Montreal, Quebec, Canada, H3A 2A7 (sylvie.lambert@mail.mcgill.ca).

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information sought. This analysis documents variations in active HISB often overlooked in the cancer literature. Findings may assist healthcare professionals in tailoring their informational interventions according to a patient's preferred HISB pattern. Furthermore, findings may inform the refinement of instruments measuring HISB to include variations in active information seeking.

Within the past 25 years, several studies have documented the key role of information seeking when coping with challenging health situations. Research on health information-seeking behavior (HISB) has focused on preferences for the type, amount, and sources of information sought and the strategies used to manage the information obtained (for a review, see Lambert and Loisel¹). Traditionally, HISB is conceptualized as either active search or avoidance.^{2,3} This dichotomy prevails in the cancer literature despite increasing reports that individuals vary to a greater extent in their information preferences within and across situations.^{4,5} The recognition of variations in HISB has prompted our interest in further exploring potential differential HISB patterns within the context of a cancer diagnosis. Our findings are presented in 2 separate papers: part 1—variations in active information seeking and part 2—information disinterest and avoidance.

■ Background

Health information-seeking behavior (HISB) is typically defined as the purposive search for health-related information to satisfy a query.^{6–9} When seeking information, individuals select the type, amount, and sources of information they need.^{1,8–10} Within the context of a cancer diagnosis, HISB has been documented as a key coping strategy to manage stressful illness-related events such as the shock of diagnosis, the burden of treatment-related decisions, daunting side effects, and the uncertainty about cure.^{11–17} Most HISB studies in the cancer literature are grounded in the coping paradigm, including the original works by Miller¹⁸ and Lazarus and Folkman.¹⁹ These authors emphasized that some individuals cope with health threats by actively seeking information (called *monitoring*), whereas others avoid information and prefer distraction (called *blunting*). Although active information seeking is associated with increased certainty and control over a situation,³ it has also been linked to intrusive ideation and psychological distress.²⁰

Although the monitoring and blunting patterns of information seeking are most often discussed in the cancer literature, a few studies have suggested that individuals diagnosed with cancer vary to a greater extent in their approach to cancer information seeking. For instance, some individuals might limit their search to cancer information that is deemed essential for self-care, purposefully avoiding any additional information.^{4,5} Others report seeking cancer information gradually as the illness experience unfolds to prevent feeling overwhelmed by too much information.²¹ Thus, cancer information seeking might be more accurately conceptualized

as varying in “degree,” that is, individuals seek more or less information according to their information need.¹⁰ Johnson⁸ suggested that variations in information seeking might cluster into patterns and their identification is required to comprehensively understand HISB.

In other information-seeking contexts, researchers have provided a finer-grained analysis of individuals' divergent preferences toward active information seeking. In the social and personality psychology literature, self-evaluation theory describes 3 main information-seeking motives: (1) self-assessment: obtaining the most accurate information; (2) self-improvement: obtaining information to get better on some aspect of self; and (3) self-verification: obtaining consistent information about the self.^{10,22,23} Self-evaluation theory calls further attention to potential differential approaches in information seeking¹⁰; however, whether these are transferable to health-related situations remains to be examined.

In the library and information science literature, some authors have reported on individuals' differential information-seeking patterns. For instance, Steinerova and Susol²⁴ defined 2 main patterns of information seeking among users of academic libraries ($n = 793$): (1) strategic pattern wherein users manifested pragmatic information seeking and obtained a broad range of well-organized information sources and (2) analytic pattern wherein users analyzed the information's deeper meaning, sought new ideas and information sources, and invested much time in information seeking. Steinerova and Susol^{24(p153)} suggested that these findings can be used as a starting point for studying “typologies of human information behavior.” Heinstrom²⁵ administered questionnaires examining the information behavior of 305 university students in various faculties and identified 3 distinct patterns: (1) fast surfers, who want information that is easily available; (2) broad scanners, who desire a comprehensive search for information which leads them to use many sources; and (3) deep divers, who put much efforts into information seeking and seek depth and quality in choosing information sources.

Together, these studies suggest that information behavior might go beyond the mere dichotomy of seeking versus avoiding. However, to date, no study has been found to comprehensively document potential variation in HISB within the context of a cancer diagnosis. The present study was designed to address this gap in the literature. The purpose of this grounded theory study was to understand variations in HISB among individuals diagnosed with cancer. At the outset of this study, it was presupposed that participants would vary (in one way or another) in their approach to cancer information seeking. However, the authors were mindful not to force any preconceptions as to the nature of these variations. Instead,

participants' descriptions guided the identification of patterns and ultimately the overarching grounded theory that emerged.

■ Methods

Grounded theory, as described by Strauss and Corbin,^{26,27} was chosen. A theory explaining differential HISB patterns was developed to the extent that participants' information-seeking accounts were condensed into concepts and arranged into HISB patterns and each pattern's antecedents, essential characteristics, and consequences were identified.²⁷

Sample and Setting

To begin, we recruited a convenience sample of men and women diagnosed with breast, prostate, or colorectal cancer who had received, were receiving, or were in the process of determining the course of treatment from the chemotherapy and radiotherapy clinics of the participating university-teaching hospital in Montreal, Quebec, Canada. The main inclusion criteria were as follows: fluent in English or French, interested in discussing his/her experience with cancer information, physically able to participate, and had no concurrent illnesses that could interfere with the discussion of the study topic. As HISB patterns emerged, we undertook theoretical sampling by recruiting additional participants with potentially different information-seeking experiences from those already recruited. For instance, it was found that age seemed to influence preference for certain HISB patterns. At that time, mostly older individuals (>55 years) had been recruited, and in an effort to maximize the opportunity to compare situations and explore variations in HISB, younger individuals (<55 years) were subsequently recruited. The information required to guide theoretical sampling was obtained from initial conversations with participants at recruitment and by asking healthcare professionals or by perusing potential participants' medical records.

Procedures

The study was approved by the institutional review board of the university and the university-affiliated hospital ethics committee. Potential participants were identified by the members of their healthcare team and were invited to participate in the study. The first author then met with potential participants during their scheduled visit at the clinic to provide detailed information about the study. Once participants' questions were answered, they were given an informed consent to read at home. All participants signed the consent form before data collection.

Data Collection

We conducted 30 individual interviews ($n = 31$) and 8 focus groups with 31 additional participants between November 2005 and September 2007. Potential participants were first asked to take part in a focus group; however, if they were unavailable for a focus group, they were offered an individual interview. Early on in

the analysis, it was noticed that complementary dimensions of HISB emerged in each data collection method and enhanced the conceptualization of the phenomenon. We then decided to use both data collection methods throughout the study. Specifically, the combination of individual interviews and focus groups led to 3 main contributions in further understanding the HISB patterns: (1) individual interviews provided more in-depth descriptions of each pattern (depth), whereas focus groups were particularly informative in indicating the range of HISB patterns (breadth); (2) greater interpretation of the circumstances surrounding the phenomenon resulted as individual data provided a concrete perspective or narration of the antecedents and the interactions among focus groups members exposed the contextual dimensions of the antecedents; and (3) convergence of the central characteristics of the phenomenon across focus groups and individual interviews enhanced trustworthiness of findings.²⁸

Most interviews were conducted by the first author in the participants' homes. Ten interviews were conducted by a research assistant to control for potential bias in data collection. Interviews ranged from 30 minutes to 2.5 hours and were structured in such a way as to obtain chronological accounts of participants' experience with cancer-related information.


Focus groups lasted from 1.5 to 2.5 hours and were planned and implemented according to the guidelines proposed by Morgan.²⁹ Focus groups ranged in size from 2 to 6 participants. We formed homogeneous groups based on cancer diagnosis to promote interaction among participants. Four focus groups were conducted with women with breast cancer, 2 with men with prostate cancer, and 2 with men and women with colorectal cancer. A moderator (first author) and comoderator were present at each group. After approximately 60 minutes, the moderator summarized the conversation using large sheets of paper taped to the wall and invited participants to correct, add, or elaborate on any topics raised during the discussion.

The semistructured interview guide was designed by the first two authors and with reference to the existing literature on HISB, the authors' previous research in this area,^{1,10} and the components of the paradigm proposed by grounded theory methodology.²⁶ Dimensions of HISB explored included antecedents or reasons to seek information, the type, amount, and sources of cancer information sought, and the outcomes of the search (Table 1 for sample questions). The interview guide was implemented with flexibility in terms of sequencing of the questions, and it was revised as the study progressed.

A brief demographic questionnaire was completed by the participants after the interview or focus group. All focus groups and individual interviews were tape recorded with the permission of the participants and transcribed verbatim by a typist using Microsoft Word. All transcripts were verified against the audiotape for accuracy by the first author.

Data Analysis

Figure 1 summarizes the steps undertaken to perform data analysis. Analysis was an ongoing process beginning with the

 **Table 1 • Examples of Questions and Probes Included in the Semistructured Interview Guide**

What importance do you give to seeking information about cancer?
How did you seek information about cancer?
Probes:
What are some strategies you use to obtain information?
Who or what has been most/least helpful in obtaining the cancer-related information you are seeking?
What type of information related to your cancer have you been searching or wanting to obtain since your diagnosis?
Probes:
How do you want the information about cancer to be presented (written, oral, both, other)?
Could you give me an example, typically, what type of information do you prefer to search for?
How much information related to your illness do you prefer to search for?
Probes:
Do you feel you limit the amount of information that you search or accept? If yes, How?
Is there some information that you prefer to avoid altogether? What type of information?
What are some reasons that lead you to seek information?
Probes:
What was your goal to seek information?
How did you use the information that you sought?

first interview and focus group and continuing throughout the study. Initially, the first author read each transcript at least once to gain a sense of the participants' experiences with cancer information. Transcripts were then analyzed using open coding. Participants' accounts of cancer information seeking across the illness trajectory constituted the units of analysis. After the comparative analysis of approximately 10 individual interviews, similar accounts in information seeking began to emerge and were grouped together. Differences among participants were also apparent based mainly on the amount of cancer information sought. Whereas some participants described seeking much cancer information, others preferred less while some reported not seeking or avoiding cancer information altogether. Analysis of these variations led to the preliminary identification of 3 HISB patterns: intense, intermediary, and minimal information seeking or avoidance.

Each transcript was then analyzed in more depth using axial coding to identify the antecedents, characteristics, and consequences of a HISB pattern. These conceptual dimensions were compared across experiences that seemed similar (and different). At this time, a model explaining the various patterns began to emerge. As additional data were collected and analyzed, they were integrated into the descriptions of the patterns. Analysis of the focus group interactions was particularly useful during this time to further determine the range of HISB patterns. Questions proposed by Stevens³⁰ and Lehoux et al³¹ guided this analysis. At this stage, we had identified a total of 5 patterns: intense,

complementary, fortuitous, minimal, and guarded information seeking. We selected these labels to qualify the HISB particular to each pattern using either the participants' own words or concepts in the literature.

Selective coding focused on developing a detailed conceptual description of each pattern. To guide selective coding, we used the 3-step approach to concept development by Morse³²: (1) identifying the attributes, (2) verifying the attributes, and (3) comparing components to elicit variation in the concept. At this stage (17 transcripts analyzed), we had already embarked upon step 1 and had identified the patterns emerging characteristics. Additional transcripts were coded and moved our analysis forward to step 2 wherein attention was given to corroborating (or challenging) the characteristics identified. Step 3 focused on specifying a pattern's boundaries and was achieved by comparing the characteristics of a pattern with those of an information-seeking account and considering whether it should (or should not) be integrated in the pattern.

In the final stage of the analysis, a core variable was identified by rereading all of the transcripts and answering the following question: What seems to be going on here?^{26,27} The core variable identified was "playing my part and taking care of myself."

We terminated data collection when no new HISB patterns emerged, patterns appeared sufficiently developed, and differences across patterns were readily recognized. Transcripts were coded by the primary author and 2 research assistants to enhance rigor. Both research assistants were doctoral students and participated in a training session on coding provided by the first author. Throughout the analysis, findings were discussed among the authors. The demographic data collected were analyzed using descriptive statistics. Data were managed using Microsoft Word and Excel.

■ Results

Table 2 summarizes the demographic characteristics of the participants. An equal amount of men and women participated in this study. Participants ranged in age from 30 to 81 years old (mean age = 61). Mainly, they were married, middle class, living with their spouses, and retired from the paid workforce. More than two-thirds of the sample reported that they completed postsecondary education. Although most participants were white, few were from other ethnic backgrounds (eg, Korean, African, and Hungarian). Most were newly diagnosed with cancer (<3 years) and had received a combination of 2 to 3 treatment modalities.

Early on in data collection and analysis, it was apparent that experiences with cancer information seeking ranged from intense information seeking to avoidance of information, including certain intermediary or "it depends" preferences. Participants varied in their reasons to seek cancer information, as well as in the type, amount, and sources of cancer information sought and the information management strategies used. A total of 5 patterns were identified to capture these variations: (1) intense information seeking—a keen interest in detailed cancer information; (2) complementary information seeking—the process of getting

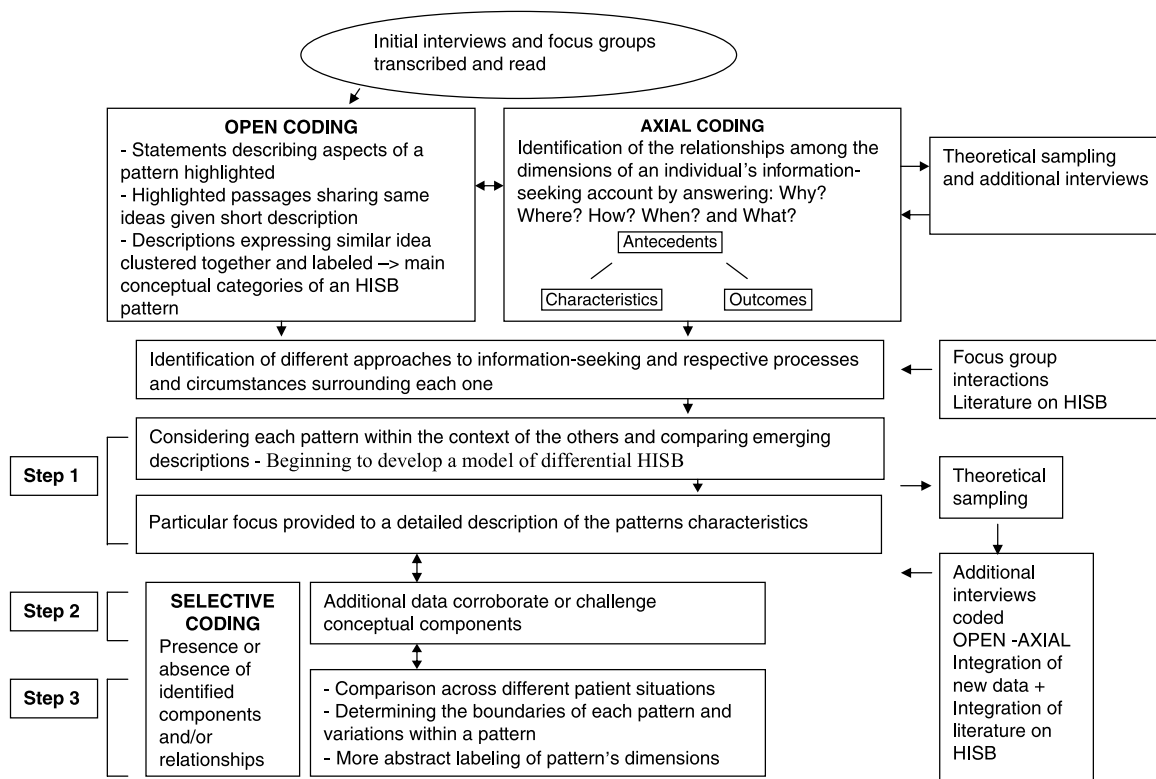


Figure 1 ■ Data analysis. HISB indicates health information-seeking behavior.

good enough cancer information; (3) fortuitous information seeking—the search for cancer information mainly from others diagnosed with cancer; (4) minimal information seeking—a limited interest for cancer information; and (5) guarded information seeking—the avoidance of some cancer information. The focus group interaction included in Table 3 among women diagnosed with breast cancer illustrates the differences in HISB that led to the identification of the patterns. In this interaction, information-seeking accounts such as not wanting “to look into it [information] too much” (participant 04) led to recognizing complementary information seeking, whereas statements such as “I wanted to cover every single-minded detail” (participant 03) contributed to identifying intense information seeking. The grounded theory that emerged is depicted in Figure 2 and describes the patterns: (1) antecedents: reasons for information seeking; (2) essential characteristics: type, amount, and sources of information sought and information management strategies; and (3) outcomes. Each of the theory’s components is now described in turn.

Antecedents: Explaining Variations in Cancer Information Seeking

The core variable that emerged and seemed to explain most of the variation in cancer information seeking was “Playing my part and taking care of myself.”


You can’t expect the doctor to explain everything [...] he doesn’t have time, people have to take responsibility,

they have to play their part [...] you have to do some things on your own.

“Playing my part and taking care of myself” emerged across participants regardless of diagnosis, sex, education, or HISB pattern. Participants described reacting, in one way or another, to aspects of their situation that they thought was most important for them and putting forth the necessary efforts to respond accordingly. Which aspect of their situation the participants wanted to take care of or which role they wanted to play in the illness experience seemed to depend on their interpretations of what was happening. For instance, as described by the following participant, although the oncologist took the treatment decisions, he still felt a responsibility to become more knowledgeable about self-care strategies once at home:

Although the doctor may take care of you [...] you still have a responsibility to play; you can’t rely on them to tell you everything about what is best for you. He may decide on the treatment, but then you go home and you have to manage remaining issues.

As participants varied in their perceptions of the situation, they also identified different preferred roles. Some participants felt that they should avoid any additional angst evoked by the diagnosis and escape in noncancer-related activities, whereas others exerted as much control as possible over treatment decision making. In this sense, it seemed that participants described a continuum of roles they wanted to engage in. Interestingly, participants discussed the importance

 **Table 2 • Participants' Background Information**


	Individual Interviews (n = 31)	Focus Groups (n = 31)
Diagnosis, %		
Prostate	39	35
Breast	35	45
Colorectal	26	20
Sex		
Male	52	48
Female	48	52
Mean age, y	59	62
Marital status, %		
Married	74	61
Common law	13	3
Single/divorced	13	16
Widowed	0	20
Employment, %		
Full time	23	10
Part time	8	10
Unemployed	0	6
Sick leave	13	13
Retired	53	58
Homemaker	3	3
Country, %		
Canada	73	74
Other	27	26
Income, %		
<\$10,000–29,999	21	28
\$30,000–79,999	63	38
\$80,000–119,999	8	24
>\$120,000	8	10
Education, %		
Elementary	0	3
High school	33	16
CEGEP	30	16
University	37	65
Years since diagnosis, %		
<1	21	39
1–3	41	26
3–6	10	26
>6	28	9
Treatment, %		
Surgery	83	71
Radiotherapy	83	94
Chemotherapy	52	55
Brachytherapy	3	3
None	0	3
Other	6	13

Abbreviation: CEGEP, Collège d'enseignement général et professionnel.

they gave to cancer information seeking within the context of the kind of role they wanted to fulfill. That is, participants explained selecting the cancer information that they felt was necessary to fulfill their chosen roles and responsibilities (as variant roles and responsibilities were identified, differences in the type, amount, and sources of information sought were also elicited).

In general, participants were able to play their preferred role; however, for some participants, it was determined by their oncologist. For instance, when treatment decision making was delegated, participants had a limited opportunity to consider any other role. Hence, “playing my part and taking care of myself” seemed to be determined by the (1) context of cancer care (eg, delegation of decision making) and (2) individual differences (eg, curiosity, access to information) (Figure 2). A change in any one of these seemed to shift the reasons underpinning cancer information seeking. In Figure 2, the roles that we identified to contribute to intense, complementary, and fortuitous information seeking, respectively, were as follows: (1) develop an “expertise” and participate in treatment decision making, (2) reach a comfortable level of knowledge of what is going on, and (3) know what others are doing and examine one’s situation accordingly.

Intense information-seeking behavior can be depicted by a commitment for thorough, in-depth information seeking. These participants were mostly engaged in and attributed the highest importance to cancer information seeking. As explained by a man diagnosed with prostate cancer, an intense search for cancer information was undertaken to develop an expertise and take treatment-related decisions: “I am a very curious man [...] I want to have the *maximum* amount of information. If I have the maximum amount of information, this may help me take the [treatment] decisions that are best for me.” Typically, these participants described that the responsibility for decision making was delegated to them by their oncologists, even when they actually preferred not to participate in decision making. Most often, this situation was described by men with prostate cancer. A few of these participants indicated that they would have sought less cancer information if they had not been “forced” in decision making by their oncologist. Some intense seekers chose to participate in treatment decision making

 **Table 3 • Focus Group Interaction Among Women With Breast Cancer to Illustrate Differential Approaches to Information Seeking**

- 04: “I found it easier to look into it after my visits with the doctor because I didn’t want to look into it too much. Because I realize it was so fast and if you’re positive in this and negative in that, it was just so much [...] So I tried to wait for my appointments [...] I would take notes if I had to and look into what she [oncologist] said and clearly look into it [...] My next visit I would ask or call, she would always be very helpful.”
- 03: “That’s interesting because that’s exactly the opposite of how I felt, I wanted to read everything. I wanted to cover every single-minded detail. At my first visit with the oncologist I brought along my tape recorder and an 8X10 with the questions you know. [...] But I couldn’t have waited until the next visit for answers, I wanted to be ahead of the game and have all my questions first.”
- 01: “It would get me so anxious to get so much information, I was just so paranoid, I was just scared there’s so much and I maybe you don’t need to worry about that.”

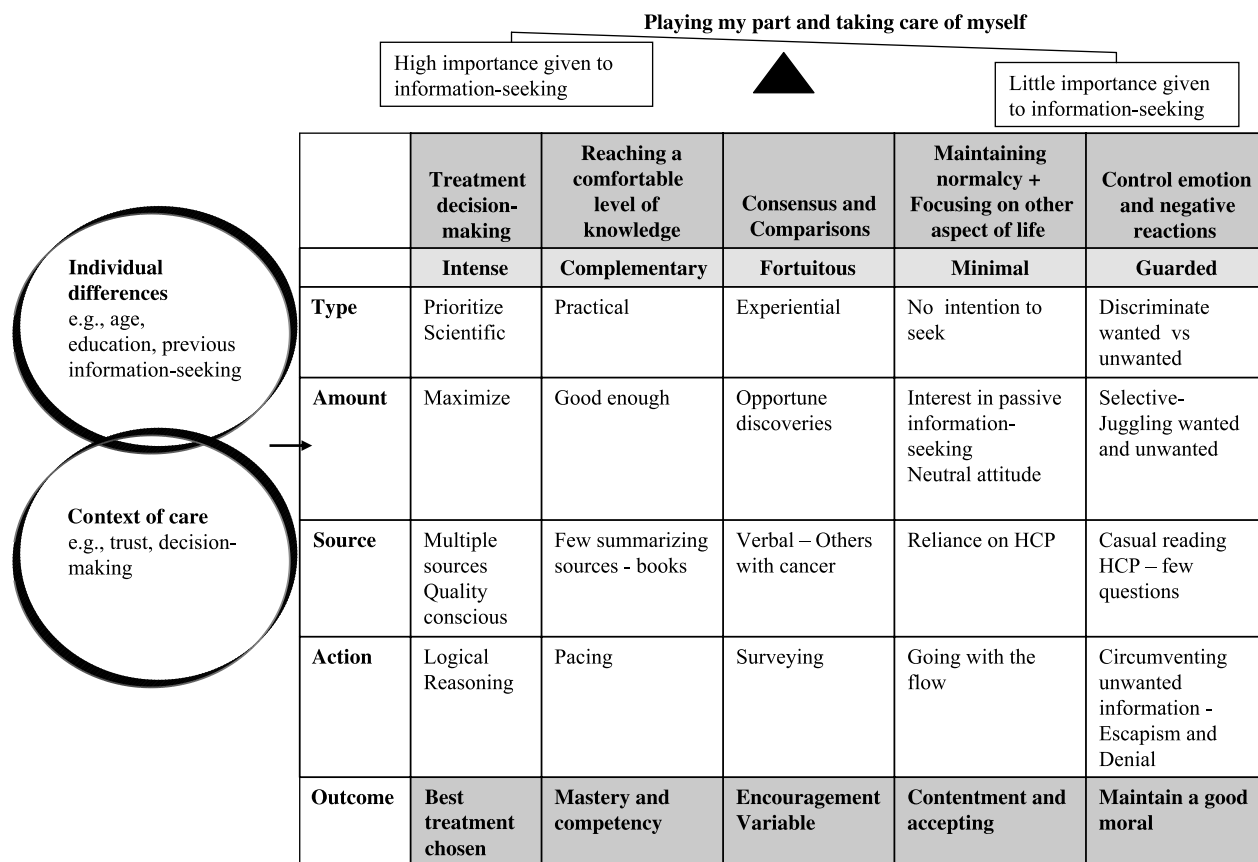


Figure 2 ■ A theory of differential health information-seeking behavior patterns in cancer. HCP indicates healthcare professional.

because they either did not trust that the best treatment was selected by their oncologist or they had a poor prognosis and wanted to find a better treatment than what was offered by their oncologist. In the focus groups, intense information seekers were often the dominant talkers and established themselves as experts within the group. Interestingly, all participants who described intense information seeking hold a university degree (Table 2).

Complementary information-seeking behavior was coined as another pattern to illustrate that some participants were interested in cancer information seeking; however, they restricted the amount of information obtained. Participants who seemed to prefer complementary information seeking described wanting to reach a comfortable level of knowledge of what is going on. The focus group interaction in Table 4 among 3 men diagnosed with prostate cancer exemplifies the differences between intense and complementary information seeking. Two of the participants (02 and 05) expressed their need for intense information seeking to participate in treatment decision making, whereas the other participant (03) sought enough cancer information to understand his situation. Participants whom we found to describe this pattern explained preferring a passive role in treatment decision making, as treatment “was being taken care of” by their oncologist. However, they did want to experience the cancer trajectory knowledgeably (eg, side effect management) and sought the cancer information required to fulfill this role.

The emergence of fortuitous information-seeking behavior emphasized that some cancer information-seeking efforts were not as planned as they might have been in the 2 previous patterns. These participants “picked-up” cancer information or made useful information discoveries as they went along. Most often, they described learning about cancer when interacting with others diagnosed with cancer.

Table 4 • Focus Group Interaction Among Men With Prostate Cancer to Illustrate Difference Between Intense and Complementary Information Seeking

- 02: “I wanted to know and I was interested in knowing, I was interested so I can verify [...] In all of this I was brought to say, yes this is a good treatment; I verified it [...]”
- 03: “It’s interesting to see the behavior of everybody. You it’s like that, for me if a professional gives me.... In whom I trust, gives me their opinion, I stop there, I won’t verify, people will tell me: Did you think about another treatment, maybe more current? [...] No, each of us to their own business. I might start looking for information and find something and then I’ll start panicking [...] It’s a question of temperament!”
- 05: “But when he [oncologist] puts on the table all the possibilities available, there are several [...] you have a choice, you can’t say I abandon myself to your care, he is going to turn around and say sign here.”

For me radiation would be burning me up, that's what I thought of radiation. But the guys [waiting to have radiation] said no you don't feel nothing.

In fortuitous information seeking, this "experiential" information is highly valued and used to make comparisons between one's experiences and those of others. Through these comparisons, participants described being able to evaluate their own situation and know how they should react.

Essential Characteristics: Type and Amount, Sources, and Actions

As illustrated in Figure 2, the type, amount, and sources of cancer information selected and the strategies used to process and manage cancer information were identified as the essential characteristics of each pattern. To facilitate compar-

isons among the patterns, quotations illustrative of each characteristic across the patterns are included in Table 5.

Type and Amount of Cancer Information

In intense information seeking, the amount of cancer information sought was labeled *maximizing* because participants described obtaining "everything" about a particular topic (obtaining the complete range of information potentially available). Intense seekers described complex information needs, requiring sophisticated information not reported by the other participants. At times, fellow focus group members would challenge intense seekers and questioned the need to seek such an extensive amount of information. Although individuals reported seeking a lot of information, as illustrated by quotation 1 in Table 5, intense information-seeking efforts were *prioritized* to treatment options. As participation in



Table 5 • Quotations Depicting Differences Among the Intense, Complementary, and Fortuitous Information-Seeking Patterns Along Their Essential Characteristics

	Intense Information Seeking	Complementary Information Seeking	Fortuitous Information Seeking
Type and amount	<p>(1) Prioritized maximizing: "Obviously, if you are aware of all the options, it may be easier to make a decision [...] I wanted explanations about all the possible options available."</p> <p>(2) Scientific: "Give me a little bit of proof, give me some research data that show [...] what is the degree of confidence in that data is it 100% or 99% or is it 50%? [...] then based on [...] those probabilities [...] you can make an informed decision."</p>	<p>(3) Good enough: "She [nurse] explained to me overall what the treatment was about and I felt good with that [...] I read the booklets, I was given at the hospital and that was enough for me, enough in the sense that I understood that it would kill good cells and bad cells and that their were side effects."</p> <p>(4) Practical: "They told me that they would apply the chemotherapy using the Mayo protocol. OK, let's find out what's the Mayo protocol."</p>	<p>(5) Experiential: "I had no knowledge of anything, so when I saw this weekend seminar I said Hum! I had to go to that. Probably they will cover a lot of stuff [...] each person has their story to give and we learn something from listening to what other people have gone through."</p>
Sources	<p>(6) Quality conscious: "I like to cross reference you know, I'll cross reference, I'll take what this institution says [...] then I'll try to cross reference with another institution."</p>	<p>(7) Summarizing sources: "I have to say the library was the most useful in bringing my state of knowledge up from basically ground 0, this was a field that I never had any dealings with."</p>	<p>(8) Others with cancer: "I had seen in the paper, the newspaper that there was [...] a prostate support group [...] and it happen to be where I live. So I went."</p>
Action	<p>(9) Scientific, logical reasoning: "I happen to be analytical about it [cancer] so I tried to understand it [cancer] [...] I sorted it out in my own mind. I guess the logic behind what they [MDs] were saying. More chemotherapy you tell me will not get rid of it because it will grow back, so why are we doing chemotherapy? [...] I was pondering this stuff."</p>	<p>(10) Pacing: "What I did is that I sought information as I needed it [...] I will read on that, when the appropriate time comes [...] When she [nurse] confirmed that, yes, I will loose my hair, ok I am going to read on the topic, I obtained my information little by little if you want. When I was told that I would not have hormone therapy, don't need to read on that."</p>	<p>(11) Surveying: "I was inquiring with people, you know [...] I was just getting their opinion [...] Then I spoke to another man, he told me, that yes he had his prostate remove [...] and then I spoke to another man [...] yeah he had his removed also."</p>

treatment decision making was the main reason prompting intense information seeking, individuals naturally focused their efforts toward obtaining “all” available information about treatment options. They wanted to make sure that any significant cancer treatment information that could alter their decision would be obtained. In intense information seeking, the amount of cancer information sought seemed to increase exponentially: as one treatment option was explored, this led to the realization that another type of treatment should also be examined and so on and so forth. In addition to having high expectations regarding the amount of cancer information that should be available, intense seekers were acutely aware of the quality of the cancer information sought. These participants described wanting the “best” or most “up-to-date” information. As depicted by quotation 2 in Table 5, participants *avored scientific* information and wanted “proof,” “facts,” or “evidence” to find the “true” answers to their questions.

In complementary information seeking, although individuals knew that much cancer information could be obtained, they were not interested in obtaining all of it. Rather, HISB remained within the boundaries of what was labeled *good enough* cancer information. In Table 5, quotation 3 illustrates the preference of a woman with breast cancer for information that is necessary; she did not need to obtain detailed information about the treatment received. Whereas “maximizing” was pursued to develop a complete understanding of the situation, good enough aimed to reach a comfortable level of knowledge. In addition, during complementary information seeking, participants described wanting to obtain easy to understand overviews of cancer or *practical* information to understand what was most relevant to them. The types of practical cancer information described by participants were categorized into 2 main topics: orientation and preparedness cancer information. Orientation information included mainly specific explanations about one’s diagnosis, prognosis, or treatment. For instance, as exemplified by quotation 4 in Table 5, information was sought to clarify what the oncologist meant by the “Mayo protocol.” The need for orientation-type information was often triggered by the “language” or cancer jargon used by healthcare professionals. Preparedness information primarily focused on learning more about what to expect as the illness trajectory unfolds and being able to safely manage any event. Particularly, participants wanted to be able to predict the occurrence of side effects and prepared themselves as much as they could. For these participants, side effect management was an important aspect of self-care; however, it was not sufficiently addressed by healthcare professionals and they felt the need to undertake independent searches.

In fortuitous information seeking, the type of information sought was labeled *experiential* to emphasize the value participants gave to the experiences of others diagnosed with cancer in understanding their own situation (see quotation 5 in Table 5). For these participants, experiential information was considered most useful because it provided tips and recommendations thought to be accessible only when you have had first-hand experience with cancer. This type of information

seemed to be mostly used to compare and interpret one’s experience. Here, participants explained that they did not wish to undertake information seeking in books or online; however, they did want to “find out” about others in a similar situation. In this regard, information was somewhat incidentally acquired as they interacted with others. Although these participants often began their search uncertain of their information needs, as they engaged in information seeking, they identified the “kind of information that is good to have.”

Sources of Information

As participants sought different types and amount of cancer information, they also described variant preferences for the sources of cancer information selected (Figure 2). According to the HISB pattern, participants accessed scientific information sources, sources of information that provided a summary of the knowledge needed, or exchanged with others diagnosed with cancer.

In intense information seeking, related to the desire to maximize or obtain the “total picture” about treatment options, participants described consulting many sources of information. Participants seemed particularly concerned with accessing the best information sources available to satisfy their information need. For instance, a Web site might provide all the information on radiotherapy; however, information about brachytherapy was obtained by talking to an expert. Many intense seekers described evaluating a source’s trustworthiness and ensuring that the information obtained was accurate. To ensure that the best cancer information available was sought, participants (1) targeted “scientific” sources of information such as Internet sites of distinguished academic quality (eg, Johns Hopkins University) and (2) cross-referenced the cancer information they obtained. In Table 5, quotation 6 demonstrates a participant’s efforts to cross-reference, that is, he compared the information obtained across several sources for consistency in content. Participants were aware of the potential “biases” their oncologist might have for particular treatments, and thus, they verified his/her recommendations with written documentations or by seeking a second (and even a third) opinion.

Complementary information-seeking efforts were described as “catching up” promptly with the cancer literature to efficiently reach the level of knowledge desired. Thus, participants seemed to favor information sources that concisely summarized most of the cancer information needed. In this regard, books were often considered valuable sources because essential cancer-related topics were found (see quotation 7 in Table 5). Although books might not provide the most-up-to-date information, they were practical and useful in addressing most information needs. In contrast with intense information seeking, complementary information seekers were not interested in consulting many sources of information and online information was considered to be too much.

In fortuitous information seeking, participants did not routinely seek information from the Internet or books, rather, most often, participants attended information sessions or support groups in anticipation that useful conversations

would be initiated with others diagnosed with cancer (see quotation 8 in Table 5). Some participants also took the opportunity to interact with others while in the waiting room. As the kind of information desired was not always precise, reading a book or browsing the Internet might not be useful. Some participants accessed written materials but only when a particular topic of interest was identified. Participants did not seem to ask many questions to their oncologists, unless prompted by the experiential information found.

Actions to Process and/or Manage Information

In addition to differential preferences for the type and amount of cancer information sought and sources accessed, participants also described different strategies used to attend to, process, and/or manage the cancer information sought (Figure 2). Intense seekers most often described a scientific, *logical reasoning* process to coherently interpret all of the detailed treatment information sought and obtain a clear answer to their main concern: what is the best treatment? In this reasoning process, as described by the participant in quotation 9 in Table 5, much time was devoted to scrutinizing the cancer information found and developing an understanding of what is going on and what should be happening. In this way, participants seemed to act much like “scientists” and generated and evaluated propositions about the cancer information obtained. Although several intense information seekers described that it was in their nature to be “analytical,” the decision-making context seemed to accentuate the need to methodically reason through their situation. Participants described wanting to transfer the scientific evidence to their situation with little discrepancy and construct justifications to their decisions with few doubts. However, cancer information was often criticized as being “blurry,” noncommittal and contradictory about the best treatment. Many participants were disappointed when they were unable to clearly decide on the best treatment. In the end, some participants relied on a more “intuitive” decision-making process.

In complementary information seeking, participants described that they purposefully focused on seeking cancer information that was useful to understand what was going on at a specific point in time. This approach to managing cancer information was labeled *pacing*. The participant in quotation 10 (Table 5) explained how she paced her information-seeking behavior by only attending to the cancer information that was applicable to the events she was facing as the situation unfolded. For some participants, pacing was described in the context of being emotionally ready to learn. Individuals might have postponed information seeking of certain “bad” information until they were “emotionally” ready to deal with it (eg, list of side effects).

In fortuitous information seeking, asking questions or *surveying* others diagnosed with cancer seemed to be the main action to obtain the experiential information desired. The participant in quotation 11 (Table 5) explained how he went about surveying the different individuals attending a seminar.

Participants either asked specific questions to others or simply listened to individuals as they spontaneously engaged in conversations with them. Participants seemed to prefer surveying individuals who were similar to themselves and, hopefully, “better off.” Surveying was at times focused on one type of information, and at other times, it was continuous, and participants attended several groups or initiated several conversations with others.

Outcomes of Active Information Seeking


The main outcome or consequence of each pattern was also identified (Figure 2). These were found to be closely linked to the initial reason triggering the pattern. Quotations illustrative of each outcome are included in Table 6. The main outcome of intense information seeking was reassurance and comfort that all treatment options were explored and that the best treatment option was chosen. Not obtaining the necessary information was frustrating, disappointing, and confusing. Most participants did not anticipate this later outcome at the onset of their search.

Complementary information-seeking behavior led to acquiring sufficient knowledge of what is going on and acquiring a certain level of mastery (ie, grasping what was going on) and competency (ie, developing necessary skills). Specific indicators of mastery and competency emerging from the analysis included being able to (1) gauge one’s illness experience (evaluating situation against expected norms), (2) anticipate the illness trajectory and act effectively (predicting events and preparing for these), and (3) communicate with healthcare professionals and friends/family (discuss situation intelligibly) (Table 6).

Fortuitous information seeking was undertaken to make comparisons with others diagnosed with cancer and obtain a consensus about different cancer-related issues. Through these comparisons, participants often described feeling encouraged or gaining hope as they realized that others have survived cancer and moved on with other life activities (Table 6). However, the outcome of fortuitous information seeking was determined by the information obtained. For instance, a participant described engaging in treatment decision making when he noticed that others were not undergoing the treatment he was offered by his oncologist.

■ Discussion

The present study described differential HISB patterns within the context of a breast, prostate, or colorectal cancer. Our findings emphasized that participants varied in their preference for the type, amount, and sources of information sought and information management strategies used according to how they thought they should take care of themselves. Although other authors have reported on the different dimensions of HISB (eg, preferences for sources), no other published study has examined how these might vary and cluster into patterns among individuals diagnosed with cancer. Descriptions of active information

 **Table 6 • Quotations Depicting the Outcomes of Intense, Complementary, and Fortuitous Information Seeking**

Outcomes	Quotations
Intense information seeking	
Best treatment chosen	"To have the possibility of making the best possible choice [...] by having the maximum information it may help me to take the best decision given my situation."
Complementary information seeking	
Gauge one's illness experience	"It's a tool to study our case and determine if we can improve it by ourselves [...] Is it better or worse than me?"
Anticipate the illness trajectory and act effectively	"I take care of my own world where I have control [...] I have to have confidence in the people treating me. But then for the rest... the rest of my life that's up to me (laugh)."
Communicate with healthcare professionals and friends/family	"I wanted to be able to converse on a reasonably intelligent level with physician who were the expert in the field. To understand what they would say."
Fortuitous information seeking	
Encouragement	"Certainly, I would want to see myself in a positive thing like that you know, like, for him he was diagnosed, he had the operation, the outcome was good. That was a boost."

seeking were categorized into 3 patterns: (1) intense information seeking, (2) complementary information seeking, and (3) fortuitous information seeking. A theory of differential HISB was developed to illustrate the circumstances and processes underlying each pattern and their essential characteristics.

Our findings corroborate those of previous studies examining preferences for active information seeking. The characteristics of intense information seeking echo the descriptions of "monitoring,"¹⁸ "self-assessment,"¹⁰ "analytic pattern,"²⁴ and "deep divers."²⁵ Intense information seeking also shares characteristics with "vigilant" coping, including optimizing resources, considering the advantages and disadvantages of options, remaining open to new ideas, and undertaking decision making.³³ Similar to other studies on monitoring,^{2,34-36} we found that intense seekers wanted to obtain all information on cancer and seemed to be most knowledgeable about their situation. However, monitoring, as currently described in the cancer literature, does not capture the variations in information seeking described by the complementary and fortuitous patterns. Although aspects of the fast surfers' or brood scanners pattern described by Heinstrom²⁵ are comparable to complementary information seeking and other researchers^{15,37} have reported the participants' preferences to obtain cancer information from others diagnosed with cancer, the complementary and fortuitous patterns have not been described as comprehensively elsewhere.

Individuals diagnosed with cancer often report a preference for collaborative participation in treatment decision making.^{11,36,38-40} Although we did not explicitly measure decision making in a manner comparable to these studies, only a few participants described such a preference for decision making. More often, participants, especially men with prostate cancer, were delegated decision-making responsibility by the oncologist despite their preference for passive decision making. Logical reasoning in intense information seeking was identified to describe the laborious process undertaken by participants needing to decipher treatment options. As also reported by Reaby,³³ we found that most participants preferring less intense information seeking seemed satisfied with passive decision making. Although

involvement in decision making is often considered empowering,³⁵ several participants in our study did not want to be "empowered" in this regard. Rather, they identified other aspects of the illness experience in which they preferred to take on such responsibility (eg, manage side effects).

Information needs of individuals diagnosed with breast, prostate, or colorectal cancer typically pertain to diagnosis, prognosis, treatment options, and related side effects.^{16,38,41,42} Although participants in this study described similar information needs, variations were noted in preferences for the specific features of that information. For instance, treatment information was sought by most participants; however, intense seekers wanted detailed and in-depth facts about all treatment options, whereas those undertaking a complementary search preferred practical treatment information and those engaging in fortuitous searches were interested in knowing about the treatment others have undergone. Labeling this information need as merely *treatment* does not reflect the information's characteristics according to the preferred HISB pattern. Similar to other studies,^{43,44} we found that several participants reported sub-optimal information-seeking experiences. Particularly, intense information seekers expressed frustration, as they were unable to find clear information about the best treatment option provided their situation. However, more participants expressed satisfaction with the cancer information they found.

The concepts of good enough coined to indicate the amount of cancer information sought in complementary information seeking are similar to "satisficing," as described by Simon's⁴⁵ framework of bounded rationality. Complementary information seekers "satisficed" in that sufficient information was sought to make sense of what was going on; once "enough" cancer information was obtained, information seeking was ceased. Similar to our findings, satisficing has been related to a preference for passive decision making.³³

Similar to Johnson,⁸ we found that participants carefully selected their cancer information source according to the type and amount of information needed. In line with the findings of Balmer,³⁷ most participants in our study sought cancer information from another media as an adjunct (not necessarily an alternative) to the information received from healthcare

professionals. Although the Internet is an information source increasingly popular among individuals diagnosed with cancer,^{37,46–48} in our study, this source was mainly favored by participants undertaking intense information seeking, as it provided the most up-to-date cancer information. However, many participants, particularly in complementary information seeking, still preferred the practicality of printed information sources and felt overwhelmed by the thought of having to seek online information. Most often, in fortuitous information seeking, participants initiated casual conversations with others diagnosed with cancer while in the waiting room or when attending a seminar. Fisher⁴⁹ has labeled as *information grounds* these settings wherein casual interactions among individuals lead to serendipitous information sharing. Similar to Fisher et al,⁵⁰ we found that participants appreciated these information grounds because the information obtained was deemed important and influenced how they felt toward their situation.

■ Conclusion

Our findings contribute to the theoretical understanding of HISB by documenting why individuals with cancer make certain decisions as to how, when, where, and what to seek in terms of cancer information (Figure 2), all of which are crucial aspects of information seeking to consider when supporting patients in their search. Increasingly, healthcare professionals are encouraged to tailor their information interventions to an individual's needs.⁴⁰ Understanding differential HISB patterns is a first step in that direction in that findings further detailed the type, amount, and sources of cancer information that individuals with breast, prostate, or colorectal cancer prefer. Current tools measuring HISB do not adequately capture the variability in information seeking described in this study. Future work would refine such instruments to capture these nuances.

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