AN IN-DEPTH EXPLORATION OF HEALTH INFORMATION-SEEKING BEHAVIOR AMONG INDIVIDUALS DIAGNOSED WITH PROSTATE, BREAST, OR COLORECTAL CANCER

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Abstract

Background: Seeking cancer information is key in coping with the feelings (e.g., fear, uncertainty) and other challenges (e.g., treatment decision-making) confronting individuals diagnosed with cancer. Despite recognition of a variation in why, when, how, and where individuals diagnosed with cancer seek information, few efforts have been made to systematically document patterns in information-seeking. **Aim:** To explore individuals' patterns of health information-seeking behaviors (HISB) including the type, amount, and sources of information and the strategies used to process and/or manage cancer information. **Method:** Using a grounded theory approach, data were collected through in-depth semi-structured individual interviews and focus groups. The interviews and focus groups were audio-recorded and transcribed verbatim. Analysis was consistent with grounded theory methodology and was characterized by constant comparison analysis of data, a flexible and evolving coding scheme, and ultimately the generation of a theory of information-seeking. **Setting:** Chemotherapy and radiotherapy ambulatory clinics of a university teaching hospital in Montreal, Quebec. **Participants:** 30 face-to-face individual interviews and eight focus groups were conducted with individuals diagnosed with breast, prostate, or colorectal cancer at different stages of the illness. **Findings:** Five HISB patterns were identified: : 1) intense information-seeking (i.e., a keen interest in detailed cancer information); 2) complementary information-seeking (i.e., the process of getting "good enough" cancer information); 3) fortuitous information-seeking (i.e., the search for cancer information mainly from others diagnosed with cancer); 4) minimal information-seeking (i.e., a limited interest for cancer information); and 5) guarded information-seeking (i.e., the avoidance of certain types of cancer information). A core variable was identified to explain variations in HISB across participants: 'playing my part and taking care of myself'. Each pattern is explained, including its antecedents, the type, amount, and sources of information sought, and consequences. **Conclusion:** Findings provide a comprehensive description of HISB in cancer and add a finer-grained analysis of the general patterns of information-seeking and avoidance. Findings might assist health care 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.

Résumé

Contexte : La recherche d'information sur le cancer est d'une importance déterminante pour les personnes atteintes de cette maladie dans le contexte où elles ont à gérer des émotions intenses (p. ex. : peur, incertitude) et font face à plusieurs défis (p. ex. : processus de décision relatif au traitement). Des variations concernant la recherche d'information par les individus diagnostiqués avec un cancer ont été observées et reconnues notamment en termes des raisons qui motivent la recherche d'information et des moyens utilisés pour obtenir l'information désirée. Cependant, à ce jour, peu d'efforts ont été déployés pour documenter de manière systématique les différents types de comportements de recherche d'information. **But :** Explorer les types de comportement de recherche d'information liée à la santé manifestés par les individus ayant été diagnostiqués d'un cancer. Notamment le type, la quantité et les sources d'information recherchées, de même que les stratégies utilisées pour gérer l'information sur le cancer ont été explorées. **Méthodologie :** L'étude repose sur l'approche de théorisation ancrée. Les données pour cette étude ont été collectées au moyen d'entretiens individuels semi dirigés, ainsi que des groupes de discussion. Ces entretiens et discussions ont été enregistrés et transcrits. L'analyse a été réalisée en fonction de la méthodologie de théorisation ancrée et s'est caractérisée par une comparaison systématique des données, une stratégie de codification souple et évolutive et l'élaboration d'une théorie liée à la recherche d'information. **Site :** Cliniques ambulatoires de chimiothérapie et de radiothérapie d'un centre hospitalier universitaire de Montréal (Québec). **Participants :** Trente entretiens individuels et huit groupes de discussions ont été menés avec des individus ayant un diagnostique de cancer du sein, de la prostate ou colorectal à divers stades de la maladie. **Résultats :** Cinq types de comportements de recherche d'information liée au cancer ont été libellés : 1) Recherche soutenue d'information (l'individu cherche intensément de l'information détaillée sur le cancer); 2) Recherche complémentaire d'information (l'individu cherche à obtenir une information « suffisante »); 3) Recherche d'information par contact fortuit (l'individu s'informe principalement auprès d'autres patients diagnostiqués avec un cancer); 4) Recherche minimale d'information (l'individu a un intérêt peu marqué quant à l'information sur le cancer); 5) Recherche prudente d'information (l'individu évite de chercher certains types d'information liée au cancer). Une variable clé pour démontrer les variations observées dans les comportements des participants a été déterminée, à savoir « faire ma part et prendre soin de moi ». Chaque type de comportement est expliqué, notamment par rapport à la raison motivant la recherche d'information, le type, la quantité et la source d'information recherchée, ainsi que les répercussions engendrées. **Conclusion :** Les résultats de cette étude montrent de manière détaillée quels sont les comportements de recherche d'information des individus diagnostiqués avec un cancer, et fournissent de surcroît une analyse pointue des différents types de comportement de recherche d'information. Ces résultats pourront éventuellement guider les professionnels de la santé dans leur choix d'interventions en ce qui a trait à l'information à fournir, en fonction des comportements de recherche d'information adoptés par le patient. De plus, ces résultats pourront servir à soutenir l'amélioration éventuelle des outils de mesure des comportements de recherche d'information par l'inclusion des différents types de comportement documentés.

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Preface

The earliest studies exploring health information-seeking behavior (HISB) were published in the mid-1980s (e.g., Lenz, 1984; Miller, 1987), and since then the body of literature examining HISB has increased exponentially. Traditionally, studies have focused on exploring two main patterns of HISB: monitoring (active information-seeking) and blunting (information avoidance). However, contemporary research looks to move beyond the dichotomous conceptualization of HISB and shifts analysis towards a more comprehensive documentation of individual variations in information-seeking (e.g., Loiselle, 1995). A systematic documentation of differential patterns of HISB is not found in the published literature.

The importance of differential patterns of HISB was recognized when I began my graduate studies with Dr. Loiselle. Dr. Loiselle's program of research focuses on documenting and examining differential approaches to information-seeking within the context of a cancer diagnosis. Loiselle's (1995) dissertation introduced Self Evaluation Theory (SET) as a novel theory to guide the exploration and analysis of various approaches to information-seeking. Based on SET, Dr. Loiselle developed the Differential Health Information-Seeking Behavior (DHISB) scale (Figure 1) (Loiselle, 2002). Pilot testing of the DHISB scale suggested that the scale provides information on an individual's preferred HISB, however the homogeneity of some subscales was low (alpha= .05-.47) (Loiselle & Lambert, 2008; Loiselle, Lambert, & Boisclair, 2003).

Initially, for this dissertation project, it was proposed that a grounded theory study would be undertaken to explore HISB patterns within the context of a cancer diagnosis. Subsequently, these findings were to contribute to the refinement of the DHISB scale. At the proposal defense, committee members suggested that the grounded study could be the focus of this thesis. As we began data analysis, Dr. Loiselle and I recognized that the scope of the grounded theory study was increasing and it was decided to focus on thorough analysis and documentation of the emerging HISB patterns. This also explains the discrepancy between the title of this thesis and the one included on the consent forms. Through a collection of manuscripts, this doctoral thesis presents an in-depth exploration of differential patterns of HISB among individuals diagnosed with prostate, breast, or colorectal cancer.

Organization of the Thesis

This thesis is organized around five main chapters. Chapter 1 is an introduction to the thesis and includes a description of some of the theoretical frameworks that explains HISB.

Chapter 2 includes the first manuscript entitled: "Health Information-seeking Behavior". This manuscript is an in-depth concept analysis of HISB. The analysis includes a review of the concept's definitions, contexts, boundaries, theoretical underpinnings, and operationalisations. Also, HISB's antecedents, characteristics, and outcomes are clarified.

Chapter 3 includes the second manuscript entitled: "Combining individual interviews and focus groups to enhance data richness". This chapter examines the data obtained from the individual interviews and focus groups conducted and the implications of combining these two data collection methods.

Chapter 4 includes two manuscripts describing the findings of the grounded theory study undertaken to explore patterns of HISB among individuals diagnosed with breast, prostate, or colorectal cancer. Part 1 of the findings describes the *active* information-seeking patterns that emerged from the analysis, whereas part 2 includes the patterns of information disinterest and avoidance.

Chapter 5 concludes the thesis with a discussion related to implications, limitations, and suggestions for future research.

Contributions of Authors

The manuscripts included in this thesis are the original work of the candidate and her supervisor, Dr. Carmen Loiselle. All authors have made substantial contributions to the intellectual content of the paper. A statement of authorship is included for each manuscript.

Manuscript #1: Health Information-Seeking Behavior

The candidate and Dr. Carmen Loiselle decided on the specific method for conducting the concept analysis. The candidate was responsible for collecting, analyzing, and synthesizing the literature, and presenting a first draft of the manuscript to Dr. Carmen Loiselle. The candidate and Dr. Carmen Loiselle then made several critical revisions to the manuscript.

Manuscript #2: Combining Individual Interviews and Focus Groups to Enhance Data Richness

The candidate and Dr. Carmen Loiselle decided on writing this second article and identified key contributions to the current literature. The candidate was responsible for identifying the implications of combining individual interviews and focus groups and presenting a first draft of the manuscript to Dr. Carmen Loiselle. The candidate and Dr. Carmen Loiselle then made several critical revisions to the manuscript.

Manuscript #3: An In-Depth Exploration of Information-Seeking Behavior among Individuals with Cancer: Part 1 Understanding Differential Patterns of Active Information-Seeking

The candidate and Dr. Carmen Loiselle conceptualized and designed the study. The candidate collected and analyzed the data. Drs. Carmen Loiselle and Mary Ellen Macdonald provided critical guidance during data analysis and interpretation. The candidate was responsible for providing an initial draft of the manuscript. The candidate and Drs. Carmen Loiselle and Mary Ellen Macdonald then made critical revisions to the manuscript.

Manuscript #4: An In-Depth Exploration of Information-Seeking Behavior Among Individuals with Cancer: Part 2 Understanding Patterns of Information Disinterest and Avoidance

The candidate and Dr. Carmen Loiselle conceptualized and designed the study. The candidate collected and analyzed the data. Drs. Carmen Loiselle and Mary Ellen Macdonald provided critical guidance during data analysis and interpretation. The candidate was responsible for providing an initial draft of the manuscript. The candidate and Drs. Carmen Loiselle and Mary Ellen Macdonald then made critical revisions to the manuscript.

Statement of Originality

The concept analysis of health information-seeking behavior (HISB) (manuscript #1) is the first of its kind to be published in the literature. Although a substantial body of literature exists on the concept of HISB, a systematic analysis of the concept's maturity and essential characteristics was lacking. This concept analysis provides important avenues for future theorizing on HISB (e.g., the analysis challenges the traditional dichotomous conceptualization of HISB).

Although individual interviews and focus groups are often discussed in the nursing research literature, manuscript #2 considers these data collection methods in combination and adds to the literature in this area by discussing: 1) the main methodological issues to consider when integrating individual interview and focus group data (e.g., purpose of data integration, the types of data collected through each method, and the insights into the phenomenon obtained across data sets), 2) the process undertaken to integrate individual interview and focus group data (e.g., identification of data convergence, divergence, and complementarity), 3) the issue of rigor when combining individual interview and focus group data (e.g., recognition of the epistemological underpinnings of method triangulation), and 4) the outcomes and enhanced understanding of the phenomenon obtained.

Manuscripts #3 and #4 present the actual findings of the research undertaken as part of the dissertation work. Although other authors have reported on the different dimensions of HISB (e.g., preferences for sources), no other published study has examined how these might vary and cluster into patterns among individuals diagnosed with cancer. This study offers a more comprehensive analysis of HISB and contributes to its theoretical understanding by documenting why individuals with cancer make certain decisions as to how, when, where, and what to seek in terms of cancer information. Findings characterize some HISB that have not yet been described in the published cancer literature.

CHAPTER 1 INTRODUCTION

The significance of information-seeking behavior when coping with cancer-related stressors and anxieties has been extensively documented (Hoskin & Haber, 2000; Mills & Sullivan, 1999; van der Molen, 1999). The benefits of acquiring timely cancer information include increased control (Echlin & Rees, 2002), reduced anxiety and uncertainty (Feltwell & Rees, 2004), and enhanced support for treatment decision-making (Davison et al., 2002; Hack, Pickles, Bultz, Ruether, & Degner, 2007; Mills & Sullivan, 1999). However, some individuals do not benefit from seeking or receiving cancer information. For these individuals, cancer information-seeking has been found to contribute to increased worry and anxiety, and decreased hopefulness (Leydon et al., 2000; Skalla, Bakitas, Furstenberg, Ahles, & Henderson, 2004) and is preferably not obtained or avoided (Leydon et al., 2000; Miller, 1995).

Theoretical Frameworks

A review of the nursing and allied health literature reveals that many theoretical frameworks are available to explain health information-seeking behavior (HISB). Most often, Lazarus and Folkman's (1984) Stress, Appraisal, and Coping Theory and Miller's (1987) Monitoring and Blunting Hypothesis are referenced (see Lambert & Loiselle, 2007 for a review). These frameworks explain responses to stress and highlight that some individuals react to a threatening event, such as the diagnosis of cancer, by seeking information and confronting the situation (also termed problem-focused coping strategy), whereas others prefer to avoid information and distract themselves from the aversive situation (also termed emotion-focused coping strategy) (Lazarus & Folkman, 1984). Miller (1987) used the label 'monitor' to indicate a preference towards information-seeking and 'blunting' to signify information avoidance.

Other frameworks or models of information-seeking behavior are also referenced in the health literature including: Lenz's (1984) Information-Seeking Model, the Health Information Acquisition Model (Freimuth, Stein, & Kean, 1989), the Comprehensive Model of Information-Seeking (Johnson, 1997; 2003), and the Expanded Model of Health Information-Seeking Behaviors (Longo, 2005). These information-seeking models are essentially flow charts that describe a series of steps through which individuals proceed as they seek information and identify factors explaining HISB (e.g., background, individual, and/or contextual factors). HISB is generally assumed to be triggered by an internal (e.g., experience of symptom, injury) or external (e.g., test results, advertisement on the television) stimulus (Longo, 2005). When confronted with the stimulus, individuals evaluate whether they have enough current information to respond to it. If a 'gap' is perceived between what is known and what one would like to know (i.e., information need), information-seeking is initiated. Lenz (1984) and Freimuth et al. (1989) emphasized that information-seeking behavior varies along two dimensions: (a) the extent of the search which includes the scope and depth of information-seeking and (b) the method or the sources of information used. Johnson's (1997) model focuses on explaining selection of information sources and identifying the factors influencing these choices (e.g., demographics, previous experience). Some information-seeking models give consideration to instances when individuals, despite needs for information, do not initiate information-seeking or cease a search in progress. For instance, both Freimuth et al. (1989) and Lenz (1984) highlighted that if the costs of information-seeking (e.g., time, frustration) outweigh the benefits (e.g., decreased uncertainty, support in treatment decision-making); it is unlikely that information-seeking will be pursued. However, most information-seeking models reviewed focus on whether individuals seek information or not and do not take into consideration the possible variability contained within these extreme HISB. Longo (2005) is the only model reviewed in the health literature that considers different information-seeking outcomes (e.g., someone might access the information but is unable to use it or he/she might need information but does not know where to access it).

Library and Information Science Literature

In addition to these models, the library and information science (LIS) literature abounds with information-seeking models. Fisher, Erdelez, and McKechnie (2005) published a compendium of these writings in: *Theories of information behavior*. From the many models or frameworks described in this book, three are most often referenced in the LIS literature: Wilson's (1996) Model of Information-Seeking Behavior, Dervin's (1999) Sense-Making Theory, and Kuhlthau's (1991) Model of the Stages of Information-Seeking Behavior. Wilson's (1996) model focuses on the (a) information needs, (b) barriers to information-seeking, and (c) possible forms information-seeking behavior might take, including passive attention, passive search, active search, and ongoing search. Dervin's (1999, 2003) theory of sense-making (also termed 'gap-bridging') focuses on the process of building an understanding or attributing meaning to a situation (Kari, 1998). Dervin's (1999, 2003) theory of sense-making is composed of four main elements: (a) a situation or a unique context where sense-making occurs; (b) a gap in knowledge (e.g., questions, confusions, anxiety) and the identification of the need to gain understanding of what is going on; (c) the outcomes or consequences of sense-making; and (d) the bridge or the answers, questions, ideas, and/or resources needed to make sense of the situation. Kuhlthau's model (1991) specifies six stages of the information search process: initiation, selection, exploration, formulation, collection, and presentation, and draws attention to the affect associated with each stage. Feelings of uncertainty, confusion, frustration, and doubt, for example, are associated with the early stages of information-seeking (Kuhlthau, 1991). Overall, the authors' works offer useful explanations for the process of information-seeking, including salient antecedents, barriers, and its consequences. Although much has been invested in documenting the process of information-seeking, few authors have systematically described patterns of behavior when individuals engage in information-seeking about health and illness.

A Novel Perspective on Information-Seeking: Self-Evaluation Theory

An exception to this state of knowledge is Loiselle's (1995) introduction to the health literature of a novel theoretical framework which captures differential information-seeking motives: Self-Evaluation Theory (SET). SET is referenced mainly in the personality and social psychology literature and describes selectivity when seeking information to better understand oneself (Loiselle, 1995; Trope & Neter, 1994). When seeking information about the self, individuals may take several avenues (e.g., social comparison), however regardless of how or where information is gathered, an individual's evaluation or judgment of their self-concept is likely to be motivated (Sedikides, 1993). Over the years, five motives are documented to guide self-evaluation: (a) *self-assessment*: the desire to obtain the most accurate information about oneself, (b) *self-enhancement*: the desire to maintain a positive sense of self, (c) *self-verification*: the desire for consistency in gaining information about the self, (d) *self-improvement*: the desire to obtain information to get better, and (e) *self-protection*: the desire to guard the self from potentially aversive information (Dauenheimer, Stahlberg, Spreeman, & Sedikides, 2002; Loiselle, Lambert, & Boisclair, 2003; Sedikides,1993; Taylor & Gollwitzer, 1995). The remainder of this chapter further details each self-evaluation motive. My introduction to SET by Dr. Loiselle prompted my interest in examining and characterizing further differential approaches to information-seeking about health and illness.

Self-assessment is pursued by individuals to obtain objective and accurate knowledge about the self (Roney & Sorrentino, 1995; Sedikides, 1993). Strivings for self-assessment is usually described as obtaining all available information to reduce uncertainties about abilities, weaknesses, or personality characteristics (Dauenheimer et al., 2002; Loiselle, 1995; Sedikides, 1993; Strube, Lott, Le-Xuan-Hy, Oxenberg, & Deichmann, 1986). Self-assessors seek information regardless of whether it has negative or positive implications. When motivated by self-assessment, people are presumed to be predominantly interested in learning about relatively unknown aspects of the self and to be less concerned with knowledge about well-known personality characteristics (Roney & Sorrentino, 1995; Sedikides, 1993). Underlying the self-assessment view is the assumption that a realistic and accurate portrayal of abilities contributes in effectively managing and responding to one's environment (Strube et al., 1986). In theory, accurate self-knowledge leads to selecting the most appropriate behaviors according to an individual's level of skills in a particular context (Dunning, 1995; Taylor, Neter, & Wayment, 1995).

According to SET, an individual striving for *self-enhancement* desires, above all, to maintain a positive sense of self (Gaertner, Sedikides, & Graetz, 1999; Sedikides, 1993; Taylor et al., 1995). Thus, people select information that has favorable implications for the self and avoid information that might threaten their self-esteem (Dauenheimer et al., 2002; Sedikides, 1993). The self-enhancement perspective predicts that people prefer to seek information on positive aspects of self to gain credible confirmation of their favorable characteristics, but seek little or no information on negative traits to avoid damaging the self (Sedikides, 1993). When individuals are mainly motivated by self-enhancement, they are not concerned with how much information they obtain or whether this information is accurate or not (Sedikides, 1993). Rather, they are worried about whether the information will have positive or negative implications on self-evaluation outcomes (Sedikides, 1993). Unlike individuals who prefer self-assessment, people favoring self-enhancement can tolerate some ambiguity about themselves in exchange for maintaining a positive view of self (Sedikides, 1993). Some self-evaluation theorists have argued that the need for a positive self is an omnipresent concern; whereas others have suggested that the need for self-enhancement becomes particularly acute following failure or threat (Taylor, Wayment, Neter, & Woo, 1994). Self-enhancement may manifest in many ways, including overly optimistic biases, preference for downward social comparisons (Jussim, Yen, & Aiello, 1995), and taking credit for successes and blaming failures on external circumstances (Dunning, 1995). Self-enhancement has been shown to operate during life transitions (e.g., illness) and is associated with gains in psychological well-being (e.g., self-esteem, personal growth) and reduction of depressive symptoms (Kwan, Love, Ryff, & Essex, 2003).

Self-verification refers to the desire for consistency (Dauenheimer et al., 2002; Taylor et al., 1995) and confirmation of existing views of the self (Roney & Sorrentino, 1995). When motivated by self-verification, people desire to confirm that what they think about themselves is correct (maintain existing beliefs about self) (Taylor et al., 1995). The self-verification view predicts that individuals select information based on the likelihood that it will confirm what they already believe, to be true about themselves (highly certain self-knowledge). Hence, positive self-conceptions are verified by seeking favorable information and negative self-conceptions are confirmed by soliciting unfavorable information. What matters is the consistency between self-conceptions and information-seeking, regardless of whether this information is positive or negative – unlike self-enhancement (Dunning, 1995; Sedikides, 1993). However, in self-verification, information that disconfirms beliefs or that challenges self-views is avoided (to avoid confusion about the self) (Roney & Sorrentino, 1995; Sedikides, 1993; Swann, Pelham, & Krull, 1989). Researchers have found evidence for the operation of the self-verification motive in how people select a partner – people are often found to prefer partners that confirm their self-conceptions and respond less favorably to non-confirming partners (Katz & Beach, 1997).

Sedikides (1993) conducted a comparative study of the self-assessment, self-enhancement, and self-verification motives to examine the strength of influence of each motive on the self-evaluation process. Findings provided unequivocal support for self-enhancement. Overall, participants preferred much information on positive aspects of self and less information about negative ones.

The *self-improvement* motive is concerned with getting better in some aspect of the self (Taylor et al., 1994; Taylor et al., 1995). Many life activities, including education, work, and leisure activities, have as their aim the improvement of specific skills (Taylor et al., 1995). Self-improvement is distinguished from self-enhancement, as it focuses on getting better rather than feeling better and by being oriented towards the future rather than the present (Taylor et al., 1995). Unlike self-verification, self-improvement emphasizes changing personal qualities rather than confirming them (Taylor et al., 1995). Taylor et al. (1995) suggested that when self-improvement needs were salient, individuals preferred upward social comparison, whereas when individuals were mainly motivated by self-enhancement, downward social comparison was usually preferred. Although this suggests that different self-evaluation motives are satisfied by different sources, SET offers little indication as to what these sources are.

The *self-protection* motive posits that individuals are guided by the desire to protect themselves from potentially aversive information (Loiselle, 1995). The main goal of self-protection is to avoid exposing unfavorable characteristics. Thus, all sources of information are avoided to safeguard from any negative self-knowledge (Wood, Giordano-Beech, Taylor, Michela, & Gaus, 1994). Although, obtaining information might reveal positive aspects of self, individuals do not want to risk coming across information that might also reveal flaws. Conceptually, self-protection differs from self-enhancement in that in the former individuals prefer to shun away from information to avoid the risk of coming across negative information, whereas those who self-enhance venture to seek positive information (Wood et al., 1994).

Although all five motives appear to be clearly developed and are presented here as a unified 'theory' or body of knowledge; more often, descriptions of the self-evaluation motives are scattered in the personality and social psychology literature across several authors and some motives are described and examined more frequently (e.g., self-assessment) then others (e.g., self-improvement). Despite much research on SET, certain aspects of this theory remain ambiguous. For instance, it is debatable how many motives are actually included in the core theory. Some authors have suggested that there are three main self-evaluation motives: self-enhancement, self-verification, and self-assessment (e.g., Dauenheimer et al., 2002; Helgeson & Mickelson, 1995; Sedikides, 1993; Sedikides & Strube, 1995). Others have also included self-improvement (e.g., Taylor et al., 1994) or self-protection (e.g., Wood et al., 1994) alone or in combination with the other motives. Also, some authors have suggested additional self-evaluation motives. For example, Swann and Schroeder (1995) referred to self-discrepancy as seeking information on attributes individuals think they ideally should have or ought to have. Kowalski and Leary (1990) referred to self-derogation as seeking information to fabricate or exaggerate negative attributes. In addition, labels used to designate the different self-evaluation motives seem to have been used interchangeably and are not always consistent across studies. For example, in some studies self-verification seems to have been termed self-consistency (e.g., Jussim et al., 1995). Self-protection is often described in similar ways to self-enhancement and considered by some to be the same motive (e.g., Gaertner et al., 1999; Sedikides, 1993). In consequence, further inquiry is needed to explore the essence and relevance of the self-evaluation motives.

Increasingly, SET researchers are attempting to define the contextual circumstances that prompt people to rely on one motive over another (the 'when' question) or the personal variables that might lead an individual to be more inclined towards a motive (the 'who' question). For instance, individuals with low self-esteem are found to prefer self-protection, whereas those with higher self-esteem tend to favor self-enhancement (Seta & Donaldson, 1999; Wood et al., 1994) or self-verification (Bernichon, Cook, & Brown, 2003). Mood is also identified as a potential moderator in the self-evaluation process. Sadness has been related to self-assessment, whereas happiness to self-enhancement (Sedikides, 1993). Dunning (1995) examined the influence of trait modifiability and trait importance on preference for self-assessment versus self-enhancement. Findings indicated that participants preferred self-enhancement when important traits or abilities were fixed and unchangeable, however in circumstances when participants thought they could control whether they possess the trait or not, they preferred self-assessment. Despite the important contribution of these studies, there is no comprehensive framework of the factors involved in the self-evaluation process. In addition to delineating when or by whom a particular motive is preferred, further integration of SET would explore whether and how multiples motives might be operating (Taylor et al., 1995). It has been proposed that self-evaluation motives are not mutually exclusive and individuals might pursue more than one motive in certain circumstances (Dunning, 1995; Jussim et al., 1995). However, to date, ways in which multiple motives might be simultaneously satisfied remain speculative.

Despite these limitations SET is unique because it considers the possible nuances or biases that occur when individuals seek information about themselves (Loiselle, 1995). Although, self-assessment echoes the traditional ‘monitor’ and self-protection can be associated with the description of ‘blunter’; other SET motives are not typically accounted for in the health literature. Health research documenting the operation of self-evaluation motives is scant. Helgeson and Taylor (1993) found that most individuals (n=60) enrolled in a cardiac rehabilitation preferred downward social comparisons and upward affiliations. These findings are consistent with the self-enhancement and self-improvement motives respectively. Similarly, Wood, Taylor, and Lichtman (1985) found that the women with breast cancer interviewed (n=78) preferred downward social comparisons. However, provided that few studies have corroborated the self-evaluation motives within a health context, any discussion of transferability is tentative (Loiselle, 1995). Nevertheless, SET remains a possible useful framework to examine differential preferences for health information-seeking (Loiselle, 1995). For this dissertation, SET was found to have heuristic value as it calls attention to areas of research not yet explored in great depth in the cancer literature. Although I was aware of this theory prior to data collection, I was cautious not to impose SET on data collection and analysis. For instance, interview questions remained broad and were not exploring specific aspects of SET. Also, codes emerged from the data and were not pre-determined by the theory.

Given that the literature on information-seeking is vast and HISB is a complex phenomenon, a concept analysis was undertaken at the outset of this dissertation to clarify the dimensions of HISB (Lambert & Loiselle, 2007). From this analysis, we developed a simplified conceptual model of HISB (Figure 1) which elucidated the dimensions of HISB and guided the exploration of the concept in this study. Also, according to the findings of the concept analysis, and aforementioned theorizing on HISB, it was presupposed that participants in this study would vary (in one way or another) in their approach to cancer information-seeking. However, I was mindful not to force any preconceptions as to the number and the nature of the emerging patterns. Corbin and Strauss (2008) emphasized that in grounded theory the issue is not necessarily whether previous literature or theoretical frameworks are used or not, but rather how this knowledge is used. My previous knowledge of HISB shaped the conception of the study and served as the groundwork from which a research purpose and related questions were formulated. Throughout this study, data collected were compared with what is already known about HISB and this knowledge was used to stimulate further the analysis (e.g., establish connections between previous knowledge and the data, enhance sensitivity to subtle nuances). However, the study's findings evolved from the participants' experiences and new ideas and concepts described by participants were identified and integrated in the emerging theory. Findings from this study thus extend, validate, and refine the knowledge base in the field of information-seeking.

Overall Research Purpose and Questions

The purpose of this dissertation work was to explore and understand individuals' HISB patterns within the context of a diagnosis of breast, prostate, or colorectal cancer. For the purpose of the study, a HISB pattern is defined as the particular way in which an individual approaches the search for health information, including the type, amount, and source of information sought (Lambert & Loiselle, 2007). The overall research question is: How do individuals diagnosed with cancer seek to meet their information needs? Specifically, the following questions guided data coding: how, why, when, where, and to what extent do individuals diagnosed with cancer seek health or illness-related information. These questions led to examining potential variations in cancer information-seeking and to characterizing different HISB patterns. To my knowledge, this is the first qualitative study that aims to obtain an in-depth understanding of differential HISB patterns among individuals diagnosed with breast, prostate, or colorectal cancer.

Ethical Considerations

Ethics approval from the McGill University Faculty of Medicine Institutional Review Board and McGill University Health Centre ethics committee was obtained (Appendix A). The study was explained to all participants and signed consent was obtained prior to each interview or focus group (Appendix B). During the study, information provided by the participants was not publicly reported or made accessible to parties other than those involved in the research. Participants were assured that their involvement in the study would have no impact on their healthcare and that their participation was entirely voluntary. They were also informed of their right to discontinue participation at any point in the study. Participants were also informed that they can request to have the tape recorder stopped at any time during the interview or focus group. The confidentiality of participants was strictly observed by assigning a code to each interview and focus group participant. Any information or data that could lead to the identification of participants were deleted or substituted (e.g., names) in subsequent publications. Privacy was maintained during the interview process, by interviewing participants in their home or a place at the hospital away from other patients and health care professionals. Focus group participants were asked to respect others privacy by not discussing the content of the focus group once they leave. Reprint permission of published articles and authorizations from the co-authors of the manuscripts are included in Appendix C.

CHAPTER 2 CONCEPT ANALYSIS

Preface

This chapter presents the first manuscript of the thesis published in *Qualitative Health Research*: Health information-seeking behavior (Appendix D). Since the mid-1980s and 1990s, the nursing and allied health literature on HISB has increased exponentially. HISB is studied in several normative (e.g., breastfeeding) and illness-related (e.g., cancer) contexts. Many studies have documented the antecedents and processes related to HISB (e.g., Boudioni et al., 2001; Hansen, Derry, Resnick, & Richardson, 2003; Leydon et al., 2000) and individuals' discretionary actions when seeking health-information (e.g., Beisecker & Beisecker, 1990; Hansen et al., 2003), preferences for the type, amount (e.g., Friis, Elverdam, & Schmidt, 2003; Huber & Cruz, 2000; Leydon et al., 2000; Shuyler & Knight, 2003), and sources of information used (e.g., Huber & Cruz, 2000; Kakai, Maskarinec, Shumay, Tatsumura, & Tasaki, 2003). At first glance, it would appear that the concept of HISB is well developed in the literature and used without apparent debate about its meaning. Following an initial review of the literature, however, it became apparent that researchers conceptualize HISB differently according to the objectives of their study and HISB thus affords multiple understandings. In addition, a comprehensive definition of HISB is difficult to locate and in most studies, the concept's essential attributes remain unspecified. Despite the abundant literature on HISB, this initial review raised important questions about HISB's attributes and conceptual components. Therefore, a concept analysis according to Morse and colleagues' (Morse, Hupcey, Mitcham, & Lenz, 1996; Morse, Mitcham, Hupcey, & Tason, 1996) was undertaken to further explore the nature of HISB. The findings of this systematic analysis were deemed critical to guide the exploration of HISB in this study.

Manuscript #1

Health Information-Seeking Behavior

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Abstract

Seeking information about one's health is increasingly documented as a key coping strategy in health-promotive activities and psychosocial adjustment to illness. In this article, the authors critically examine the scientific literature from 1982 to 2006 on the concept of health information-seeking behavior (HISB) to determine its level of maturity and clarify the concept's essential characteristics. A principle-based method of concept analysis provides the framework for exploring the nature of HISB. The authors reviewed approximately 100 published articles and five books reporting on HISB. Although HISB is a popular concept used in various contexts, most HISB definitions provide little insight into the concept's specific meanings. The authors describe the concept's characteristics, contributing to a clearer understanding of HISB, and discuss operationalizations, antecedents, and outcomes of HISB. Such an analysis of HISB may guide further theorizing on this highly relevant concept and assist health care providers in designing optimal informational interventions.

From the late 1980s to mid-1990s, only a few seminal works addressed the concept of health information-seeking behavior (HISB) (e.g., Lenz, 1984; Loiselle, 1995; Miller, 1987). However, the advent of the information age and related increase in the amount of information potentially available (Vakari, Savolainen, & Dervin, 1996), and an enhanced focus on self-monitoring and self-care, as well as renewed interest in predictors of health promotion and illness prevention activities, contributed to HISB's taking center stage (Johnson, 2003; Loiselle & Dubois, 2003). Since the mid-1990s, studies examining HISB abound in the health-related scientific literature. Researchers and clinicians, alike, are interested in understanding how and why individuals obtain health information, where they go to retrieve such information, what particular types of information they prefer, and how the health information sought is used. At first glance, the concept of HISB appears to be well developed and used without apparent controversies or debate about its meaning. However, on closer examination, the concept affords multiple understandings. Despite the abundant theoretical and empirical literature on HISB, no article reviewed to date critically examines the concept. Such an analysis might further clarify the concept and contribute to a more fully developed concept and more accurate assessments of HISB. Hence, the purpose of this article is to present a comprehensive analysis of the concept of HISB.

From Wilson (1963) to the Present

One challenging and critical issue in concept analysis is the selection of the most appropriate analytical method. Traditionally, concept analysis has been addressed primarily through Wilsonian-derived methods introduced mainly by Walker and Avant (1995) and Chinn and Jacobs (1987). These methods are widely used, as they offer structure and guidance for concept analysis. However, the end product of such analysis often lacks depth, with resulting concept attributes that are vague and of limited utility. An additional criticism is that these methods are based on demised positivist philosophy (Hupcey, Morse, Lenz, & Tason, 1996; Morse, Hupcey, et al., 1996). For these reasons, authors have recommended alternate methods, such as critical analysis of the literature and the use of qualitative approaches (Hupcey et al., 1996; Morse, Hupcey, et al., 1996; Rodgers, 1989; Schwartz-Barcott, 2003).

Rodgers (1989) proposed an evolutionary method to concept analysis that moves away from a static view of concepts to a more fluid one and overcomes some of the aforementioned weaknesses (Hupcey et al., 1996; Morse, Hupcey, et al., 1996). However, certain aspects of the evolutionary method remain disputable. The analysis still focuses mainly on the linguistic aspect of the concept (Morse, Hupcey, et al., 1996) and is often limited to a single exemplar (limiting the richness of the data obtained) (Hupcey et al., 1996; Morse, 1995; Morse, Hupcey, et al., 1996). Furthermore, the selection of one exemplar that encompasses all contexts contradicts Rodgers's statement that concepts are context bound. In addition, Rodgers's recommendation that data analysis be delayed until last violates standards of qualitative inquiry (Hupcey et al., 1996).

Morse and colleagues have contributed a criteria- or principle-based method to concept analysis (Morse, 1995; Morse, Hupcey, et al., 1996; Morse, Mitcham, et al., 1996; Penrod & Hupcey, 2005). Morse et al.'s (Morse, Hupcey, et al., 1996; Morse, Mitcham, et al., 1996) method is selected for the present analysis, as it promotes the use of rich data sources and provides clear criteria on which to base the analysis and it is more flexible and less decontextualizing than the abovementioned methods (Penrod & Hupcey, 2005). According to Morse, Hupcey, et al. (1996), concept analysis "refers to a process of inquiry that explores concepts for their level of development or maturity as revealed by their internal structure, use, representativeness, and/or relations to other concepts" (p. 255). The initial phase focuses on analyzing extant literature on the concept and determining its level of maturity. Maturity is a criteria-based determination of the concept's clarity from epistemological (i.e., definitions), linguistic (i.e., contexts within which the concept is used), logical (i.e., boundaries and theoretical integration with other concepts), and pragmatic (i.e., operationalization) perspectives (Hupcey, Penrod, Morse, & Mitcham, 2001; Morse, Hupcey, et al., 1996; Morse, Mitcham, et al., 1996; Penrod & Hupcey, 2005). Each criterion "contributes to an understanding of the strengths and limitations of the present state of the concept in the scientific literature" (Penrod & Hupcey, 2005, p. 403). A concept is mature if it is well defined; it has distinct characteristics, delineated boundaries, and well-described preconditions and outcomes; and a consensus exists on its use (Morse, Mitcham, et al., 1996). For the concept of HISB, an exploration of the literature reveals that the concept is partially developed. The second part of the analysis clarifies HISB by delineating its conceptual components, including its antecedents, characteristics, and outcomes.

Sample for Data Collection

The literature reviewed for this analysis includes book chapters, theoretical, and empirical articles on HISB, instruments that attempt to assess the concept, and review articles. The inclusion criteria for the chosen literature were: (a) works written in English or French, (b) those with a focus on actual behaviors of individuals when seeking health-related information, (c) the inclusion of "information-seeking" in the title or the text, and (d) scholarly work published in a peer- reviewed journal. A computer-generated search was performed using OVID software, accessing the Medline, CINAHL, psychINFO, HEALTHSTAR, Web of Science, and Health and Psychosocial Instruments databases.

The search was conducted in various disciplines to obtain a broad perspective on the concept (Morse, 2000; Penrod & Hupcey, 2005). The period from 1982 to 2006 was retained, as it represents a period long enough to detect seminal work undertaken on HISB. Examples of terms (used alone or in combination) included information-seeking behavior, information needs, health information, coping, decision-making, information services (use), and health education (use). In addition, a perusal of the reference lists of each article was conducted to retrieve potentially relevant work not initially identified. Five books and approximately 100 published articles were reviewed. Of the articles, approximately 60% were quantitative studies (e.g., information-seeking styles, correlates of information-seeking), 15% were qualitative studies (e.g., type and sources of information preferred), 15% were reviews (e.g., information needs), and 10% were theoretical papers (e.g., model or theories of information-seeking behavior). The references were organized using Reference Manager.

Data Analysis

Analysis was carried out according to an in-depth content analysis of each source (Morse, 2000). First, we read each article and book chapter two to three times to identify general content and to gain a sense of the overall meaning given to HISB. Analysis then proceeded inductively; within each article, statements or paragraphs providing information on some aspect of the concept (i.e., components, maturity) were identified and noted. The following questions guided the analysis: Is the concept clearly defined? Is the concept used consistently and appropriately within context? Does the concept hold its boundaries? Has the concept been theoretically integrated with other concepts? Has the concept been appropriately operationalized? What are the key characteristics of HISB? What are the relationships among the characteristics? Is HISB treated as a fixed personality characteristic or as a behavioral context-bound strategy? What are the antecedents to HISB (e.g., is an information need sufficient to enact HISB)? What are some of the outcomes or consequences of HISB? Detailed analysis and interpretation of notes resulted in our identifying main themes related to HISB. We described each aspect of the concept further by continually organizing and reorganizing key points in the literature until cohesive and comprehensive descriptions were obtained. Articles reviewed were constantly compared and contrasted with each other, and similarities and differences among authors were identified. Rigor was supported by our reviewing a large amount of the literature on HISB from the various disciplines (Morse, 2000; Penrod & Hupcey, 2005). In addition, findings were discussed between the authors until a consensus was reached.

Findings

Maturity of the Concept

Is the Concept Clearly Defined?

Explicit definitions of HISB are difficult to locate, and there is no apparent dominant definition. Typically, definitions are inferred by the purpose or focus of the article. The meaning of HISB is often thought to be obvious, and what individuals do to obtain information taken for granted (Case, 2002). The broad sense attributed to HISB relates to the ways in which individuals go about obtaining information, including information about their health, health promotion activities, risks to ones' health, and illness.

Few authors use the complete label health information-seeking behavior (e.g., Baker & Pettigrew, 1999; Gollop, 1997; Gray, Klein, Noyce, Sesselberg, & Cantrill, 2005; Kakai et al., 2003). Most authors of articles reviewed use the term i*nformation-seeking behavior*. The word *health* is implied by the type of information sought (i.e., individuals seek health-related information) and/or the context (i.e., information sought within a health-related context) (e.g., Beisecker & Beisecker, 1990; Borgers et al., 1993; Czaja, Manfredi, & Price, 2003; Szwajcer, Hiddink, Koelen, & van Woerkum, 2005). Others use the term h*ealth information-seeking* or simply *information-seeking*. Authors imply that "behaviors" or "actions" to obtain information are an inherent component of i*nformation-seeking* (e.g., Meischke, Eisenberg, Rowe, & Cagle, 2005; Shi, Nakamura, & Takano, 2004). For the purpose of the present analysis, the comprehensive label of health information-seeking behavior (HISB) is used.

Various definitions of HISB found in the literature are presented in Table 1. Most authors have proposed that HISB entails the use of specific actions and/or strategies by individuals to acquire information. However, little insight or description is provided as to what those behaviors or actions consist of (circular definitions). Lenz (1984) appears most informative in her treatment of the concept by specifying that HISB varies along two main dimensions: extent (scope and depth of search) and method (information source used). Czaja et al. (2003) and Johnson (1997) have focused primarily on the method dimension of HISB in their definition.

The definitions proposed by van der Molen (1999) and Rees and Bath (2000, 2001) suggest an antecedent or cause (i.e., stress or threat), and/or a purpose (i.e., coping) to HISB. These definitions limit HISB to situations of threat; one of several possible situations where individuals would seek health-related information. Other authors are less prescriptive and more general about the situations in which the information is sought (e.g., Barsevick & Johnson, 1990; Conley, 1998; Loiselle, 1995) or the antecedents to HISB (e.g., Baker & Connor, 1994).

Is the Concept used Consistently and Appropriately within the Context?

Overall, HISB is studied within the context of (a) coping with a health threatening situation, (b) participation and involvement in medical decision-making, and (c) behavior change and preventive behavior. Each context as related to HISB is reviewed in turn.

HISB in the context of coping with a health-threatening situation

Processes related to HISB are becoming increasingly central to how individuals cope with health-threatening situations (Davison et al., 2002; Garvin et al., 2003; Hoskins & Haber, 2000; Ramson, Jacobsen, Schmidt, & Andrykowski, 2005; Rees & Bath, 2000). Within this context, researchers have identified the type of information individuals seek to cope with stressful situations, the amount of information sought, how the information is obtained, and when or under what circumstances the information is needed (Loiselle, 1995; Rees & Bath, 2001; van der Molen, 1999). HISB is typically referred to as a problem-focused coping strategy (or monitoring) and implies that individuals focus their attention on the threatening situation and direct their efforts at becoming more engaged with and aware of stressors (Livneh, 2000; Rees & Bath, 2001; Shiloh, Sinai, & Keinan, 1999). Information-seeking is suggested to enhance coping by helping individuals understand the health threat and the associated challenges that it brings (Clark, 2005; Davison et al., 2002; Flattery, Pinson, Savage, Salyer, & Virginia, 2005; Henman, Butow, Brown, Boyle, & Tattersall, 2002), help to evaluate what is at stake (Flattery et al., 2005; van der Molen, 1999), contribute to attaching appropriate meanings to events (Rees & Bath, 2001; Rees, Sheard, & Echlin, 2003; Shiloh, Mahlev, Dar, & Ben-Rafael, 1998), help individuals rehearse or work through their experiences (Rees, Sheard, et al., 2003), provide ways of managing the stressors (Davison et al., 2002; Feltwell & Rees, 2004; Huber & Cruz, 2000), determine what resources are available to manage the stressors (van der Molen, 1999) and make informed decisions (Henman et al., 2002; Loiselle, 1995; Rees & Bath, 2001), and increase predictability and feelings of control over situations (Andreassen, Randers, Naslund, Stockeld, & Mattiasson, 2005; Case, Andrews, Johnson, & Allard, 2005; Flattery et al., 2005; Henman et al., 2002; Rees, Sheard, et al., 2003). HISB is also argued to have emotion-focused coping functions, in that information reduces negative reactions linked to uncertainty (e.g., anxiety) and provides reassurance, which might account for the observation that information-seeking is often positively related to both problem-focused and emotion-focused coping (Shiloh et al., 1999). Overall, information-seeking efforts serve to manage or alter the relationship between an individual and the source of stress, potentially contributing to positive health outcomes and psychosocial adjustment (van der Molen, 1999). Although, many individuals choose to cope with a health-related threat by seeking information, others are found to purposefully avoid such information. Information avoidance, also referred broadly as denial, blunting, or repression, emphasizes that some individuals choose to divert their attention from the perceived threat (Feltwell & Rees, 2004; Livneh, 2000; Loiselle, 1995).

HISB in the context of participation and involvement in medical decision-making

As the trend toward shared or collaborative medical decision-making between health care professionals and patients continues (Warner & Procaccino, 2004), much attention is given to individuals' preferred role in medical decision-making (Beaver et al., 1996; Davison et al., 2002; Hack, Degner, & Dyck, 1994; Hashimoto & Fukuhara, 2004). Individuals' preferences for medical decision-making range from wanting to be able to understand health care professionals' decisions about care, to wanting their views to be heard and considered, to making the final decision (Beaver et al., 1996; Hack, Degner, Watson, & Sinha, 2006; Henman et al., 2002). HISB is conceptualized as a means of obtaining the type and amount of information needed to participate in medical decision-making. In general, studies have shown that individuals who prefer an active or collaborative role when making decisions with health professionals are also more active in their search for health-related information (Davison et al., 2002; Hack et al., 1994). Seeking information contributes to participation in medical decision-making by helping individuals identify possible options, weigh and evaluate the different options, reduce uncertainty and doubt about alternatives, and decide whether a particular option is appropriate (Brown, Carroll, Boon, & Marmoreo, 2002; Budden, Pierce, Hayes, & Buettner, 2003; Huber & Cruz, 2000; Johnson, 1997). The assumption is that individuals who seek out information might be better prepared to engage in medical decision-making (Beaver et al., 1996; Brown et al., 2002; Hashimoto & Fukuhara, 2004; Radecki & Jaccard, 1995; Shuyler & Knight, 2003). However, individuals seeking large amounts of health-related information do not consistently play an active role in decision-making (Czaja et al., 2003; Hashimoto & Fukuhara, 2004; Henman et al., 2002). Here, information might be sought for other purposes, such as anticipating the sequence of events or evaluating appropriateness of treatment proposed (Czaja et al., 2003; Hashimoto & Fukuhara, 2004).

HISB in the context of behavior change and preventive behavior

HISB is often perceived as a crucial step in the enactment of discretionary health-related and preventive behaviors (Budden et al., 2003; Fahrenwald & Walker, 2003; Shi et al., 2004; Shuyler & Knight, 2003; Warner & Procaccino, 2004; Yu & Wu, 2005). Theoretically and empirically, information-seeking is identified as a significant factor influencing the extent to which individuals decide to engage in healthy lifestyles and/or preventive behaviors (e.g., Burbank, Reibe, Padula, & Nigg, 2002; Fahrenwald &

Walker, 2003; Yu & Wu, 2005). Although information alone does not guarantee healthy behaviors, acquiring adequate information might motivate individuals to make positive changes in their health practices (Loiselle & Delvigne-Jean, 1998; Meischke et al., 2005; Shi et al., 2004; Szwajcer et al., 2005). Individuals' specific HISB might influence the scope and nature of the information on which judgments, beliefs, and attitudes toward the health behavior are based, the number of alternative courses of action known to individuals, and knowledge about the pros and cons of different actions (risk perception) and resources available to carry out the different behaviors (Burbank et al., 2002; Griffin, Dunwoody, & Neuwirth, 1999; Holmes & Lenz, 1997; Huber & Cruz, 2000; Johnson, 1997).

Does the Concept Hold its Boundaries, and Has it Been Theoretically Integrated with Other Concepts?

The boundaries of a concept are traditionally identified by what is and what is not part of the concept (Morse, Mitcham, et al., 1996). One commonality across several authors is that HISB is an intentional, overt action; individuals make a conscious choice to seek health-related information (Case, 2002; Johnson, 1997; Lenz, 1984; Longo, 2005; Rees & Bath, 2001; Warner & Procaccino, 2004). This intentionality is suggested to be related to the accomplishment of some particular information-related goal (Johnson, 1997). HISB does not include instances in which individuals are being exposed to health-related information without a specific request (passive receipt of information) (Barsevick & Johnson, 1990; Lenz, 1984; Loiselle, 1995; Longo, 2005) or when information is retrieved from memory (Johnson, 1997). For instance, if information is acquired, but not purposefully sought, while the individual is engaging in another activity such as watching television, this is not considered to be HISB (Lenz, 1984). Furthermore, HISB does not include information received from health professionals unless this information was specifically requested (Barsevick & Johnson, 1990). However, passive acquisition of information can occur during active information-seeking (Lenz, 1984; Longo, 2005). Case (2002) has used the term *information behavior* to encompass information-seeking or avoidance as well as unintentional or passive behaviors.

A concept often found to be used interchangeably with HISB is preference for information within health-related contexts. A review of authors using this term revealed that it is most often used to emphasize the extent to which an individual reports a *desire,* from an affective perspective, to seek or receive specific types of health information (e.g., Garvin et al., 2003; Hack et al., 1994; Loiselle, 1995). Individuals with high preference for information wish to seek or receive as much health information as possible; however, this high preference does not ensure that they will subsequently carry out their information search (Garvin & Kim, 2000; Loiselle, 1995). Other factors, such as the complexity of the situation or individuals' physical or psychological health, might influence whether a high preference for information will translate into actual behavior (Harrison, Galloway, Graydon, Palmer-Wickham, & Rich-Van, 1999).

Theoretical underpinnings of HISB

Although the majority of empirical studies reviewed do not specify a formal model or theoretical framework for HISB, six models or theories related to HISB are found in the health-related literature. These include: (a) Lazarus and Folkman's (1984) Stress, Appraisal and Coping Theory, (b) Miller's (1987, 1989) Monitoring and Blunting Hypothesis, (c) Lenz's (1984) Information-Seeking Model, (d) The Health Information Acquisition Model (Freimuth et al., 1989), (e) The Comprehensive Model of Information-Seeking (Johnson, 1997; 2003), and (f) The Expanded Model of Health Information

Seeking Behaviors (Longo, 2005). Lazarus and Folkman's (1984) theory and Miller's (1987) framework are most frequently referenced. Both authors focus primarily on individuals' differential responses to stress. Although, Lazarus and Folkman (1984) did not expand on HISB, Miller (1987) provided specific characteristics that differentiate an information seeker (i.e., monitor) from an information avoider (i.e., blunter). Although the concept of monitoring/blunting is popular, it is suggested that this concept is not specific to information-seeking and, rather, mingles different types of coping strategies (Ransom et al., 2005). Therefore, the concept of monitoring/blunting may not best capture individuals' HISB. Neither of these specifically describes the process of HISB.

The other four models are, in essence, flowcharts that describe a series of steps through which individuals progress to seek information (information-seeking process) and identify the underlying factors that might explain HISB. One appealing aspect of these models is their simplicity. However, some models appear to oversimplify HISB and represent the information-seeking process as linear (e.g., Johnson, 1997); no feedback loops are included, overlooking the iterative nature of HISB. A more fluid and nonlinear model (e.g., Freimuth et al., 1989) is suggested to be more appropriate (Case, 2002; Foster, 2004). Although most models have theoretical and/or empirical justifications, some provide little evidence to support their depiction of HISB and the associated variables.

Typically, the models or theories reviewed specify several background, personal and/or contextual factors that motivate a person to seek information (or not) and attempt to predict HISB (Case, 2002). Some authors, particularly Lenz (1984) and Freimuth et al. (1989), have focused on a conception of HISB as a process initiated by a stimulus. The key role of a stimulus or a recognized information need in initiating HISB is empirically reported by several authors (e.g., Griffin et al., 1999; Szwajcer et al., 2005; Warner & Procaccino, 2004). Johnson (1997) acknowledged the critical role of a stimulus; however, this variable is not explicitly depicted in the model. Lenz (1984) and Freimuth et al. (1989) also call attention to intermediary steps following the stimulus, particularly the perception of a positive cost-benefit ratio, which influence an individual's search for information. Although these models move away from conceptualizing HISB as a simple stimulus-response reaction and include cognitive activities, the need for a positive cost-benefit ratio can be challenged. Some authors have contended that most individuals seek information that is relevant to them regardless of the potentially negative or positive implications (Dauenheimer et al.., 2002).

Lenz (1984) and Freimuth et al. (1989) also provided the most comprehensive understanding of the different dimensions of HISB: extent and method, as defined earlier. Longo (2005) and Johnson (1997) focused primarily on the method dimension. Johnson (1997) provided an extensive description of the method dimension and emphasized that information sources are selected on the basis of their match with individuals' information needs. Although Johnson (1997) did not exclude the extent dimension, it is not explicitly depicted in the model (Johnson, Andrews, & Allard, 2001). Most models or theories reviewed focus merely on whether individuals seek information or not and do not take into consideration the possible variability contained within these extreme HISB. Longo's (2005) is the only model reviewed that considers different information-seeking outcomes (e.g., a patient might access the information but be unable to use it). Together, all models provide important insights into the study of HISB and increase our understanding of why certain individuals might choose to seek information whereas others do not to the same extent.

Has the Concept Been Appropriately Operationalized?

Most often, authors operationalize the concept of HISB in terms of (a) type of health-related information sought, (b) amount of health-related information sought, (c) information sources used, or (d) discrete actions implemented (e.g., Loiselle, 1995). Some authors have captured HISB by examining the specific kinds of health-related information sought (e.g., information about disease and disease process, information on self-care and self-management strategies) (e.g., Borgers et al., 1993; Butow, Maclean, Dunn, Tattersall, & Boyer, 1997; Szwajcer et al., 2005). Individuals have also been asked about the general type of information sought. For example, are individuals seeking all possible information, most pertinent information, or only "good news" or "bad news"? Amount of information sought is most often documented by asking individuals about the extent of details sought (e.g., Butow et al., 1997; Hack et al., 1994; Loiselle, 1995). HISB is also frequently operationalized through descriptions of sources used (type and number, frequency of use) (e.g., Gollop, 1997; Loiselle, Edgar, & Batist, 2002; McGuffin & Wright, 2004; Rees & Bath, 2001). Some authors have focused on surveying individuals' discrete behaviors when seeking information, such as how frequently they ask questions to HCPs or initiate discussions about specific issues (e.g., Borgers et al., 1993).

Authors have also used various scales to measure HISB. Four relevant published scales have been identified: (a) the Miller Behavioral Style Scale (MBSS) (Miller, 1987), (b) the Threatening Medical Situation Inventory (TMSI) (van Zuuren, deGroot, Mulder, & Muris, 1996), (c) the Krantz Health Opinion Survey (KHOS) (Krantz, Baum, & Wideman, 1980), and (d) the Autonomy Preference Index (API) (Ende, Kazis, Ash, & Moskowitz, 1989). Although most of these scales have been used in several studies for their ease of administration and acceptable reliability and validity, several shortcomings are noted. For instance, the MBSS measures individuals' tendency either to seek or to avoid information within hypothetical threatening situations; the MBSS items are not specific to health-related contexts (Garvin & Kim, 2000). In an effort to design a scale that would be more relevant to health contexts, van Zuuren et al. (1996), inspired by the MBSS, designed the TMSI and included health-related hypothetical scenarios. The use of hypothetical scenarios, by both the MBSS and TMSI, might lead to discrepancies between how individuals think they might behave in a particular situation and their actual HISB (Garvin & Kim, 2000; Loiselle, 1995). As such, the MBSS and TMSI appear to be measuring preference for information rather than HISB. The KHOS focuses mainly on individuals' preferences for asking questions directed at health professionals when undergoing medical treatments but provides little information on the type or amount of health-related information individuals seek. The API appears to measure what individuals think others should provide them with in terms of health-related information rather than the actual search for information. One of the most significant criticisms of the scales reviewed is that HISB is conceptualized primarily as an all-or-nothing phenomenon; that is, individuals either seek or avoid health-related information. Such a dichotomous operationalisation of the concept has often been identified as insufficient; individuals' HISB are actually found to be more variable on a continuum from avoidance and selectivity to complete search (Johnson, 1997; Loiselle, 1995; Szwajcer et al., 2005).

Concept Clarification: Key Components of HISB

Based on the above analysis of the concept's maturity, HISB is partially developed, and further concept clarification is needed. One of the main weaknesses of the concept is that its essential characteristics are not clearly delineated. Despite the popularity of the concept and its extensive use, much about the essence of HISB remains implicit. Based on the literature reviewed, key components of HISB were extracted. These include the concept's characteristics, antecedents, and consequences.

Characteristics of HISB

Essential characteristics of HISB are those that are present in all instances in which the concept appears, but they can vary in strength of association and be present in different forms (Morse, Mitcham, et al., 1996). Throughout the literature, two main dimensions of HISB emerge: (a) the information dimension and (b) the method dimension. The information dimension emphasizes the characteristics of the information sought, particularly in terms of type and amount. The type refers to the content and diversity of the search. The amount refers to how much information (details) about a given topic one seeks, underlining the depth of the search. Individuals have been found to vary greatly along this dimension: Some might search a lot of health-related information on a wide array of topics (Clark, 2005; Echlin & Rees, 2002; Leydon et al., 2000; Szwajcer et al., 2005); whereas others might choose to seek little or no health-related information (Case et al., 2005; Echlin & Rees, 2002; Longo, 2005; Szwajcer et al., 2005). Some individuals might seek health-related information only on a particular issue but avoid other types of health-related information (Friis et al., 2003; Leydon et al., 2000; Loiselle, 1995), or some might seek general information, whereas others prefer details or specifics (Ford, Wilson, Foster, Ellis, & Spink, 2002).

The method dimension of HISB focuses on the discretionary actions individual use to obtain health-related information and sources of information used. Discrete information-seeking activities or strategies include direct and indirect questioning (e.g., Borgers et al., 1993; Brashers, Goldsmith, & Hsieh, 2002; Feltwell & Rees, 2004; Johnson, 1997), asking for clarifications (e.g., Beisecker & Beisecker, 1990), discussing and exchanging information with others (e.g., Beisecker & Beisecker, 1990; Friis et al., 2003; Matthews, Sellergren, Manfredi, & Williams, 2002), reading (e.g., Brereton & Nolan, 2002; Feltwell & Rees, 2004), observing (e.g., Brereton & Nolan, 2002), use of a third party (e.g., Johnson, 1997), browsing (e.g., Johnson, 1997), and listening (e.g., Brereton & Nolan, 2002).

Most often, individuals seek health-related information, at any given time, from a combination of personal (e.g., self, friends, family) and impersonal (e.g., book, Internet) sources. The use of multiple sources might reflect individuals' desire to acquire as much information as possible (Brown et al., 2002; Shuyler & Knight, 2003) and/or to validate (Gray, Fitch, Greenberg, Hampson, Doherty, & Labrecque, 1998; Muha, Smith, Baum, Maat, & Ward, 1998) or complement information received from a prior source (Brereton & Nolan, 2002; Fleming, Goodman, Graghty, West, & Lancaster, 2002; Muha et al., 1998). Johnson (1997) referred to the sources of information an individual consults to obtain information as their information field. Most individuals indicate a preference for health professionals when seeking medical facts (Andreassen et al., 2005; Brown et al., 2002; Johnson, 1997; Loiselle, Semenic, Côté, Lapointe, & Gendron, 2001; Warner & Procaccino, 2004). This might reflect individuals' belief that professionals can provide unbiased, reliable information that is in their best interest (Brown et al., 2002; Gollop, 1997; James, James, Davies, Harvey, & Tweddle, 1999). Individuals also report a preference for other sources of information, such as friends or others experiencing the same health issue, when seeking psychosocial information (Beresford & Sloper, 2003; Dunne, 2002) or the Internet when seeking sensitive information (anonymity provided) (Gray et al., 2005). As such, the type and amount of information desired influence which source(s) of information one will consult (Beresford & Sloper, 2003; Gray et al., 2005;

Griffin et al., 1999; Johnson, 1997; Szwajcer et al., 2005). General properties of information sources that influence their use include accessibility, credibility, and accuracy of the source (Gray et al., 2005; Johnson, 1997), and the style and comprehension of information presented (Johnson, 1997; Szwajcer et al., 2005). Other frequently stated sources of information are television (e.g., Carlsson, 2000; McGuffin & Wright, 2004), magazines or newspapers (e.g., Andreassen et al., 2005; Feltwell & Rees, 2004; McGuffin & Wright, 2004; Shi et al., 2004), pamphlets and/or books (e.g., Loiselle et al., 2002; Szwajcer et al., 2005; Warner & Procaccino, 2004), and support groups (e.g., Rees & Bath, 2001).

In sum, HISB is characterized by the type and amount of health-related information sought, the specific actions implemented to obtain the information, and the sources individuals use. Although, authors have reported that individuals might have a general or stable tendency to either seek or avoid information (Butow et al., 1997; Echlin & Rees, 2002; Garvin & Kim, 2000), actual HISB are dynamic and might be expected to vary according to changing personal and contextual variables and time (Garvin & Kim, 2000; Szwajcer et al., 2005).

Antecedents of HISB

Typically, individuals' HISB are recognized as initially motivated by an information need (Dunne, 2002; Griffin et al., 1999; Holmes & Lenz, 1997; Johnson, 1997; Szwajcer et al., 2005; Warner & Procaccino, 2004), generally defined as a perceived gap between what an individual knows and what he or she wants to know to achieve a certain goal (Case, 2002; Griffin et al., 1999; Johnson, 1997; Loiselle, 1995; Szwajcer et al., 2005). However, several authors have reported that even if an individual has a need for information, he or she might not actually seek the information (Loiselle, 1995; Matthews et al., 2002; Rees & Bath, 2001; Szwajcer et al., 2005). Although significant, an information need is not sufficient to prompt HISB; rather, several personal and contextual factors influence whether and how an individual responds to an information need (Allen, 1996; Case et al., 2005; Czaja et al., 2003; Loiselle, 2001; Loiselle & Delvigne-Jean, 1998; Shiloh et al., 1999). Personal and situational factors are reported to influence what type of and how much information is sought, what sources are used, and how the information is obtained. Personal factors include individuals' socio-demographic characteristics as well as psychosocial variables such as personality traits and individuals' expectations, goals, beliefs, values, attitudes, emotions and moods, skills and/or resources (Borgers et al., 1993; Loiselle, 2001; Matthews et al., 2002). For example, women (Czaja et al., 2003; Johnson, 1997) and educated and younger individuals (Czaja et al., 2003; Johnson, 1997; Muha et al., 1998) are often reported to be active information seekers. Personality characteristics such as high internal locus of control (Hashimoto & Fukuhara, 2004; Johnson, 1997), self-esteem (Radecki & Jaccard, 1995), a preference for involvement in health-related decision-making (Czaja et al., 2003; Davison et al., 2002), and self-efficacy (Brown, Ganesan, & Challagalla, 2001; Griffin et al., 1999; Johnson, 1997) are shown to contribute positively to information-seeking. Other individual's reactions are found to limit HISB, such as feelings of guilt (Dunne, 2002), fear of social stigma regarding certain types of information (Matthews et al., 2002), and concern that information will contribute to more worry and anxiety (Borgers et al., 1993; Case et al., 2005).

Contextual or situational factors emphasize the characteristics of the individuals' environment, source of information, and information-seeking context (Allen, 1996; Czaja et al., 2003; Dunne, 2002; Loiselle, 2001; Matthews et al., 2002). For example, an accessible information source might be more likely to be used than one perceived to be difficult to access (Gollop, 1997). Furthermore, trust in HCPs is shown to contribute to asking questions and seeking more information from HCPs (Borgers et al., 1993; Czaja et al., 2003). Individuals' social network and the informational support received from family and friends are also found to affect their HISB (Brashers et al., 2002; Czaja et al., 2003; Johnson, 1997; Loiselle, Lambert, & Cooke, 2006). Family members and partners' contribution to individuals' HISB appear dependent on whether the information needs coincide with those of their family members (Brashers et al., 2002; Loiselle et al., 2006). For example, if both family members and individuals desire information, family members are often found to aid individuals in their search (Brashers et al., 2002; Echlin & Rees, 202; Johnson, 1997; Loiselle et al., 2006). Conversely, a "mismatch" between individuals' HISB and those of their family members is shown to limit individuals' HISB. For example, individuals might seek as much information as possible and wish to share it with their partners, whereas partners might decide to avoid discussion on information-related issues; this pattern of communication might, in turn, lead individuals to refrain from seeking and/or disclosing further information (Brashers et al., 2002; Loiselle et al., 2006).

Findings from these studies particularly emphasize the importance of considering the *interaction* among personal (i.e., individual information preference) and situational factors (i.e., family members' HISB) in predicting individuals' HISB (Loiselle, 2001; Loiselle & Delvigne-Jean, 1998). In most studies reviewed, the influences of personal and contextual factors were analyzed independently, and the main effect of each variable on HISB was determined separately. An interactional approach ("person x context") focuses on the relation between personal and contextual factors and how these, together, determine HISB (Loiselle, 2001). Although few researchers have carried out interactional analyses, this approach is suggested as most promising to evaluate the predictive value of specific personal and contextual antecedents on individuals' HISB (Loiselle, 2001).

Outcomes of HISB

Several studies reviewed measured the influence of HISB on individuals' health-related outcomes. Commonly, outcomes or consequences of seeking information include: (a) cognitive outcomes, such as increased knowledge (Andreassen et al., 2005; Muha et al., 1998), informed decision-making (Davison et al., 2002; Muha et al., 1998; Warner & Procaccino, 2004), increased perception of control (Echlin & Rees, 2002), and coping (Edgar, Remmer, Rosberger, & Fournier, 2000); (b) behavioral outcomes, including discussing information obtained with HCPs (Andreassen et al., 2005; Czaja et al., 2003; Muha et al., 1998), increased self-care abilities and adherence to treatment (Gray et al., 2005), and change in health behavior (Shi et al., 2004; Szwajcer et al., 2005; Warner & Procaccino, 2004); (c) physical outcomes, such as increase physical quality of life (Ransom et al., 2005); and/or (d) affective outcomes, including decreased anxiety, fear, and distress (Brereton & Nolan, 2002; Huber & Cruz, 2000) and increased hope (Huber & Cruz, 2000) and empowerment (Gray et al., 2005).

Although outcomes of seeking information are generally reported as positive, in some instances information seekers experience negative outcomes (e.g., feeling overwhelmed, more worry) than information avoiders (Clark, 2005; Echlin & Rees, 2002; Feltwell & Rees, 2004; Garvin et al., 2003; Loiselle et al., 2003; Miller, 1995). It appears that when determining outcomes of individuals' HISB, the congruence between the information individuals wanted and what they obtained needs to be taken into consideration. In general, HISB outcomes are reported to be more positive when individuals sought or received the information desired (Butow et al., 1997; Garvin et al., 2003; Loiselle, 2001; Miller, 1995; Shiloh et al., 1998). For example, information seekers who obtain the information they want report less anxiety than those that do not, and information avoiders who obtain more information than they desire report more anxiety than information avoiders who do not receive voluminous amount of information (Garvin et al., 2003; Miller, 1995). Therefore, empirical studies emphasize that an *interactional analysis* of the person and the context is also most predictive not only for determining individuals' HISB but also its outcomes (Loiselle, 2001).

Conclusion and Implications

Findings of this concept analysis provide up-to-date conceptual and operational foundations for clinicians, researchers, and theorists interested in the concept. To our knowledge, this is one of the first articles exploring in such depth the concept of HISB. This analysis initially examined the definitions of and contexts related to HISB and the concept's boundaries and operationalizations. This section of the analysis was challenging primarily because of the large amount of literature available and lack of clear definitions and/or theoretical frameworks, and consensus on the meaning of HISB. It is apparent that the concept of HISB is used within many contexts, particularly in relation to illness-related coping, and has great appeal to multiple disciplines. Together, researchers have attempted to understand, explain, or predict individuals' quests for health-related information, with an underlying assumption that seeking information is often desirable and central to health and illness behaviors. In addition, insights into whether HISB is a trait (i.e., a relatively stable characteristic) or a state (i.e., according to the particular circumstance) has been provided, which, in turn, is important to consider when measuring HISB.

In the second part of the analysis, we focused on clarifying and offering additional insights into the concept's key components, including its antecedents, characteristics, and outcomes. Although HISB has received considerable attention in the literature, there has been less focus on examining the concept's key dimensions. Identification of the two main dimensions of HISB (information and method dimension) clarifies the core meaning of the concept. Using these key dimensions affords a more thorough identification and discussion of individuals' actual HISB. The degree to which emphasis has been put on each dimension of HISB varies among authors. Most researchers have examined either dimension of HISB, but rarely have they attended to both despite suggestions that HISB is best understood as a composite of information and method-related behaviors (Lenz, 1984). Therefore, a more comprehensive understanding of HISB might lie in examining individuals' patterns of HISB, that is, the particular ways in which individuals sequence components of the information and method dimensions within a given situation (and over time) to satisfy their information needs (Dunne, 2002; Echlin & Rees, 2002; Huber & Cruz, 2000; Szwajcer et al., 2005). Patterns of HISB reflect individuals' selectivity in the type and amount of information needed and sources and actions used, and best capture the uniqueness of each individual search for information. As such, HISB might best be reconceptualized from an either/or single behavior to an agglomeration of information and method behaviors. Such a re-conceptualization further challenges traditional operationalization of HISB as categorically seekers or avoiders (Loiselle, Lambert, & Dubois, 2006). General definitions of seekers and avoiders focus on whether the information is sought or not, with little consideration of the individual's overall information environment. Typical categorizations of seekers or avoiders do not optimally capture differential patterns of HISB and might contribute to the misclassification of individuals' HISB. For example, if a pregnant woman does not want to be told the sex of her fetus as it might appear on the ultrasound but might be opened to "folk" tales about how to tell whether the fetus is a girl or a boy (Loiselle et al., 2006); how should this HISB be categorized?

Findings from this concept analysis can be used to theorize on HISB. Particularly, a fine-grained analysis of HISB requires attention to individuals' patterns of HISB, its situational and personal antecedents, and their interaction effects. Some of the following questions could be considered: What differentiates individuals' patterns of HISB? How do patterns of HISB vary across context and time? What are the consequences of different patterns? Such analysis would further document individuals' selectivity and variability when seeking information and can be integrated into current models to explain HISB beyond the mere seeker-versus-avoider dichotomy. In addition, much of the research on HISB centers on illnesses, such as cancer, HIV, and heart disease, there is a need to also understand patterns of HISB in a variety of other contexts and in various stages of health and illness. How patterns of HISB differ in different groups, such as across cultures and within different age groups, also needs to be explored further. All of these questions indicate further areas in which to develop and clarify the concept of HISB and demonstrate the need to collect new data using qualitative methods. We have recently undertaken a qualitative study to explore further patterns of HISB among individuals diagnosed with breast, prostate, or colorectal cancer (Lambert & Loiselle, 2005). This exploration is contributing to a better understanding of the complexities and subtleties of HISB. Qualitative studies may also lay the groundwork for the development of a tool that measures the different patterns of HISB, such as the Differential Health Information-Seeking Behavior scale (Figure 2) (Loiselle, 2002; Loiselle & Lambert, 2008).

HISB is of interest to health professionals because of its potential influence on the process and outcome related to psychosocial adjustment to illness. In addition, the concept of HISB as presented herein might be most relevant to practice as key dimensions are clearly outlined; making its assessment more accessible and comprehensive. Such a clear and precise definition of HISB will also assist researchers and clinicians in tailoring their informational interventions to individuals' needs and preferences.

CHAPTER 3 DATA COLLECTION METHODS

Preface

This chapter includes the second manuscript recently published in the *Journal of Advanced Nursing* (Appendix E). This paper critically reflects on the process and outcomes of combining the two qualitative data collection methods used in this study: individual interviews and focus groups. Initially, we conducted focus groups and individual interviews for pragmatic reasons and with the implicit assumption that similar data would emerge from each methods. Simply, participants who refused or were unable to participate in a focus group were invited to take part in an individual interview. However, as data collection and analysis occurred, we noted that different types of data were collected according to methods and their combination seemed to contribute more to the analysis of HISB than initially anticipated. A search of the literature revealed that no published paper addressed this issue. This called for a meticulous examination of the type of data obtained by each data collection method and consideration of how the combination of methods enhanced the understanding of the emerging HISB patterns.

Many methodological papers tackle the combination of quantitative and qualitative data collection methods, including its challenges, benefits, and practicalities (Morse, 2003; Sandelowski, 2000). However, few researchers explore the implications of combining qualitative data collection methods. The disproportionate attention given to combining qualitative-quantitative methods versus qualitative-qualitative methods may be attributable to a perception that combining methods within a research paradigm is less paradoxical than integrating methods across research paradigms (Barbour, 1998). This second paper addresses this gap in the literature and considers the implications of combining individual interviews and focus groups for this study.

Manuscript #2

Combining Individual Interviews and Focus Groups to Enhance Data Richness

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Abstract

Aim: This paper is a presentation of the critical reflection on the types of findings obtained from the combination of individual interviews and focus groups, and how such triangulation contributes to knowledge production and synthesis. **Background**: Increasingly, qualitative method triangulation is advocated as a strategy to achieve more comprehensive understandings of phenomena. Although ontological and epistemological issues pertaining to triangulation are a topic of debate, more practical discussions are needed on its potential contributions, such as enhanced data richness and depth of inquiry. **Method:** Data gathered through individual interviews and focus groups from a study on patterns of cancer information-seeking behavior are used to exemplify the added-value but also the challenges of relying on methods combination. **Findings:** The integration of focus group and individual interview data made three main contributions: a productive iterative process whereby an initial model of the phenomenon guided the exploration of individual accounts and successive individual data further enriched the conceptualization of the phenomenon; identification of the individual and contextual circumstances surrounding the phenomenon, which added to the interpretation of the structure of the phenomenon; and convergence of the central characteristics of the phenomenon across focus groups and individual interviews, which enhanced trustworthiness of findings. **Conclusion:** Although the use of triangulation is promising, more work is needed to identify the added-value or various outcomes pertaining to method combination and data integration.

Introduction

The purpose of this paper is to discuss the implications of combining qualitative methods within a single study. In the nursing literature, the combination of multiple methods to study the same phenomenon is most often designated as triangulation (Loiselle, Profetto-McGrath, Polit, & Beck, 2007). Although, the triangulation of qualitative methods continues to be advocated as a strategy to increase understanding of a phenomenon, little attention is given to the types of data each method provides and the impact of subsequent data combination on knowledge generation. Failure to recognize the implications of combining methods can lead to research resource misuse and methodological chaos (Morse, 1999).

Recently we conducted individual interviews and focus groups to explore people's patterns of information-seeking behavior (ISB) in cancer (Lambert & Loiselle, 2005). During the initial analysis, we began to reflect critically on the use of these methods separately and in combination. In this paper we present the outcomes of this reflexive analysis to further stimulate discourse on the use of these methods and their contribution to knowledge acquisition. The discussion moves beyond the nature of knowledge generated to include pragmatic issues of method triangulation. It is based on an epistemological position that underscores the importance of various types of knowledge to obtain a comprehensive understanding of complex nursing phenomena.

Background

Individual Interviews as a Data Collection Method

Individual interviews are the most widely-used data collection strategy in qualitative research (Nunkoosing, 2005; Sandelowski, 2002). Researchers typically choose individual interviews to collect detailed accounts of participants' thoughts, attitudes, beliefs, and knowledge pertaining to a given phenomenon (Fielding, 1994; Loiselle et al., 2007; Speziale & Carpenter, 2003). This approach assumes that if questions are formulated correctly, participants' expressions of their experiences will reflect their reality (Macdonald, 2006; Morse, 2000; Sandelowski, 2002). There is also the presupposition that participants will be able to formulate answers to the questions (Macdonald, 2006).

Although assumed to be a 'generic' data collection method, individual interviews come in a variety of forms (e.g., structured, semi-structured) (Bernard, 2002). Each interviewing approach assumes a philosophical orientation and may be more or less appropriate according to context and the qualitative methodology retained (Fielding, 1994). For instance, grounded theory's underlying philosophical assumption (i.e., symbolic interactionism) implies reliance on semi-structured rather than structured interviews (Duffy, Ferguson, & Watson, 2004; Fielding, 1994). Ethnographic studies, on the other hand, use informal interviews (Macdonald, 2006).

Although individual interviews contribute in-depth data, the assumption that words are accurate indicators of participants' inner experiences may be problematic. Interviewees may choose to withhold certain descriptions—or alternatively, embellish them—particularly if the 'truth' is inconsistent with their preferred self-image or if they wish to impress the interviewer (Fielding, 1994). Such considerations raise the issue of whether interviewee-interviewer characteristics (e.g., demographics) should, at times, be matched (Fielding, 1994). Also, although interviewers may wish to adopt a rather neutral role, they may inadvertently demonstrate a preference for a particular perspective and, in the process, bias the findings.

Focus Groups as a Data Collection Method

Focus groups are used by researchers worldwide to explore a range of phenomena (e.g., Brajtman 2005; Oluwatosin, 2005; van Teijlingen & Pitchforth, 2006). The primary goal of this method is to use *interaction data* resulting from discussion among participants (e.g., questioning one another, commenting on each others' experiences) to increase the depth of the inquiry and unveil aspects of the phenomenon assumed to be otherwise less accessible (Duggleby, 2005; van Eik & Baum, 2003; Freeman, O'Dell, & Meola, 2001). Group interactions may accentuate members' similarities and differences and give rich information about the range of perspectives and experiences. However, regrettably, more often they are used as an 'inexpensive' substitute for individual interviews (Barbour, 2005; Hollander, 2004), and group transcripts are analyzed for the content of 'individual' discussion (Hydén & Bütow, 2003). Increased attention to interaction analysis and the unique insights obtained about the phenomenon in this process are critical to reach the full potential of this method (Freeman, 2006).

Focus group data are the product of context-dependent group interactions (Duggleby, 2005; Hollander, 2004; Lehoux, Blake, & Daudelin, 2006). Hollander (2004) discusses four types of social contexts that may be created within a group and influence members' interactions (type and amount): (a) associational context (i.e., a common characteristic that brings the participants together); (b) status context (i.e., positions of participants in local or societal status hierarchies); (c) conversational context (i.e., flow of the discussion and types of discussion within the group); and (d) relational context (i.e., degree of prior acquaintance with participants). According to the contexts created within a particular group, participants may or may not disclose certain information (Hollander, 2004; Kidd & Parshall, 2000). If focus groups are seen as a 'social space' where participants construct their experiences based on how the discussion evolves and how participants interact, then an additional layer of data may be obtained (Lehoux et al., 2006). Stevens (1996) suggests a series of analytical questions to identify the nature of group interactions. These include: "How closely did the group adhere to the issues presented for discussion? Why, how, and when were related issues brought up? What statements seemed to evoke conflict?" (p. 172). Similarly, Lehoux et al. (2006) propose an analytical template to understand group interactions and ask, for instance: To what extent do the interactions among participants represent broader social contexts (e.g., age, gender)? How do dominant participants affect the contribution of other participants? How do participants respond to passive participants? Also, Hydén and Bütow (2003) suggest conducting an interaction analysis by examining whether an individual is interacting as a member of the group or as an individual in a group context and how these interactions may shift throughout the session. Therefore, rather than labeling certain interactions among participants as group consensus, a finer-grained analysis might reveal important aspects of the phenomenon of interest (Lehoux et al., 2006; Stevens, 1996).

Integrating Focus Group and Individual Interview Data

Although attention is increasingly placed on the combination of quantitative and qualitative methods, fewer authors (Barbour, 1998; Morse, 1999) have explicitly addressed the implications of combining qualitative data collection methods. The disproportionate number of methodological papers addressing qualitative-quantitative triangulation versus qualitative-qualitative triangulation may be due to a misperception that combining methods within the same research paradigm is less paradoxical than integrating methods across paradigms (Barbour, 1998). However, researchers also need to be explicit about the reasons for combining qualitative methods, as these can involve potentially divergent epistemological assumptions (Barbour, 1998) and an *ad hoc* combination of methods may threaten the trustworthiness of findings (Morse, 2003).

A search of the CINAHL database (1984-2007) using the keywords 'focus group' and 'individual interview' reveals that many researchers favor the combination of these methods. Although focus groups and individual interviews are independent data collection methods; their combination can be advantageous to researchers as complementary views of the phenomenon may be generated. A reading of nursing studies reveals three broad rationales for this combination: (a) pragmatic reasons, (b) the need to compare and contrast participants' perspectives (parallel use), and (c) striving toward data completeness and/or confirmation (integrated use).

Some researchers combine both methods for practical or pragmatic considerations. For instance, individual interviews may be offered to participants unable or unwilling to attend a focus group (e.g., Rees, Ford, et al. 2003; Taylor, 2005). This type of combination may lead to fewer refusals or withdrawals, as individuals can choose the method that is most convenient for them. However, each method's particular contribution to the understanding of the phenomenon is often not explicitly analyzed - similar, dissimilar or complementary data are not taken into account. Also, consideration should be given to whether individuals participating in one type of interview are any different in relation to the phenomenon of interest than those participating in the other method.

Others use focus groups and individual interviews in parallel to explore the phenomenon of interest. Each method is used with a different group of participants, and the data from one method do not influence the implementation of the other. For example, if the aim of a study is to evaluate the process and outcomes of a health education programme, focus groups may be used with nurses who implemented the programme and the programme participants may be interviewed individually (e.g., Leung, Ho, Foong, Ho, Lee, & Mak, 2005). Although data source triangulation may provide different views about the same phenomenon and contribute to the credibility of the findings (Loiselle et al., 2007), the rationale for selecting a particular method for a sub-group of participants is often not explicit. For instance, why is a sub-group of participants interviewed individually and not invited to take part in a focus group (or vice versa)? In addition, it may be challenging to determine if disparate views are expressed because different sources of data are used or because different methods are implemented.

Individual interviews and focus groups also may be combined for the purposes of data completeness and/or confirmation (Adami, 2005; Halcomb & Andrew, 2005). When seeking data completeness, it is assumed that each method reveals different parts of the phenomenon of interest (complementary views) and contributes to a more comprehensive understanding (expanding the breadth and/or depth of the findings). For example, individual interviews may be used to explore personal experiences, whereas focus groups may be used to examine opinions and beliefs about the phenomenon (Molzahn, Starzomski, McDonald, & O'Loughlin, 2005). Sandelowski (1995) argues that triangulation with the intention of completeness in fact defies the original metaphor of a triangle. The term 'triangulation' should be reserved for when methods are combined for the purpose of confirmation. Rather, the metaphor of a 'crystal' better represents the integration of a phenomenon's multiple dimensions. A crystal is three-dimensional, changes and has multiple facets and angles, whereas a triangle is two-dimensional, fixed, and rigid (Sandelowski, 1995; Tobin & Begley, 2004).

When authors combine individual interviews and focus groups for confirmation, the data obtained by one method are anticipated to corroborate those acquired with the other.

Some authors first obtain individual interview data and then carry out focus groups to confirm the findings (e.g., Plack, 2006). Alternatively, others initially implement focus groups and later verify these findings with individual interview data (e.g., Dick & Frazier, 2006). However, combining methods for confirmatory purposes may inadvertently lead to an erroneous hierarchy of evidence, where one data collection method is judged to yield more 'accurate' findings than the other (Barbour, 1998). Also, combination for confirmation assumes that there is a "reality on which it is possible to converge" (Sandelowski, 1995, p. 572), an assumption that is typically challenged within the qualitative paradigm.

Overall, when integrating focus group and individual interview data, the trustworthiness of the findings may be threatened if each method's particular methodological underpinnings are overlooked and the data sets are assumed to be equivalent (Barbour, 1998; Tobin & Begley, 2004). To increase the rigour of method combination, consideration should be given to the correspondence of the study aims with the data collection methods, the rationale underpinning the combination of methods, and the epistemological assumptions of each method and their compatibility. Also, authors need to specify the relative weight of each data set (e.g., hierarchical, equal value) and identify the particular insights into the phenomenon obtained from each method and the added-value of the combination.

The Study

Aim

We undertook a grounded theory study (Lambert & Loiselle, 2005) to explore the ISB patterns of individuals diagnosed with breast, prostate, or colorectal cancer.

Method

Consistent with grounded theory methodology, we conducted semi-structured interviews and focus groups. Participants were recruited from two ambulatory oncology clinics of a university-affiliated public teaching hospital in Montreal, Canada. All individual interviews were conducted between November, 2005 and September, 2007 and lasted from 20 minutes to 2.5 hours. Individual interviews (n=31) and focus groups (n total=31) were not conducted in a predetermined sequence. That is, some interviews were conducted prior to focus groups, others took place iteratively with focus groups, and approximately half of the interviews were conducted after the focus groups. Eight focus groups were conducted from January to June 2006: four with women diagnosed with breast cancer, two with men diagnosed with prostate cancer, one with men diagnosed with colorectal cancer, and one with men and women diagnosed with colorectal cancer. A moderator (the first author) and a co-moderator were present for each focus group. The focus groups lasted for 1.5 to 2.5 hours. Informed by our previous work on ISB (Lambert & Loiselle, 2007; Loiselle, 1995; Loiselle et al., 2006), a semi-structured interview guide was developed for use with both focus groups and individual interviews. The questions explored different aspects of ISB, including the motivation to seek cancer-related information and the type of information sought. All interviews were tape-recorded with participants' permission and transcribed verbatim. Ethics approval was obtained from the university and hospital ethics review boards. All the participants in the study signed an informed consent (Appendix B).

Methodological Observations

Initially, we combined individual interviews and focus groups for pragmatic reasons. Simply, participants who refused or were unable to participate in a focus group were invited to take part in individual interviews. However, as we proceeded with data analysis we noted that different types of data were collected according to the method, and their combination contributed to a more nuanced understanding of the phenomenon than initially anticipated. The focus then became to investigate how the combination of methods enhances our understanding of ISB patterns. In this particular context, data triangulation led to: (a) A productive iterative process whereby an initial model of the phenomenon guided the exploration of individual accounts and successive individual data further enriched the conceptualization of the phenomenon; (b) Identification of the individual and contextual circumstances surrounding the phenomenon, which added to the interpretation of the structure of the phenomenon; and (c) Convergence of the central characteristics of the phenomenon across focus groups and individual interviews, which enhanced the trustworthiness of findings.

Iterative Process Guiding the Exploration of the Phenomenon

When comparing the transcripts from the focus groups and individual interviews, two levels of understandings of the phenomenon were noted. The focus group data reflected a general understanding of the range of ISB patterns and contributed to developing an initial model of the phenomenon. This model was subsequently used to guide the exploration of the phenomena as the study progressed. The individual interviews supplied detailed descriptions of how individuals proceeded through a particular ISB pattern, and further enriched the initial conceptualization of the phenomenon. Thus, the separate data sets were mutually informative.

At the outset of the study, we assumed that participants would describe variability in information-seeking. However, we did not know how many ISB patterns would emerge. The second or third focus group led to the formulation of a general model pertaining to

ISB pattern and substantiated the claim that ‘differential ISB patterns’ were present within this group. In fact, this initial model contained most of the patterns that emerged throughout the study. Many follow-up individual interviews were required before a similar range of ISB patterns was identified. During individual interviews, the interviewer used this model as a guide by considering whether and how an individual ISB pattern was embedded in the overall model or context of ‘differential ISB patterns’. In this way, individual patterns were not explored in isolation.

Focus group findings helped to determine the most pertinent questions to be further explored during an individual interview. For instance, choosing the ‘best’ treatment was identified in the first few focus groups as a key motivation to pursue information-seeking intensely. According to the pattern identified in an individual interview, this motivation was more or less explored - the interviewer pursued in-depth exploration of this motivation only if pertinent for the pattern described. By concentrating only on the relevant aspects of a pattern, the interviewer optimized the time spent in the interviews. The data from the individuals were found to be particularly important when fine-tuning the descriptions of a pattern. They allowed us to zero-in on a particular ISB pattern and further differentiate it from others. From the general model of ISB patterns, we were able to move back and forth between individual and group data, putting forward hypotheses about the phenomenon that were further explored through either individual interviews or focus groups.

Interactions among focus group participants were key in developing the initial model of the phenomenon. As the focus group discussions progressed, participants were more likely to associate with members of the group sharing similar ISB, while differentiating from those who described disparate approaches to information-seeking. Also, we found that some types of interactions were more likely to occur among individuals sharing the same approach to information-seeking, while other interactions occurred among individuals thought to be different. Thus, considering the specific types of interactions among participants served to further delineate ISB patterns. The types of interactions identified across the focus groups included: validating or challenging interactions (e.g., argumentation, agreement), clarifying interactions (e.g., asking others to explain their opinion), criticizing interactions (e.g., lack of informational support), contrasting interactions (e.g., comparing experiences with cancer information), supporting interactions (e.g., commendation), venting interactions (e.g., expression of frustration), and information exchanging interactions (e.g., seeking/giving advice). Table 2 gives an example of a challenging/clarifying interaction among women with breast cancer and underscores the importance of interaction analysis. Here, participant FG7-03 was most pro-active in seeking information about cancer. Both FG7-01 and FG7-02 showed a middle-ground approach to information-seeking, whereas FG7-04 sought information the least in comparison to the other group members.

Context as Adding Further Structure to the Phenomenon

Combining individual interview and focus group data also contributes to an enhanced understanding of the structure of the phenomenon. Structure is defined within the context of grounded theory analysis as "the circumstances in which problems, issues, happenings, or events pertaining to a phenomenon are situated or arise" (Strauss & Corbin, 1998, p. 127). Although within both data sets similar antecedents to a pattern of ISB were identified, the extent to which these factors were delineated or interpreted by participants differed. An individual account typically offered a concrete perspective or narration of the antecedents that motivated a pattern - participants clearly described how they proceeded through a set of circumstances contributing to information-seeking. Although during focus groups similar antecedents were mentioned, these were not necessarily described with the same level of detail. Rather, the animated discussions among group members exposed the contextual dimension of the antecedents and provided a wider-angled lens to interpret individual-level data. For example, across methods, treatment-related decision-making was identified as an important antecedent to seeking cancer information. The analysis of individual data showed how participants might have proceeded through the decision-making process (procedural description) and how this was related to cancer information-seeking. Focus group discussions did not emphasize the actual process of decision-making, but rather broad contextual factors that might have been involved (e.g., physicians' preferences for patient involvement). Table 3 provides a concrete example of the discussion that occurred in the focus groups about decision-making. Here, participant FG6-03 sought intense information as the oncologist did not give clear indications as to the best treatment, whereas participant FG6-02 did not experience the same context of care and was identified as describing an intermediary approach to information-seeking. FG6-03 did not give an actual description of her decision-making process, however much information was obtained about the context of care that 'obliged' her to participate in decision-making and why these factors were not as relevant for FG6-02. Overall, this interaction further contributed to a contextualized description of the process of decision-making.

Characteristics of the Phenomenon Further Delineated Across Focus Groups and Individual Accounts

Analysis of the focus group data led to the identification of a model for the phenomenon, which was substantiated by individual interview data. However, as the essential characteristics of the various ISB patterns were compared across data sets, some discrepancies arose. This instigated further analysis of the process to elucidate the nature of each ISB pattern. Particularly, certain characteristics were prominently identified from the individual interview data and not mentioned or elaborated upon by participants of the focus groups who were thought to share the same pattern. The focus group findings seemingly provided a 'partial' picture of each pattern when compared to what appeared to be the pattern's equivalent description obtained from individual interviews. It was unclear how these discrepancies should be interpreted and whether similar patterns were in fact captured by each method. Such considerations were particularly important when determining how many patterns were described by the participants and whether certain descriptions should be collapsed into the same pattern.

Apparent variations in meaning were better understood when we further attended to the process by which the patterns' descriptions emerged according to each method. The individual interview context allowed most questions included in the interview guide to be systematically explored. That is, each dimension of the concept that the interviewer hoped to address was explored. Obviously, focus groups did not allow the exploration of all questions included in the interview guide. Rather, focus group participants spontaneously discussed dimensions of the concepts relevant to the group conversation and according to the specific type of ISB patterns discussed; the group progressively co-constructed the various components and meaning of the phenomenon. Each focus group elucidated particular characteristics of a pattern and discussed 'a' version of the phenomenon as relevant in that group context. As a result, a characteristic of a pattern might or might not have been discussed by all members of a group or might not even have been raised by a particular group. Therefore, it was not optimal to initially consider participants' group conversations separately – assuming that interview questions had been explored - and compare these with individual interview data. However, when all focus group data were taken together and summarized, we did obtain a more 'complete' picture of each pattern as discussed across groups. When this alternate approach to analysis was adopted, most pattern characteristics were corroborated across methods and data convergence became appropriate as a mean to increase the trustworthiness of findings.

Discussion

The main challenge addressed in this paper pertains to the optimal integration of individual interview and focus group data. In the examples given, side-by-side and non-hierarchical comparisons of the data sets revealed overlapping and rich complementary findings that contributed to a coherent and more nuanced understanding of ISB patterns.

Morse (1999, 2002) emphasizes that the qualitative 'tool box' offers multiple methods to choose from to enhance the exploration of complex phenomenon, and she advocates for the competent use of multiple qualitative methods within a single study and within a programme of research. Researchers are encouraged to use multiple qualitative methods to enhance the analysis of a phenomenon and to broaden its conceptualization (Morse, 1999, 2002). However, the unskillful mixing and matching of methods may threaten the trustworthiness of findings (Barbour, 1998; Morse, 1999; Tobin & Begley, 2004). Although authors may contend that multiple methods were used to obtain a more in-depth understanding of the phenomenon, the essence of that enhanced understanding is rarely explicitly presented. Hence, the practical discussion about the added-value of the integration of multiple qualitative methods presented in this paper is timely.

Even if few papers explicitly elaborate on the combination of qualitative methods, there are many papers in the nursing literature discussing the epistemological and methodological benefits and potential drawbacks of triangulation (e.g., Breitmayer, Ayres, & Knafl, 1993; Sandelowski, 1995; Tobin & Begley, 2004). These are useful to guide a reflection on approaches to method combination and to avoid common methodological mistakes. For instance, we avoided claiming that one method might be better at uncovering the essence of the phenomenon, that convergent findings supported the validity of methods used, or that the 'strengths' of one method offset the weaknesses of the other (Massey, 1999). Although we do not claim that triangulation may be used as a form of validity, we acknowledge that the data may be similar, different or complementary, and that the combination of methods is useful to understand the different representations of the phenomenon. Findings from this study were integrated into a workable model to account for diverse ISB patterns, such that similar or complementary findings increased our level of confidence in some of the concepts and areas of disagreement were further interpreted.

In research environments where resources are increasingly scarce, researchers need to be explicit about the added benefits of investing resources in the use of multiple data collection methods within a single study. In our study, the integration of data sets led to an iterative process of data collection and analysis and enhanced understanding of the structure and essential characteristics of the phenomenon within the context of cancer. Moezzi (2007) also found that focus groups were particularly useful at cataloguing the range of participants' experiences and that individual interviews contributed to a detailing of these experiences. In addition, we note that for this type of combination to be fruitful, attention must be given to the nature and context of focus groups that are more productive (e.g., that facilitate and enhance interactions among participants and that create a context encouraging the sharing of similar or differing views). Moreover, individual interviews should build on the information gathered through focus groups. Hall and Rist (1999) did not find their focus groups to be particularly useful in answering the research questions and, therefore, additional qualitative methods were used. However, the authors acknowledged some limitations in the implementation of the focus groups (e.g., type of participants, timing) which may have contributed to their unproductiveness.

Sands and Roer-Strier (2006) identify five types of data obtained in their study through data triangulation (i.e., different data sources): (a) same story, same meaning (when similar interpretations of the phenomenon are provided); (b) same story, different interpretations (when similar answer to questions are provided but a different meaning to the phenomenon is ascribed); (c) missing pieces (when information is provided by one participant but not another) ; (d) unique information (when some information is only reported by one participant); and (e) illuminating (when data are different but not contradictory). Although the focus of Sands and Roer-Strier (2006) is on data triangulation and not on method triangulation, we have documented similar findings. For instance, our discussion about the different levels of interpretations of the phenomenon (individual versus contextual) bears some resemblance to what Sands and Roer-Strier (2006) describe as 'same story, different interpretations' or 'illuminating'. In addition, Pamphilon (1999) contributes The Zoom Model, which can be applied to the combination of methods discussed in this paper. The Zoom Model underscores that three levels of meaning may be found in participants' narrations of a phenomenon: macro-zoom (corresponding to the socio-historical dimension, collective meanings), meso-zoom (reflecting personal level of values), and micro-zoom (which examines emotions and characteristics of voice). The combination of these three levels of meaning reveals the complexity of the phenomenon better than any one level of meaning alone (Pamphilon, 1999). These types of data were also identified in our study across methods. For instance, the focus groups were particularly useful at uncovering macro-level data. In combination with the findings presented in this paper, the findings of Sands and Roer-Strier (2006) and the model by Pamphilon (1999) are helpful tools to guide the identification and categorization of the different data obtained through each method and their combination.

Vandermause (2007) raises challenges, comparable to those identified in this paper, to consider when using multiple methods, including identification of a method fitting the question and the intended study outcome(s) and the combination of methods while maintaining methodological rigour. Furthermore, Vandermause (2007) emphasizes that the complexity of healthcare phenomena calls for innovative combinations of qualitative methods that include multidisciplinary – different methods implemented by researchers from several disciplines – and multi-media research – integrating, for instance, poetic interpretation with theatrical or photographic interpretation. This type of research raises additional challenges, including the coordination of a process that permits different researchers to work together effectively and to arrive at a consensus for data interpretation (Vandermause, 2007). Hence, methodological discussion providing guidelines for the rigorous combination of qualitative methods is needed to further address such complex, yet increasingly common, research designs.

Conclusion

Future discussion about method triangulation may be most productive when efforts are directed towards the identification of the various types of knowledge obtained (Foss & Ellefsen, 2002; Jones & Bugge, 2006). Future studies could benefit from the development of a matrix of findings that would identify the data obtained by each method across themes and categories. The visual depiction of a matrix can assist researchers in systematically comparing the data sets, thereby enhancing the identification of the various levels of data and their mutual contribution to an enhanced understanding of the phenomenon (Averil, 2002; Farmer, Robinson, Elliott, & Eyles, 2006).

CHAPTER 4 GROUNDED THEORY STUDY AND FINDINGS

Preface

This chapter includes the third and fourth manuscripts recently accepted in *Cancer Nursing* (see Appendix F for confirmation of acceptance). The findings of this study are presented in the form of two manuscripts: Part 1 discusses the active information-seeking patterns that emerged from this grounded theory study and Part 2 presents the patterns of cancer information disinterest and avoidance. The methodology of the study is summarized mainly in Part 1, however given page limitations for publication, further information is presented below. First, a justification for choosing grounded theory methodology is offered. Second, a discussion about sampling and determining sample size is presented. Third, the approach to data analysis is detailed.

Rational for Methodology

Qualitative methods are most appropriate to obtain intricate details about a phenomenon such as thought processes and emotions that may be difficult to identify through more conventional quantitative research methods like standardized questionnaires (Speziale & Carpenter, 2003; Strauss & Corbin, 1998). This study was designed with the intent to learn more about individuals' cancer HISB, identify variations in HISB across participants or HISB patterns, describe the characteristics of emerging HISB patterns, and identify the circumstances surrounding a particular HISB pattern. Much of the literature on cancer information-seeking is derived from quantitative studies (Lambert & Loiselle, 2007). Whilst these studies certainly contribute to an understanding of the antecedents, correlates, and outcomes of information-seeking (or avoidance), the structure of most questionnaires used to assess HISB in such research presupposes that individuals either intensely seek information or avoid it and limit the possibility of exploring variability in information-seeking. For instance, one of the most popular questionnaires used to measure HISB in the cancer literature is the Miller Behavioral Style Scale (MBSS) (Miller, 1987; Rees & Bath, 2000). The MBSS is a 30-item self-administered questionnaire designed to identify preferences for monitoring (or information-seeking) versus blunting (or information avoidance). The MBSS consists of four hypothetical stress-evoking scenarios: a dentist appointment, being held hostage by a group of armed terrorists, losing a job, and being in an airplane that makes a deep dive and levels off. Each scenario is followed by eight statements that represent different ways of dealing with the situation. Four of the statements describe monitoring (e.g., "I would carefully read the information provided about safety features in the plane") and four describe blunting (e.g., "I would watch the in-flight film even if I had seen it before"). Such a dichotomous conceptualization of information-seeking (i.e., monitoring versus blunting) has been argued to be inappropriate, as it does not take into account possible variations in information-seeking (Lambert & Loiselle, 2007). Provided this limitation, qualitative research methods were thought to be most appropriate to further explore and document variations in HISB. The particular emphasis of this study on explaining why, how, where, when, and under what conditions people engage in certain HISB (and not others) and wanting to integrate the identified HISB patterns into a framework pointed to grounded theory, as described by Strauss & Corbin (1998; Corbin & Strauss, 2008), as the most appropriate qualitative research approach.

Grounded Theory Origins and Characteristics

Grounded theory was developed in the early 1960s by two sociologists Barney Glaser and Anselm Strauss. Since the publication of their seminal work: *The Discovery of Grounded Theory* (1967), the methodology has gained popularity across several disciplines, including nursing (Benoliel, 1996; Bryant & Charmaz, 2007; Glaser, 1999; Woods, 2003). Grounded theory refers to a specific research methodology and guiding procedures to systematically develop a theory based on the data collected (Glaser, 1999). At the time, grounded theory was revolutionary because it offered an alternative to the traditional logico-deductive, hypothesis-driven approach to theorizing (Walker & Myrick, 2006). One main assumption of grounded theory is that "theory derived from data is more likely to resemble the 'reality' than is theory derived by putting together a series of concepts based on experience or solely through speculation" (Strauss & Corbin, 1998, p. 12). Hence, grounded theory presupposes that knowledge is generated by developing new theories rather than analyzing data within existing ones (Bryant & Charmaz, 2007; Heath & Cowley, 2004). The basic research process in grounded theory includes: gathering data, coding, comparing, categorizing, theoretical sampling, developing a core category, and generating a theory (Walker & Myrick, 2006). These components do not follow a linear trajectory, but rather occur concurrently or iteratively.

Grounded theory methodology is rooted in the theory of symbolic interactionism. Symbolic interactionism is concerned with the study of the inner or 'experiential' aspects of human behavior that is how people define events and how they act in relation to their beliefs (Chenitz & Swanson, 1986). Symbolic interactionism rests on three basic premises: (a) that human beings act toward things (e.g., objects, other human beings, institutions, situations) on the basis of the meanings that the things have for them; (b) the meaning of such things is derived from, or arises out of, social interactions that a person has with others; and (c) the meanings are modified through an interpretive process used by the person in dealing with the things he/she encounters (Blumer, 1969). Symbolic interactionism emphasizes the significance of studying processes and developing conditional theories from empirical data to explain specific situations (Bryant & Charmaz, 2007). Symbolic interactionism contributions to the development of grounded theory were:

> 1) The need to get out into the field to discover what is really going on; 2) the relevance of theory, grounded in data, to the development of a discipline and as a basis for social action; 3) the complexity and variability of phenomena and of human action; 4) the belief that persons are actors who take an active role in responding to problematic situations; 5) the realization that persons act on the basis of meaning; 6) the understanding that meaning is defined and refined through interaction; 7) a sensitivity to the evolving and unfolding nature of events (process); and 8) an awareness of the interrelationships among conditions (structure), action (process), and consequences. (Strauss & Corbin, 1998, p. 10)

Glaser and Strauss (1967; Strauss & Corbin, 1998) proposed six main methodological principles to grounded theory: (a) theoretical sensitivity, (b) theoretical sampling, (c) constant comparative analysis, (d) coding and categorizing the data, (e) theoretical memos and diagrams, and (f) theorizing (Klunklin & Greenwood, 2006; McCann & Clark, 2003a, b). First, theoretical sensitivity relates to the ability to have insight, understand and give meaning to the data, and decipher what is relevant from the irrelevant (Strauss & Corbin, 1998). This quality of the researcher develops as "he or she works with data; making comparisons, asking questions, and collecting more data. Through these alternating processes of data collection and analysis, meanings that often are illusive at first become clearer" (Strauss & Corbin, 1998, p. 46). According to Strauss and Corbin (1998) it is our experiences and the literature that stimulate our thinking.

Second, theoretical sampling is a data collection method for generating theory based on the concepts that emerge from data analysis (Corbin & Strauss, 2008). The researcher concurrently collects, codes, and analyses the data and then decides what data should be collected next and where to find it to further develop the theory (Corbin & Strauss, 2008; Glaser & Strauss, 1967). The purpose of theoretical sampling is to "collect data from places, people, and events that will maximize opportunities to develop concepts in terms of their properties and dimensions, uncover variations, and identify relationships between concepts" (Corbin & Strauss, 2008, p. 143). Theoretical sampling is differentiated from other types of sampling approaches in that it is responsive to or based on the data and findings (categories and concepts emerge from data analysis and these subsequently guide sampling and additional data collection) (Corbin & Strauss, 2008). A grounded theory developed without theoretical sampling is thought to lack conceptual depth (McCann & Clark, 2003a, b).

Third, constant comparative analysis is the main data analysis method in grounded theory and emphasizes that data collection, analysis, and theory development occur concurrently (Jeon, 2004). This method of analysis is thought to contribute to theoretical sensitivity by stimulating thinking and teasing out similarities and differences among events, concepts, categories, and their properties. This approach to analysis involves comparing data with data, data with category, category with category, and category with concept (Bryant & Charmaz, 2007).

Next, the intent of coding in grounded theory is the conceptualization of the data by analyzing it and identifying patterns or events in the data (McCann & Clark, 2003a). As will be reviewed in the data analysis section of this chapter, according to Strauss & Corbin (1998) there are three steps or levels of coding in grounded theory: (a) open (line-by-line analysis), (b) axial (developing categories and relationships among them), and (c) selective (refinement of theory and identification of core category) coding. For a grounded theory to be integrated, dense, and saturated, during selective coding, a core variable should be identified (Strauss & Corbin, 1998). Strauss & Corbin (1998) identified six criteria for choosing the core category: (a) all other major categories can be related to it; (b) it must appear frequently in the data; (c) the explanation that evolves by relating the categories is logical and consistent; (d) the label attributed to the core category should be sufficiently abstract that it can be used to do research in other substantive areas; (e) as the core category is integrated with other categories, the theory grows in depth and explanatory power; and (f) the core category is able to explain variation as well as the main point made by the data.

Fifth, theoretical memos and diagrams are an integral part of the analytical process in grounded theory (Strauss & Corbin, 1998). Diagrams visually represent the conceptual relationship that develops among categories (Strauss & Corbin, 1998). Memos are notes that the researcher makes throughout the study to record and explain the theory as it develops (Strauss & Corbin, 1998). These are essential analytical tools for capturing ideas, documenting thought processes, and providing direction for theoretical sampling (Corbin & Strauss, 2008).

Last, the main purpose of grounded theory methodology is to systematically develop a middle-range theory from the data collected (Bryant & Charmaz, 2007). A grounded theory is defined as: "a set of well-developed categories [...] that are systematically interrelated through statements of relationship to form a theoretical framework that explains some relevant [...] phenomenon. The statements of relationship explain who, what, when, where, why, how, and with what consequences an event occurs" (Strauss & Corbin, 1998, p. 22). Grounded theorizing involves the interplay between induction (deriving concepts from the data) and deduction (hypothesizing about the relationships between concepts) (Strauss & Corbin, 1998). Glaser & Strauss (1967) identified two types of grounded theories: substantive (i.e., phenomenon studied in one particular situational context; focus on a specific area) and formal (i.e., more abstract level of theory; phenomenon examined under several types of situations) theories.

Glaser & Strauss (1967) versus Strauss & Corbin (1998)

In the late 1980s the founding fathers of grounded theory debated and disagreed about some of the methodology's fundamental philosophical and procedural aspects (Bryant & Charmaz, 2007). This debate has led to two main approaches to grounded theory: the classic version of Glaser and Strauss (1967) and the one by Strauss and Corbin (1998). In general, researchers are invited to view these as an indication that grounded theory is maturing and branching and should not be interpreted as one approach being superior to the other (Annells, 1996; Bryant & Charmaz, 2007). These two approaches to grounded theory do share the key procedural elements to grounded theory enumerated above and do not vary in so far as the general process undertaken, however differences are noted on how these processes are carried out (Annells, 1996; Walker & Myrick, 2006). Each approach to grounded theory reflects different ontological, epistemological, and methodological assumptions that must be considered if the methodology is to be implemented rigorously (Annells, 1996; Mills, Chapman, Bonner, & Francis, 2007; Walker & Myrick, 2006). An initial challenge for researchers undertaking a grounded theory analysis is to choose which version of the methodology is most appropriate for their study (Heath & Cowley, 2004). Table 4 summarizes the main features that differentiate Glaser and Strauss (1967) and Strauss and Corbin (1998) approaches to grounded theory. The differences between the two can be summarized as follows:

> Glaser's grounded theory comes from a 'purist' approach that relies on an 'open' attitude to the research enterprise where the researcher is professionally naïve: in this way, theory generation is not compromised by researchers' prejudices but emerges directly from the data. In contrast, Strauss and Corbin's grounded theory

> could be described as a 'pragmatic' approach with a more 'structured' attitude to theory building. It prescribes the use of a set of analytical tools and guiding principles. The researcher is encouraged to [...] apply existing insights and experience to the subject matter where appropriate. (Warburton, 2005, p. 5)

In this study, four main reasons influenced the decision to use Strauss and Corbin's (1998) grounded theory approach: (a) ontology and epistemology, (b) role of the literature, (c) manner in which the research problem is determined, and (d) structure to data collection and analysis. First, Strauss and Corbin's (1998) grounded theory reflects the contemporary shift towards social constructivist and was considered more appropriate than the critical realism ontology in classical grounded theory.

Second, Strauss and Corbin (1998) emphasizes that a preliminary review of the literature before commencing data collection enhances theoretical sensitivity and contributes to generating preliminary explanations. When embarking upon this study, I was already aware of the literature on information-seeking and had written the concept analysis presented in chapter 2.

Third, Glaser and Strauss (1967) claim that the researcher should enter the field with no preconceived ideas about what constitutes the research problem. Alternatively, Strauss and Corbin (1998) propose a more flexible approach to the identification of the research problem which was more in line with how the aim of this study was determined. The aim of this study was defined according to professional experiences, the literature, and suggestions and discussions with my supervisor.

Last, Strauss and Corbin (1998) suggest a more structured approach to data collection and analysis in comparison to Glaser and Strauss (1967) by proposing the Paradigm Model. For a novice researcher, this model offers guidelines to data collection and analysis, helps in the identification of links among categories, and assists in the development of the theory (McCann & Clark, 2003b). In this study, the Paradigm Model was used for its heuristic value and I was mindful of the risk of 'forcing the data' (Glaser, 1992).

Sampling

A convenience sample of men and women diagnosed with breast, prostate or colorectal cancer that had received, were receiving or were in the process of determining the course of treatment was recruited from the chemotherapy and radiotherapy clinics of the participating University-teaching hospital in Montreal, Quebec, Canada. The main inclusion criteria were: fluent in either English or French; interested in discussing their 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, theoretical sampling was undertaken by recruiting additional participants with potentially different experiences with HISB than those already recruited (e.g., different age, receiving novel treatment). For instance, at one point in data collection, age was raised as a potential factor influencing cancer information-seeking. At that time, mostly older individuals (> 55) had been recruited in to the study and in an effort to maximize the opportunity to compare situations and explore variations in HISB younger individuals (< 55) were recruited. Some of the factors guiding theoretical sampling were noted at recruitment through observation (e.g., approximate age), following brief conversations with participants (e.g., importance given to cancer information-seeking), through chart review (e.g., treatment modality), and conversations with members of the health care team (e.g., questions asked). The study sample is described in Part 1.

Determining Sample Size

Thirty semi-structured individual interviews and eight focus groups were conducted. Four focus groups were conducted with women with breast cancer, two with men with prostate cancer, one with men with colorectal cancer, and one with men and women with colorectal cancer. The number of focus groups carried out for each type of cancer diagnosis was determined by: the rate at which participants were recruited, participants' preference for one data collection method over the other, and participants' physical ability to partake in the focus groups. With regards to the recruitment rate, more women with breast cancer received treatment at the radiotherapy and chemotherapy clinics of the participating hospital than either men diagnosed with prostate cancer or men and women with colorectal cancer. In consequence, in any given recruitment period more women diagnosed with breast cancer were approached and accepted to participate in the study. It was challenging, in fact, to recruit the smaller number of patients with colorectal cancer and form focus groups. Most individuals diagnosed with colorectal cancer preferred an individual interview. Possible reasons for this preference include: the nature of symptoms experienced (e.g., diarrhoea, gas), the presence of a colostomy, and/or the social stigma associated with a diagnosis of colorectal cancer. Also, individuals with colorectal cancer were more likely to be unavailable for the focus groups due to post-recruitment surgery.

The final sample size was also determined by the redundancy in the data collected (i.e., data saturation). When no new information was generated from the analysis of the interviews and the focus groups, it was assumed that a reasonable exploration of HISB had been achieved and recruitment was stopped. For men with prostate cancer, the focus groups were larger and no new information was collected after the second group. In the second focus group with individuals with colorectal cancer, participants were mirroring what had been previously expressed by individuals diagnosed with breast or prostate cancer and it was estimated that an additional focus group was unnecessary.

Although redundancy began to occur at the 18th individual interview, interviews were conducted beyond this point, as some participants had been recruited and agreed to participate. It was also deemed beneficial to achieve an almost equal number of participants in each cancer diagnosis and it was hoped that several participants would describe the same HISB pattern (n for each pattern > 1 or 2).

Data Analysis

The goal of analysis was to identify patterns in the data and develop a conceptual explanation of HISB. The grounded theory procedures of open, axial, and selective coding, constant comparison, and extensive diagramming constituted the basis for the analysis. Figure 3 summarizes the steps to data analysis undertaken in this study. Data analysis was an ongoing process that began with the first interview and focus group and continued throughout the study. The three types of coding used resulted in increasing levels of interpretation and abstraction of the analysis. At the outset of this study, although I was aware of previous theorizing and empirical studies on HISB, I did not have preconceived ideas about how many HISB patterns might emerge or what would characterize these patterns. Instead, an attempt was made to remain as open as possible to exploring HISB with participants and let their descriptions guide the identification of the patterns.

Initially, a transcript was read once to gain a sense of the individual's experience with information-seeking. Transcripts were then analyzed using open coding. The participants' accounts of how they went about seeking (or not) information across the cancer trajectory constituted the units of analysis. Words, statements, and paragraphs that appeared to describe significant aspects of a participant's experience with cancer information were highlighted and written on the right hand side of the transcript. All highlighted passages were then compiled and assigned a code that described its main idea. Codes that expressed a similar idea were clustered together and given a more general label. These more general labels emerged as the main conceptual components of a HISB pattern. Labels used to describe the patterns and its dimensions were words primarily used by participants, however concepts derived from the literature were also used where relevant. Comparison of transcripts led to the identification of similarities and differences among participants' HISB. Following the comparative analysis of approximately 10 individual interviews and two focus groups, similarities began to emerge across some transcripts and these were grouped together. It was also readily apparent that participants differed mainly on the amount of information sought. This analysis led to the preliminary identification of at least three HISB patterns: intense, intermediary, and minimal information-seeking or avoidance.

Following open coding, a transcript was then analyzed in more depth using axial coding. Strauss and Corbin's (1998) paradigm model guided axial coding and the conceptualization of the HISB patterns along the following dimensions: (a) *conditions*: categories of conditions that influence the phenomenon or events that lead to the development of the phenomenon; answers to questions why, where, how come, and when; (b) *actions or interactions*: responses of individuals to issues, problems or events; answers to questions whom and how; and (c) *consequences*: the outcomes, both intended and unintended, of the actions; answers to question what happens. These conceptual dimensions were compared across experiences that seemed similar (and different) and, at this time, a conceptual model explaining the various patterns began to emerge. The relationships among the components of a pattern were initially worked through on large sheets of paper and then diagrams were elaborated using Microsoft Word. As additional data from the individual interviews and focus groups were collected, they were integrated into the descriptions of the patterns.

In the focus groups, individuals' description of their approach to cancer information-seeking was analyzed as mentioned above and integrated into the description of each pattern. Given recent methodological debates on the use of focus groups as a data collection strategy (van Eik & Baum, 2003) this study gave particular attention to analyzing focus group interaction data. Interactions among group members were identified using the questions proposed by Stevens (1996) and Lehoux et al. (2006). Example of analytical questions include: Why, how, and when were related issues brought up? What common experiences were expressed? Were alliances formed among group members? Was a particular member or viewpoint silenced? Who spoke first in the discussion? The answers to these questions were tabulated and further examined for their implication in understanding HISB.

Seven types of focus group interactions were identified: validating interactions (e.g., agreements), challenging interactions (e.g., argumentation, participants challenging each other's opinions), clarifying interactions (e.g., asking others to explain their opinion, expanding on a participant's comment), criticizing interactions (e.g., lack of informational support from health care professionals), contrasting interactions (e.g., comparing experiences with an information source), supportive interactions (e.g., commending others on their efforts, mutual support of issues in common), venting interactions (e.g., expression of frustration), and information exchange interactions (e.g., questioning, seeking/giving advice, citing of information sources).

Early on in the analysis it was noticed that some interactions were more likely to occur between/among individuals sharing the same approach to information-seeking, whereas other interactions occurred among individuals thought to be different. For instance, many challenging interactions were noted across HISB patterns and were oftentimes related to questioning members' motivations to seek or not cancer information. For this reason, the recognition of group interactions and their association with a particular HISB pattern was a unique strength of the focus groups and central to the identification of different HISB patterns.

The focus group was also a rich context for observing unprompted information-seeking among participants (e.g., asking questions to other members of the group about management of treatment side effects). The extent to which participants partook in these exchanges also seemed to be associated with their expressed HISB. For instance, those identified to describe intense information-seeking were more likely to initiate and entertain this type of interaction. Attention to who initiated what topic and the extent of members' participation in the discussion also revealed characteristics of their HISB. For instance, those seeking much cancer information were often involved in treatment decision-making.

At this stage in the analysis, the intermediary information-seeking pattern was further differentiated into two distinct patterns and minimal information-seeking and avoidance were identified as separate patterns. Thus a total of five patterns emerged: intense, complementary, fortuitous, minimal, and guarded information-seeking behavior. The labels were selected to qualify the HISB particular to a pattern using either the participants' own words or concepts in the literature.

As most of the emerging patterns were seemingly novel and had not been previously described, the remainder of the analysis (i.e., selective coding) focused on developing a detailed conceptual description of each one. Although grounded theory methodology does describe how selective coding is meant to further develop the theory's concepts, Morse's (1995) guidelines to concept development complemented this stage of the analysis. Morse (1995) identified at least three steps to concept development: (a) selecting an exemplar and identifying the conceptual components, (b) confirming the identified conceptual components, and (c) comparing components to elicit variation in the manifestations of the concept. As the coding process described by Strauss & Corbin (1998) is general, it is not uncommon to integrate analytical tools to further the analysis of a particular aspect of the emerging theory (e.g., Clarke's (2005) situational analysis).

At this stage of the study (approximately 17 individual transcripts analyzed and 4 focus groups) I had already embarked upon step 1 and had identified the patterns emerging characteristics. Additional transcripts were coded and used to move the analysis forward to step 2 where attention was given to corroborating (or challenging) the patterns' characteristics. Each subsequent interview or focus group was compared and contrasted with the patterns already identified. Once an information-seeking account was thought to fit within a pattern it was analyzed for apparent commonalities. Any questionable characteristics or variations were further examined and interpreted and when appropriate the description was revised. The aim was to obtain an appropriate sample of information-seeking accounts for each emerging pattern and corroborate the conceptual components as much as possible. This step in analysis contributed to further developing incomplete patterns, expanding and refining the conceptual components of each pattern, and eliminating any repetition (Strauss & Corbin, 1998).

The final step in developing a pattern's description was to specify its boundary (i.e., step 3). A pattern's boundaries were further delineated by comparing the pattern's characteristics with additional data collected and determining why an information-seeking account should (or should not) be integrated into a pattern. These comparisons led to the identification of variations within a pattern. At this stage, the patterns appeared sufficiently developed and differences across patterns were readily recognized.

In the final stage of the analysis, a core variable was identified by re-reading all of the interviews and focus groups and attempting to answer the following questions: What seems to be going on here? What is the main issue or problem that these people seem to be grappling with? (Corbin & Strauss, 2008; Strauss & Corbin, 1998). The core variable that was identified was 'playing my part and taking care of myself'.

Throughout the analytical process diagrams were used to stimulate thinking about the emerging patterns and their components. Diagrams visually depicted the relationships among the dimensions of a pattern and were useful in pointing out gaps in the evolving theory and directing further data collection (Straus & Corbin, 1998).

Evaluating the Rigor of the Study

Criteria of credibility, dependability, confirmability, and transferability were used to evaluate the rigor of this grounded theory study (Carnevale, 2002; Chiovitti & Piran, 2003; Sandelowski, 1986; Speziale & Carpenter, 2003). Credibility refers to the confidence in how well the findings are 'true' or 'believable' (Loiselle et al., 2007). In this study credibility was increased by: prolonged data collection (Loiselle et al., 2007), discussing findings with supervisor and research assistants for consensus (external check) (Carnevale, 2002); method triangulation (Loiselle et al., 2007); acknowledging prior knowledge and experiences with the phenomenon (Chiovitti & Piran, 2003; Sandelowski, 1986); letting participants guide the inquiry process (participants were encouraged to pursue their point of view) (Chiovitti & Piran, 2003); searching for data that could challenge emerging findings (Loiselle et al., 2007); discussing the emerging theory with participants (Chiovitti & Piran, 2003); and using the participants own words to label concepts and HISB patterns (Chiovitti & Piran, 2003).

Confirmability refers to the degree to which the findings could be confirmed or corroborated by others (Loiselle et al., 2007). The main strategy used in this study to enhance confirmability was to maintain an audit trail that includes the raw data (interview and focus group transcripts), diagrams indicating the evolution of the theory, methodological notes, coding book, and many drafts of the patterns description.

Transferability refers to the degree to which the findings can be generalized or transferred to other contexts or settings (Loiselle et al., 2007). Transferability in this study was enhanced by: choosing a phenomenon known to be relevant to the target population (Chiovitti & Piran, 2003); developing a thick description of each pattern (Loiselle et al., 2007); delineating the scope of the study in terms of sample, context, and setting (Chiovitti & Piran, 2003); sampling individuals at different stages of the illness trajectory to capture different experiences with HISB (Sandelowski, 1986); presenting direct quotations (Morrison-Breedy, Côté-Arsenault, D., & Feinstein, 2001), and highlighting similarities between the findings and the literature (Chiovitti & Piran, 2003).

Manuscript #3: Part 1

An in-depth exploration of information-seeking behavior among individuals with cancer: Part 1 Understanding differential patterns of active information-seeking

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Abstract

The purpose of this 2-part paper is to describe individuals' health information-seeking behavior (HISB) patterns that emerged from our grounded theory study. Thirty individual interviews and eight focus groups were conducted with individuals diagnosed with cancer. Analysis was characterized by constant comparison, an evolving coding scheme, diagramming, and ultimately the generation of a grounded theory of HISB patterns. Five HISB patterns were identified from the data: 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 three HISB patterns, considered to illustrate variations in *active* information-seeking. Each pattern is explained, including the type, amount, and sources of information sought. This analysis documents variations in active HISB often overlooked in the cancer literature. Findings may assist health care 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 type, amount, and sources of information sought and the strategies used to manage the information obtained (for a review see Lambert & Loiselle, 2007). Traditionally, HISB is conceptualized as either active search or avoidance (Miller, 1995; Rees & Bath, 2001). 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 (Friis, Elverdam, &Schmidt, 2003; Loiselle, Lambert, & Cooke, 2006). 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 two separate papers: Part 1 - variations in active information-seeking and Part 2 - information disinterest and avoidance.

Background

HISB is typically defined as the purposive search for health-related information to satisfy a query (Case, 2002; Conley, 1998; Johnson, 1997; Lenz, 1984). When seeking information, individuals select the type, amount, and sources of information they need (Johnson, 1997; Lambert & Loiselle, 2007; Lenz, 1984; Loiselle, 1995). 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 (Davison et al., 2002; Garvin et al., 2003; Hack et al., 2007; Hoskin & Haber, 2000; McCaughan & McKenna, 2007; Mills & Sullivan, 1999; van der Molen, 1999). Most HISB studies in the cancer literature are grounded in the coping paradigm, including the original works by

Miller (1980) and Lazarus and Folkman (1984). 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 (Miller, 1995); it has also been linked to intrusive ideation and psychological distress (Schwartz, Lerman, Miller, Daly, & Masny, 1995).

Even though 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 (Friis et al., 2003; Loiselle et al., 2006). Others report seeking cancer information gradually as the illness experience unfolds to prevent feeling overwhelmed by too much information (Shaw, Wilson, & O'Brien, 1994). 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 (Loiselle, 1995). Johnson (1997) 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 towards active information-seeking. In the social and personality psychology literature, Self-Evaluation theory (SET) describes three 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 (Loiselle, 1995; Dauenheimer et al., 2002; Sedikides, 1993). SET calls further attention to potential differential approaches in information-seeking (Loiselle, 1995); 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 Susol (2005) defined two main patterns of information-seeking among users of academic libraries (n=793): 1) Strategic pattern where users manifested pragmatic information-seeking and obtained a broad range of well-organized information sources and 2) Analytic pattern where users analyzed the information's deeper meaning, sought new ideas and information sources, and invested much time in information-seeking. Steinerova and Susol (2005) suggested that these findings can be used as a starting point for studying "typologies of human information behavior" (p. 153). Heinstrom (2002) administered questionnaires examining the information behavior of 305 university students in various faculties and identified three 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 is 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 (1998; Corbin & Strauss, 2008) 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 (Corbin & Strauss, 2008).

Sample and Setting

To begin, we recruited a convenience sample of men and women diagnosed with breast, prostate, or colorectal cancer that 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: 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 than 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) had been recruited and in an effort to maximize the opportunity to compare situations and explore variations in HISB younger individuals (< 55) were subsequently recruited. The information required to guide theoretical sampling was obtained from initial conversations with participants at recruitment, by asking health care professionals, or by perusing potential participants' charts.

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 members of their health care team and 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 prior to data collection.

Data Collection

We conducted 30 individual interviews (n=31) and eight 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 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 lead to three 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 (Lambert & Loiselle, 2008).

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 ½ 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 (1997). 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, two with men with prostate cancer, and two with men and women with colorectal cancer. A moderator (first author) and co-moderator were present at each group. Following 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 semi-structured interview guide (Appendix G) was designed with reference to the existing literature on HISB, the authors previous research in this area (Lambert & Loiselle, 2007; Loiselle, 1995) and the components of the paradigm proposed by grounded theory methodology (Strauss & Corbin, 1998). 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 (Appendix G). 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 (Appendix G) was completed by the participants following 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 professional using Microsoft Word. All transcripts were verified against the audiotape for accuracy by the first author.

Data Analysis

Figure 3 summarizes the steps undertaken to perform data analysis. Analysis was an ongoing process beginning with the 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. Following 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 three 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 Stevens (1996) and Lehoux et al. (2006) guided this analysis. At this stage, we had identified a total of five 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 Morse's (1995) three step-approach to concept development: 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 where 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 re-reading all of the transcripts and answering the following questions: What seems to be going on here? (Corbin & Strauss, 2008; Strauss & Corbin, 1998). 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 two 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 5 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 post-secondary education. Although the majority of participants were Caucasian, few were from other ethnic backgrounds (e.g., Korean, African, and Hungarian). Most were newly diagnosed with cancer (< 3 years) and had received a combination of two to three 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 the type, amount, and sources of cancer information sought and the information management strategies used. A total of five 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 “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 6 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 FG7-04) led to recognizing complementary information-seeking, whereas statements such as "I wanted to cover every single-minded detail" (participant FG7-03) contributed to identifying intense information-seeking. The grounded theory that emerged is depicted in Figure 4 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, gender, education, or HISB pattern. Participants described reacting, in one way or another, to aspects of their situation they thought was most important for them and putting forth the necessary efforts to respond accordingly. Which aspect of their situation 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 non-cancer related activities, whereas others exerted as much control as possible over treatment decision-making. In this sense, it appeared that participants described a continuum of roles they wanted to engage in. Interestingly, participants discussed the importance 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 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: a) context of cancer care (e.g., delegation of decision-making) and b) individual differences (e.g., curiosity, access to information) (Figure 4). A change in any one of these seemed to shift the reasons underpinning cancer information-seeking. In Figure 4, the roles that we identified to contribute to intense, complementary, and fortuitous information-seeking respectively were: a) develop an ‘expertise’ and participate in treatment decision-making, b) reach of comfortable level of knowledge of what is going on, and c) know what others are doing and examine ones situation accordingly.

Intense information-seeking behavior can be depicted by a commitment for thorough, in-depth information-seeking. These participants were most engaged in and attributed the most 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 participating 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 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 5).

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 that 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 7 among three men diagnosed with prostate cancer exemplifies the differences between intense and complementary information-seeking. Two of the participants (FG1-02 and FG1-05) expressed their need for intense information-seeking to participate in treatment decision-making, whereas the other participant (FG1-03) sought enough cancer information to understand his situation. Participants 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 (e.g., 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 two 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.

> 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 4, 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 comparisons among the patterns, quotations illustrative of each characteristic across the patterns are included in Table 8.

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 the quotation #1 in Table 8, intense information-seeking efforts were 'prioritized' to treatment options. As participation in treatment decision-making was the main reason prompting intense information-seeking, individuals naturally focused their efforts towards 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 appeared 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 8, participants favored 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 8, the 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 two main topics: orientation and preparedness cancer information. Orientation information included mainly specific explanations about ones diagnosis, prognosis, o treatment. For instance, as exemplified by quotation #4 in Table 8, 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 health care 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 health care 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 Table 8). 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 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 4). 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 website 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 (e.g., Johns Hopkins University) and 2) cross referenced the cancer information they obtained. In Table 8, 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 Table 8). 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 Table 8). 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 material, 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 4). 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 8, 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 appeared 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 8) 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 (e.g., 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 8) 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 4). These were found to be closely linked to the initial reason triggering the pattern. Quotations illustrative of each outcome are included in Table 9. 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 and acquiring a certain level of mastery (i.e., grasping what was going on) and competency (i.e., developing necessary skills). Specific indicators of mastery and competency emerging from the analysis included being able to: 1) gauge ones 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 health care professionals and friends/family (discuss situation intelligibly) (Table 9).

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 other have survived cancer and moved on with other life activities (Table 9). 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 (e.g., 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-seeking were categorized into three 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' (Miller, 1980), 'self-assessment' (Loiselle, 1995), 'analytic pattern' (Steinerova & Susol, 2005), and 'deep divers' (Heinström, 2002). 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 (Reaby, 1998). Similar to other studies on 'monitoring' (Brashers et al., 2002; Cox, Jenkins, Catt, Langridge, & Fallowfield, 2006; Gaston & Mitchell, 2005; Miller, 1995) we found that intense seekers wanted to obtain 'all' cancer information and appeared 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 broad scanners' pattern described by Heinström (2002) is comparable to complementary information-seeking and other researchers (Balmer, 2005; Mills & Sullivan, 1999) have reported 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 (Davison et al., 2002; Gaston & Mitchell, 2005; Bilodeau & Degner, 1996; Davison, Goldenberg, Gleave, & Degner, 2003; Kiesler & Auerbach, 2006). Although we did not explicitly measure decision-making in a manor 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 (1998), we found that most participants preferring less intense information-seeking appeared satisfied with passive decision-making. Although involvement in decision-making is often considered empowering (Cox et al., 2006), 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 (e.g., 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 (Mills & Sullivan, 1999; Bilodeau & Degner, 1996; Beaver et al., 1996; Leydon et al., 2000). 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 (Arraras et al., 2007; Beckjord, Rutten, Arora, Moser, & Hesse, 2008), we found that several participants reported suboptimal 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 found.

The concepts of 'good enough' coined to indicate the amount of cancer information sought in complementary information-seeking is similar to 'satisficing' as described by Simon's (1957) 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 (Reaby, 1998).

Similar to Johnson (1997) 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 (2005), most participants in our study sought cancer information from another media as an adjunct (not necessarily an alternative) to the information received from health care professionals. Although the internet is an information source increasingly popular among individuals diagnosed with cancer (Balmer, 2005; Ankem, 2007; Loiselle & Dubois, 2003; Ziebland, 2004), 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. Fisher (2005) has labeled 'information grounds' these settings where casual interactions among individuals lead to serendipitous information sharing. Similar to Fisher, Landry, and Naumer (2007) we found that participants appreciated these 'information grounds' because the information obtained was deemed important and influenced how they felt towards 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 4). All of which are crucial aspects of information-seeking to consider when supporting patients in their search. Increasingly, health care professionals are encouraged to tailor their information interventions to an individual's needs (Kiesler & Auerbach, 2006). 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.

Manuscript #4: Part 2

An In-Depth Exploration of Information-Seeking Behavior among Individuals with Cancer: Part 2 Understanding Patterns of Information Disinterest and Avoidance

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Abstract

This is the second part of a two-part paper describing differential health information-seeking behavior (HISB) patterns within the context of a cancer diagnosis that emerged in our grounded theory study. Data from 30 semi-structured interviews and eight focus groups with individuals diagnosed with breast, prostate, or colorectal cancer were analyzed using constant comparison analysis, diagramming, and open, axial, and selective coding. In Part 1, three HISB patterns illustrating variation in *active* information-seeking behavior were described: (a) intense information-seeking (i.e., a keen interest in detailed cancer information); (b) complementary information-seeking (i.e., the process of getting "good enough" cancer information); and (c) fortuitous information-seeking (i.e., the search for cancer information mainly from others diagnosed with cancer). Part 2 describes two additional HISB patterns coined in this study as: minimal information-seeking behavior (i.e., limited interest for cancer information) and guarded information-seeking behavior (i.e., avoidance of certain types of cancer information). Part 2 challenges traditional views that consider disinterest and avoidance as similar concepts subsumed under "blunting". Findings may be used to refine informational interventions and measurement strategies to best differentiate between cancer information avoidance and disinterest.

When diagnosed with cancer, most individuals are found to prefer as much cancer information as possible (Skalla et al., 2004; Mayer et al., 2007). Models of health information-seeking behavior (HISB) focus mainly on explaining why, how, when, and where relevant information might be obtained (Case et al., 2005; Lenz, 1984). Although several studies document the processes and outcomes pertaining to active cancer information-seeking, less empirical and theoretical attention has been given to explaining when information-seeking is minimal or does not even occur (Case et al., 2005; Loiselle, 1995). A few studies have reported that some individuals prefer avoiding cancer information altogether because it is perceived as threatening and contributing to unnecessary worry (Loiselle et al., 2006; Miller, 1995; Rees & Bath, 2001). Our grounded theory study was designed to explore variations in cancer information-seeking. The findings were divided into two papers with paper 1 reporting variations in active cancer information-seeking and paper 2 focusing on cancer information disinterest or avoidance.

Background

In the context of a cancer diagnosis, information-seeking might provide the knowledge required to optimally manage illness-related stressors (Mills & Sullivan, 1999; Johnson, 1997). Most often, coping frameworks have provided the theoretical underpinnings to studies on HISB in cancer (Echlin & Rees, 2002; Jahraus, Sokolosky, Thurston, & Guo, 2002; Reaby, 1998; Rees & Bath, 2001). Within this theoretical framework, much attention has been placed on identifying information-seeking preferences in terms of monitoring (active information-seeking) or blunting (avoidance) (Baker & Pettigrew, 1999; Lazarus & Folkman, 1984; Miller, 1995). Although, most individuals diagnosed with cancer prefer actively seeking cancer information (Gaston & Mitchell, 2005; Mayer et al., 2007; Mills & Sullivan, 1999; van der Molen, 1999), some prefer blunting or distracting themselves from information (Johnson, 1997; Mayer et al., 2007). These individuals prefer knowing less about their situation rather than dealing with the increased worry that might be brought on by information-seeking (Case et al., 2005). Loiselle (1995) has used Self-Evaluation Theory (SET) to further examine preference for avoidance. SET suggests that certain individuals might prefer self-protection and guard themselves from aversive information by avoiding all information sources (Loiselle, 1995) or favor self-enhancement and venture in information-seeking only to obtain positive information (but still avoid negative information) (Sedikides, 1993).

As a cancer diagnosis is often more alarming than the diagnosis of any other illness (Mills & Sullivan, 1999; Reaby, 1998) it is not unlikely that blunting might be an attractive strategy to prevent exacerbating worry (Miller, 1995). Even though monitors also report being upset following information-seeking, gains in certainty and predictability from information-seeking seem to offset this negative arousal - a compensation not found among blunters (Miller, 1995). Several factors are identified to modulate preferences towards not seeking cancer information. Mayer et al. (2007) reported that significant predictors of not seeking information among cancer survivors included older age, being unmarried, not employed full-time, not having a regular health care provider, less education and income, no assistance with information-seeking from friends or significant others, and limited access to the internet.

In comparison to active cancer information-seeking, fewer studies have examined the phenomenon of shunning away from cancer information, despite its recognition as an important information management strategy (Brashers et al., 2002; Case et al., 2005; Loiselle et al., 2006). Hence, additional studies are needed to further document this information behavior (Case et al., 2005; Leydon et al., 2000). Our grounded theory study explored HISB patterns within the context of a cancer diagnosis. From our analysis, we found that although many participants were actively engaged in cancer information-seeking (Part 1), some described limited interest towards cancer information. These preferences were labeled minimal and guarded information-seeking and are presented herein.

Patient education is a major component of the oncology nurse's role and patient satisfaction with cancer information provided is often used as an indicator of quality of care (Arraras et al., 2007; Elf & Wikblad, 2001; Jahraus et al., 2002). Internationally, clinical practice guidelines in psychosocial oncology (NHMRC National Breast Cancer Centre Psychosocial Working Group, 1999; Turner, Zapart, Pederson, Rankin, Luxford, & Fletcher, 2005) have emphasized the importance of providing cancer information tailored to the needs of patients and families. Although health care professionals often assume that patients want as much cancer information as possible, it is important to recognize individual differences in desire for cancer information (Jahraus et al., 2002; Leydon et al., 2000). Not everyone benefits from the same kind of informational support and health care professionals are increasingly encouraged to assess individuals' preferences before offering cancer information (Barnoy, Bar-Tal, & Zisser, 2006; Butow et al., 1997; Case et al., 2005; Elf & Wikblad, 2001; 27. Garvin et al., 2003; Jahraus et al., 2002; Kiesler & Auerbach, 2006; Miller, 1995). Enhanced knowledge on nuances in preferences for cancer information (from wanting a lot to desiring more restricted content) is thus imperative. Limited health care resources and multiple demands placed on oncology nurses also make it vital that time spent with patients efficiently and effectively address their most pressing psychosocial needs. The findings from our study provide insightful groundwork to guide assessment of differential preferences for cancer information and oncology nurses' decisions when providing psychosocial care.

Methods

We used grounded theory, according to Strauss and Corbin (1998; Corbin & Strauss, 2008) to guide the conceptualization of the variations observed pertaining to cancer information-seeking behavior.

Sample and Setting

To begin, we recruited a convenience sample of men and women diagnosed with breast, prostate, or colorectal cancer that had received, were receiving, or were in the process of determining 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 their experience with cancer information, physically able to participate, and no concurrent illnesses that could interfere with participation. As HISB patterns emerged, we recruited additional participants with potentially different experiences with HISB than those already recruited (i.e., theoretical sampling). The information required for theoretical sampling was obtained from initial conversations with participants at recruitment, by asking health care professionals, or from the participant's chart.

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 health care team and 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 prior to data collection.

Data Collection

We conducted 30 individual interviews (n=31) and eight 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. Although both methods were initially used for practical reasons, early on in analysis it was noticed that complementary dimensions of HISB emerged in each one and, when taken together, provided a more comprehensive conceptualization of HISB pattern. Thus, both data collection methods were used throughout the study (see Lambert & Loiselle, 2008).

Most interviews were conducted by the first author in the participants' homes. Ten interviews were conducted by a research assistant to minimize bias in data collection. Interviews ranged from 30 minutes to 2 ½ hours and were structured in such a way as to obtain chronological accounts of a participant's experience with cancer information.

Focus groups lasted from 1.5 to 2.5 hours and were implemented according to the guidelines proposed by Morgan (1997). 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, two with men with prostate cancer, and two with men and women with colorectal cancer. A moderator (first author) and co-moderator were present at each group. Following 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.

A semi-structured interview guide (Appendix G) was developed by the first two authors and used in the individual interviews and focus groups. Questions were developed to examine active HISB as well as passive HISB, information disinterest, and avoidance. The interview guide was designed with reference to the existing literature on HISB, the authors previous research in this area (Loiselle, 1995; Lambert & Loiselle, 2007), and the components of the paradigm proposed by grounded theory methodology (i.e., antecedents, characteristics, and consequences) (Corbin & Strauss, 2008; Strauss & Corbin, 1998). In the focus groups, much attention was given to characterizing the similarities and differences among members of the group disinterested in cancer information and those actively seeking cancer information.

A brief demographic questionnaire (Appendix G) was completed by the participants following the interview or focus group. All focus groups and individual interviews were tape-recorded with the permission of participants and transcribed verbatim by a typist using Microsoft Word. All transcripts were verified against the audiotape for accuracy by the 1st author.

Data Analysis

Figure 3 summarizes the steps undertaken for data analysis. Analysis was an ongoing process beginning with the 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. Accounts of participants' cancer information-seeking across the illness trajectory constituted the units of analysis. Following comparative analysis of 10 individual interviews, similar accounts in information-seeking began to emerge and were grouped together. Differences were also apparent based mainly on the amount of information sought. Whereas some participants described seeking much cancer information, others preferred little or no cancer information and some explained purposefully avoiding it. Analysis of these variations led to the preliminary identification of three 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 accounts 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 to further determine the range of HISB patterns. Questions proposed by Stevens (1996) and Lehoux et al. (2006) guided our analysis of the focus group interaction data. At this stage of the analysis, we had identified a total of five patterns: intense, complementary, fortuitous, minimal, and guarded information-seeking. We selected these labels to qualify the HISB particular to each pattern using either participants own words or concepts in the literature.

Selective coding focused on developing an in-depth conceptual description of each pattern. To guide selective coding, we used Morse's (1995) three step-approach to concept development: 1) identifying the attributes, 2) verifying the attributes, and 3) comparing components to elicit variation. At this stage (17 transcripts analyzed), we had already embarked upon Step 1 and a pattern's characteristics began to emerge. Additional transcripts were coded and moved our analysis forward to Step 2 where attention was given to corroborating (or challenging) the characteristics of a pattern. Step 3 focused on determining a pattern's boundaries and was achieved by comparing the characteristics of that 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 our analysis, we identified a core variable by re-reading all of the transcripts and answering the following questions: What seems to be going on here? (Corbin & Strauss, 2008; Strauss & Corbin, 1998). The core variable we 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 identifiable. Transcripts were coded by the primary author and two 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 were analyzed using descriptive statistics. Data were managed using Microsoft Word and Excel.

Results

We developed a theory to explain the five HISB patterns that emerged from our analysis capturing participants variations in cancer information-seeking: 1) intense information-seeking - keen interest in detailed cancer information; 2) complementary information-seeking - "good enough" cancer information; 3) fortuitous information-seeking - seeking cancer information mainly from others diagnosed with cancer; 4) minimal information-seeking - limited interest for cancer information; and 5) guarded information-seeking - wariness when seeking certain types of cancer information (Figure

4). Part 1 presented the intense, complementary, and fortuitous information-seeking patterns. Part 2 focuses on minimal and guarded information-seeking patterns.

Description of Minimal and Guarded Information-Seeking Patterns

According to the theory we developed (Figure 4), minimal and guarded information-seeking behavior will be described in terms of: a) Antecedents - reasons for preferring little or no cancer information, b) essential characteristics, and c) outcomes.

Antecedents: Preferences for not seeking cancer information

As described in Part 1, the core variable 'playing my part and taking care of myself' emerged as an important process explaining variations in cancer information-seeking. In minimal information-seeking, participants described requiring little or no cancer information to play the role they thought was important during the course of the illness. These participants voiced wanting to 'move on with their lives' or 'maintain normalcy' and reduced the amount of energy devoted to cancer. Participants felt that because undergoing treatment was physically and psychologically consuming, once treatment was completed they did not want to think about cancer, rather they focused on taking care of other aspects of their lives that might need their attention. They wanted to minimize any reverberating effects of cancer on their family and/or work place. As explained by the following woman diagnosed with breast cancer, if all her time was spent seeking cancer information, little energy would have been left to 'control' other aspects of her life:

> Like you can't dwell on yourself [...] You just go on with life [...] we had so many kids [...] so this information is what the young parents are looking at and their kids are screaming [...] the houses are a mess because they're busy learning, I was busy caring for my little packages that God gave me, that was my job [...] this is what we control. Our life.

Seeking cancer information was often perceived as ‘complicating things’ or as another participant said: ‘I didn’t want to waste my mental energy on things I have no control over’. This participant further explained that he trusted that all was being taken care of by his oncologist and consequently had no need to seek cancer information. Participants felt that the most ‘normal’ way to carry on with life is to: “Just do what you have to do, treat it, and get on with life”. Also, in minimal information-seeking, participants often emphasized the importance of adhering to treatment recommendations as a way of ‘fighting’ the disease: “I’m going to fight this [cancer], I’ll do whatever they tell me to do, I don’t think the information is going to make much of a difference”. Interestingly, we found that focus group members showing minimal information-seeking preferences were usually more silent and interacted least with others. Although, most often, minimal information-seeking behavior precluded participation in treatment decision-making, few participants did determine with their doctor the most appropriate treatment. However, their opinions were not based on a scientific reasoning process as described in Part 1 for intense information-seeking, rather these participants seemed to rely mainly on a pragmatic reasoning of their situation. A man with prostate cancer, for instance, did not want a prostatectomy because it required an inpractical 3-day hospital stay. Watchful waiting was not an option either as “I don’t want to live with it [cancer] in me”, he therefore chose radiotherapy. For this participant and others like him, an intense search for treatment information was not necessary.

In guarded information-seeking, “Not knowing is better” was the main thought expressed towards cancer information. A guarded behavior towards information-seeking seemed to be motivated by the tremendous anxiety and fear felt following the cancer diagnosis. These participants reported wanting to control their emotions by shunning away from additional cancer information. The focus group interaction included in Table 10 depicts an interaction among two participants preferring guarded information-seeking [FG2-03 and FG2-04] and one intense information seeker [FG2-05] and illustrates the extent to which the two participants preferring guarded information-seeking associated negative thoughts to cancer. Following such a negative appraisal of the situation, it was not surprising that these participants were wary when seeking cancer information. Whereas some participants viewed seeking cancer information as a way of taking care of self, guarded information seekers achieved this goal by avoiding cancer information and consequently 'controlling' overwhelming negative affect. Guarded information seekers trusted their oncologist and did not want to become more knowledgeable about their situation, as one participant said: "I just wanted to get it [treatment] done and get rid of it [cancer]".

Overall, the core variable 'playing my part and taking care of myself' was determined by the: a) Context of cancer care and b) Individual differences (Figure 4). In minimal information-seeking, trust in the health care team, tendency not to worry about life events, concurrent life events, older age, and delegation of decision-making to the oncologist appeared to contribute to participants preference for little or no cancer information. In guarded information-seeking, participants also expressed trusting their oncologist and delegating any treatment decision-making to them, however the fear of coming across distressing cancer information prompted avoidance of certain types of cancer information.

Essential Characteristics: Type and Amount, Sources, and Actions

The theory of differential information-seeking behavior that we developed describes the essential characteristics of minimal and guarded information-seeking behavior (Figure

4). The characteristics coined in this study emphasize the differences between these patterns and those described in Part 1.

Type and Amount of Information

In minimal information-seeking, few, if any, actions were taken toward obtaining cancer information with the exception of attending to information offered by health care professionals or the environment (e.g., television advertisements). Any interest in cancer information focused mainly on general, non-detailed information and, overall, a considerable amount of cancer information was not expected. Most often, when information-seeking took place, it was in response to a specific problem needing to be resolved (e.g., hot flashes, vomiting).

Analysis of minimal information-seeking behavior revealed that participants varied on the importance they attributed to receiving cancer information from health care professionals (i.e., passive information-seeking). We conceptualized this within pattern variation on a continuum from a high preference for passive information-seeking to disinterest even for passive information-seeking.

1. High preference for passive information-seeking

As illustrated by quotation #1 in Table 11, some participants had an interest in cancer information; however they anticipated that all required information would be provided by their health care professionals. As the desired cancer information was received, one participant said: “I don’t really have to seek information. It’s forthcoming, it is very much forthcoming”. If further cancer information was desired, casual questions were directed at their health care professionals (e.g., test results).

2. Disinterest even for passive information-seeking

Other participants described a ‘neutral’ attitude towards cancer information and did not mind whether it was received or not. Overall, these participants expressed a negligible interest for cancer information altogether as illustrated by quotation #2 in Table 11. In comparison to quotation #1, this participant did not identify explicit information needs (no specific information-seeking goal) and he was satisfied with whatever information was offered.

In guarded information-seeking, participants might have an interest to seek cancer information; however they were selective about the type of cancer information they obtained. It is this cautiousness in cancer information-seeking and the desire to avoid certain types of cancer information that lead to the differentiation of this pattern. These participants described discerning between cancer information that was ‘best to avoid’ or unwanted and information that was useful and wanted. Most often they categorized the information type according to its emotional value that is whether it was negative or positive. Positive cancer information or ‘good’ news were welcomed, however negative or ‘bad’ news were not wanted. The following quotation demonstrates a participant’s preference for receiving ‘good news’ only: “I’m sure that the old male [...] they don’t want to hear about that [bad news]. Just give me the good things”. Whether a piece of cancer information was considered positive or negative was dependent on its implications for that individual. Some also described discriminating cancer information according to its level of generality as opposed to its specificity. These participants explained that, regardless of whether the cancer information was positive or negative, they wanted to seek only information that explained specific aspects of their situation. ‘General’ cancer information might not be relevant for them and, consequently, raise unnecessary concerns. The following quotation exemplifies this information-seeking preference:

> When I went to an information session […] the physiotherapist said that after the surgery your arm might swell […] I started to ask myself questions […] I don't know if they took out the lymph nodes, I don't know […] so I started to feel anxious […] because I received information that was not pertinent for me […] I find that when you get general information, when it is not personalized, it creates a lot of unnecessary questioning, so I only obtain information that is specific to my situation.

In guarded information-seeking, whether it was based on the emotional value or the generality of the cancer information, indiscriminate information-seeking was not "worth it" and contributed to feelings of anxiety and discouragement. Despite their preferences for avoiding certain types of information, guarded participants remained curious about their situation and, at times, wanted to know more. As illustrated by the following quotation, throughout the course of the illness experience, several participants were juggling their interest to seek cancer information with the apprehension of coming across undesirable cancer information: "I didn't know anything about cancer […] I asked my doctor about the side effects […] I was curious about what was waiting for me […] He said well it's this and that and some people get this […] I said, Oh! My god!" This juggling act involved learning early on what kind of cancer information can be managed and which type of information is best avoided. Even if cancer information was sought, the boundary between wanted and unwanted information remained fragile.

Sources of Information

Minimal information-seeking behavior precluded any search for information in books or online and participants relied mainly, and at times solely, on their health care professionals for information (Figure 4). Health care professionals were seen as a natural source of cancer information. As described by the following participant, health care professionals provided convenient, direct, reliable, necessary, and useful cancer information: "He [the oncologist] gave me all the explanations that [I needed] and this was satisfactory to me, I stopped there. I also read the documents that were given to me at the hospital, but I did not look any further [than this]".

This information was neither doubted nor criticized. Minimal seekers described primarily a one-way communication pattern from the oncologist to the patient. Most interactions were directed by the oncologist and he/she determined the type and amount of information that should be shared. Participants felt that the oncologist was in the best position to know what kind of information they needed and appeared satisfied with this pattern of information communication. As one woman diagnosed with breast cancer said: "I didn't, I didn't [try to know more about breast cancer] I just listened to the doctors [...] It's being taken care of, the doctors know [...] and lets just go on". Thus, in minimal information-seeking, participants took on less of an active role in medical consultations in comparison to participants describing active information-seeking (Part 1). Even if participants did not understand the lingo used by the oncologist, they did not seek clarifications.

In guarded information-seeking, participants did not report searching for additional cancer information from books or the Internet, as the information found might be too general or negative. Rather, these participants also mainly relied on their health care providers for cancer information. For many participants, information received from the oncologist was most valued, as it often dispelled fears and provided reassurance. It appeared that when participants received this type of information from their oncologist, they did not want to seek more by fear of contradicting it. Despite extent efforts to avoid unwanted cancer information, at times, participants described coming across cancer information incidentally which in turn instigated questions directed at the oncologist.

Actions to Process and/or Manage Information

As indicated in the theory of differential information-seeking behavior (Figure 4) 'going with the flow' and 'circumventing unwanted information' are actions that emerged from the participants' descriptions of minimal and guarded information-seeking.

In minimal information-seeking, 'going with the flow' meant that participants let themselves be taken care of and guided entirely by their health care professionals. Minimal information-seekers did not want to exert much influence on the course of medical events and made most reference to needing to accept the situation as it is.

> I did not really care about it [information] at that point. Whatever they give me, they give me [...] I am very neutral [...] because you know I take what they give me [...] What ever they tell me I do [...] basically I'm just going with the flow.

In guarded information-seeking, obvious efforts were put forth to circumvent or bypass unwanted cancer information and two types of strategies to achieve this seemed salient: 1) Escapism or avoidance and/or 2) Denial.

Escapism. Participants described using escapism mainly to divert attention away from or avoid unwanted cancer information. Some participants described deliberately diverting their attention to non-information-seeking activities such as traveling, gardening, or watching television. These activities seemed to allow participants time to "just forget about it [cancer]". Other participants described conscious efforts to avoid specific information sources if they thought it could contain the unwanted cancer information. Avoidance prevented participants from confronting negative sentiments that could potentially be evoked by unwanted information. Although, some participants described avoiding an information source anticipated to contain unwanted information, others described venturing in information-seeking but halting their search when they came across unwanted information. This latter situation tended to deter future information-seeking activities.

Denial. In guarded information-seeking, the word ‘denial’ was used by some participants (see next quotation) to describe their rejection of worrisome or distressing cancer information. Denial was found to include: not believing the cancer information sought or received, minimizing the information’s significance or implications, and/or reframing cancer information. None of the participants denied that a particular event (e.g., side effect) was actually occurring; however they did describe denying or discrediting cancer information that was too painful to process:

> I read a little of what was given to me. Everything that was not positive, I didn’t want to believe [...] I think that was the denial part of it [...] They say, you may have diarrhea, you may have this, you may have that [...] I thought that won’t happen to me.

Some participants did not completely reject the cancer information received, but minimized its negative implications. For instance, participants downplayed the occurrence of treatment side effects, hoping that these might not occur. The uncertainty surrounding such negative events was favored over worrying about events that might not actually occur. Whereas unwanted cancer information was avoided and/or denied, participants zeroed in on any positive cancer information. When participants found cancer information that they liked, they tended to stop their search, as they did not want to come across any information that might be contradictory. If unwanted cancer information was found incidentally, some participants attempted to reframe the content. The following woman with breast cancer explains how she attempted to make ‘negative’ information more ‘positive’:

> When I accidentally read negative things, I just try to make it positive. Coat it with sugar and candies, make it with flowers. [...] For example, like the side effects [...] I said to myself mine were not that bad, even though I felt bad Oh well! It’s not that bad.

For some guarded information seekers, both escapism and denial were described, whereas for others either one of the two strategies was favored. Despite avoidance and denial of cancer information, all participants described adhering to their treatment recommendations.

Outcomes

As specified by the theory of differential health information-seeking behavior (Figure 4), the outcomes of minimal and guarded information-seeking are ‘contentment and accepting’ and ‘maintaining a good morale’. Contentment emerged as the outcome of minimal information-seeking behavior as participants described being well taken care of. Despite the imminent threat of a cancer diagnosis, they reported being pleased with the unfolding of events. As illustrated in the following quotation, participants accepted the treatment decisions taken by their oncologist and the cancer information received from them: “If I have confidence in the doctor, then just tell me what is necessary; don’t bother me with other issues... Look you’re the professional […] I have confidence; you [oncologist] say that’s the way to go, I go with it”.

In guarded information-seeking, it seemed that participants invested much effort in escaping, avoiding, and/or denying unwanted cancer information to maintain a good morale and promote their well-being during a time of crisis. As one participant said: “It’s for your morale. A good morale […] Worries, I would rather do without.” Guarded information seekers were not concerned with acquiring a comprehensive understanding of what is going on; rather they were satisfied with a partial picture of the situation as long as it remained reassuring (as much as possible).

Variation in Cancer Information-Seeking Pattern

In Part 1 and 2, a participant’s cancer information-seeking behavior was categorized as belonging mainly to one pattern or another. However, we found that a participant's HISB might actually overlap two patterns. For example, a participant’s HISB seemed to represent the complementary information-seeking pattern; however information-seeking also included obtaining information from others diagnosed with cancer, on occasion, when waiting for an appointment. This latter behavior resonates with the fortuitous information-seeking pattern. Also, participants are not necessarily fixed in the same HISB pattern throughout the illness trajectory. Some participants, for instance, mainly sought cancer information intensely when undertaking treatment decisions, however once treatment began, they seemed to prefer complementary or minimal information-seeking. Interestingly, few participants described shifting from intense information-seeking to minimal or even guarded information-seeking, however no one described a shift from minimal (or guarded) to intense information-seeking.

Discussion

Part 2 of this paper described the minimal and guarded information-seeking behavior patterns that emerged from our grounded theory analysis. Even if it is common to assume that individuals diagnosed with cancer seek as much information as possible, this study further supported the observations that some individuals might not engage actively in cancer information-seeking (Jahraus et al., 2002; Loiselle et al., 2006; Mayer et al., 2007). The present analysis led us to identify key differences between information disinterest (minimal information-seeking) and avoidance (guarded information-seeking). Although, traditionally these information behaviors have been subsumed under the general label of 'blunting', our findings suggest that such conceptualization might be inappropriate. Even if minimal information seekers might not actively seek cancer information, they do not seem to fear or avoid cancer it either – a behavior more indicative of blunting. Few studies have distinguished minimal information-seeking behavior from guarded information-seeking behavior. Reaby (1998) found that some women diagnosed with breast cancer preferred ‘complacency’, whereas others ‘defensive-avoidance’. Similar to minimal information-seeking, complacency emphasizes acceptance of information and advice without questions or full comprehension. Defensive-avoidance shares characteristics with guarded information-seeking, including denial and avoiding discussions about cancer related issues. Health care professionals need to be aware of the differences between minimal and guarded information-seeking and be able to assess these individuals need for cancer information to improve the quality of patient-health care provider information communication and design optimal cancer supportive interventions. Minimal information seekers’ lack of questioning should not automatically be interpreted as indifference towards cancer information. Although these individuals might not voice their information needs, health care professionals are encouraged to assess their interest in receiving cancer information (i.e., passive information-seeking). However, satisfying minimal seekers need for cancer information, goes beyond simply giving cancer information. Minimal seekers expressed contentment with the cancer information received when health care professionals provided the most pertinent information for their situation and refrained from providing detailed, overwhelming amount of information. In guarded information-seeking, participants described most often appraising their situation negatively and preferring that communication with health care professionals focus on positive cancer information and reassuring emotional support. These individuals might be optimally assisted by health care professionals providing them with strategies to manage their anxiety and distress rather then receiving voluminous cancer information.

Consistent with other studies (Cox et al., 2006; Mayer et al., 2007; Skalla et al., 2004; Leydon et al., 2000; Loiselle et al., 2006) we found that a smaller number of participants preferred information avoidance in comparison to active information-seeking. Only the participants preferring guarded information-seeking selected information based on its emotional value and expressed concerns about the possible impact of cancer information on their morale. Although other participants spoke of the potential negativity of cancer information, they also felt that it was necessary to obtain an unbiased depiction of what was going on and therefore still sought cancer information. Other authors have reported that some individuals diagnosed with cancer prefer not to seek cancer information to remain hopeful and prevent the exacerbation of fears and worries (Leydon et al., 2000; Loiselle et al., 2006; Rees & Bath, 2001). The juggling of fears and curiosity described in guarded information-seeking has been reported elsewhere (Leydon et al., 2000; Loiselle et al., 2006). Loiselle et al. (2006) found that many of the women interviewed (n=12) were balancing their fear of knowing more about breast cancer with their fear of being overwhelmed by the information. Typically, within the context of a health threat, individuals are considered to avoid mainly information that is negative to prevent exacerbating worry (Case et al., 2005), however we found that some participants avoided cancer information because it exposed them to irrelevant information and triggered unnecessary worry (regardless of whether it was positive or negative). These participants seemed to benefit most from individualistic information received from their health care professionals.

Over the last 20 years, researchers have increasingly advocated a shared mode of treatment decision-making whereby physicians are encouraged to support patient involvement in active or collaborative treatment decision-making (Bilodeau & Degner, 1996; Davison et al., 2003; Gaston & Mitchell, 2005; Kiesler & Auerbach, 2006). However, as also reported by Reaby (1998), we found that the participants in our study preferring minimal or guarded information-seeking favored a more traditional, paternalistic relationship with their oncologist and did not want to participate in treatment decision-making. These participants recognized the complexity surrounding a cancer diagnosis and felt more content relying on the 'experts'. Interestingly, we found that few minimal seekers undertook collaborative decision-making; however the process was more intuitive and based on pragmatic reasoning rather than a detailed, scientific reasoning as described in intense information-seeking (Part 1). Several participants found to prefer minimal information-seeking were also older and mentioned that 'being a good patient' meant not questioning what the oncologist tells you.

Comparable to other studies (Czaja et al., 2003; Johnson, 1997; Mills & Sullivan, 1999) our findings recognize the contribution of individual differences and/or contextual variables on information-seeking preferences. For instance, many participants explained that minimal information-seeking behavior was preferred because they were older, trusted their health care professionals, believed that the oncologist is the expert, delegated decision-making to the oncologist, had a tendency not to worry about life events, were busy taking care of other aspects of their life, and had limited access to the internet. As reported by others, we also found that trust in medical expertise seemed to preclude supplementary information-seeking (Leydon et al., 2000; Reaby, 1998).

One of the main underlying processes in cancer information-seeking identified across transcripts was: 'Playing my part and taking care of myself'. Similar to the core category 'never-ending making sense' identified by McCaughan and McKenna (2007) in their grounded theory study of information-seeking behavior among individuals newly diagnosed with cancer, we found that participants attributed a particular meaning to their experience and continually re-interpreted what was happening to them throughout the illness trajectory. According to the sense participants made of their situation, they determined their reaction to the cancer diagnosis. In this regard, our core category of 'playing your part and taking care of self' is also comparable to the concept of self-regulation (Johnson, 1999; Leventhal, Leventhal, & Contrada, 1998). That is, according to their perceptions of what was going on, participants determined the roles and responsibilities they wanted to take on and the importance that information-seeking would take in fulfilling these roles. All participants were involved in regulating or determining what type, amount, and sources of cancer information were most appropriate. Conceptualizing HISB as a self-regulatory strategy emphasizes that according to an individual's representation of their illness, a graded continuum of reasons to engage in information-seeking can be identified (Loiselle, 1995). This conceptualization of HISB moves further away from the traditional dichotomy of seeking versus avoiding found in the cancer literature towards recognizing potential nuances in HISB.

Conclusion

The findings of this study contribute to the discussions about selectivity in HISB by further describing its different processes and distinguishing avoidance from disinterest. Health care professionals are encouraged to find ways of providing cancer information, while respecting individuals' limits for the type and amount of information desired. As an example, guarded information seekers might benefit from pamphlets that present only the necessary information in a non-alarming fashion. Findings also encourage health care professionals to view information-seeking in a self-regulation perspective and call further attention to understanding HISB in light of the roles that the individuals decide to play in the illness experience (Loiselle, 1995). Current tools measuring 'avoidance' do not capture the nuances between minimal and guarded information-seeking behavior. Future work could refine these instruments to capture the different HISB patterns we identified.

In addition, future research should aim to corroborate these patterns among individuals diagnosed with other types of cancer and further examine predictors of each HISB pattern.

CHAPTER 5 OVERALL CONCLUSION

Five HISB patterns emerged from the data: (a) intense information-seeking (i.e., a keen interest in detailed cancer information); (b) complementary information-seeking (i.e., the process of getting "good enough" cancer information); (c) fortuitous information-seeking (i.e., the search for cancer information mainly from others diagnosed with cancer); (d) minimal information-seeking (i.e., a limited interest for cancer information); and (e) guarded information-seeking (i.e., the avoidance of certain types of cancer information). A theory was developed to explain the patterns' antecedents, including individual differences and contextual factors, as well as their essential characteristics along the main dimensions of HISB (i.e., type, amount, and sources of information and actions used to process and manage cancer information). The outcomes or consequences of each pattern were also identified (Figure 4).

Implications for Theory and Research

These findings corroborate some of the premises put forth by other information-seeking models. Similar to Lazarus & Folkman (1984) and Miller (1980, 1987), findings emphasize that some participants prefer to seek as much information as possible (i.e., intense information-seeking), whereas others have a preference for avoidance of threatening information (i.e., guarded information-seeking). However, the findings of the present study further expand theorizing on information-seeking by proposing two additional 'active' information-seeking patterns –complementary and fortuitous information-seeking- and a pattern of information disinterest – minimal information-seeking. The identification of five HISB patterns offers a more comprehensive understanding of the possible variations in information-seeking or avoidance. Future studies could be conducted to corroborate these patterns with individuals diagnosed with other types of cancer or confronted with other illnesses. Also, it would be informative to explore the pertinence of these patterns in other normative or non-illness contexts where information-seeking is known to be relevant such as during pregnancy or breastfeeding.

Furthermore, our findings complement the frameworks introduced in chapter 1 describing the general information-seeking process (e.g., Lenz, 1984; Wilson, 1996) by suggesting clusters of antecedents that might influence an individual's preference for a particular HISB pattern. For instance, if the oncologist delegates active treatment decision-making to an individual that tends to be curious and analytical about his or her situation, intense information-seeking will most likely be triggered. However, when the treatment decision is delegated to an individual who tends not to worry about life events, is calm, and less curious, minimal information-seeking might be preferred. Future studies of the antecedents of information-seeking may further analyze some of the interactions among such individual differences and contextual variables in determining a HISB pattern.

In addition, the patterns that emerged in this study share certain similarities with the description and characteristics of the information-seeking motives described by SET (see theoretical frameworks chapter 1). Correspondence with SET is most obvious for the extreme HISB patterns that is intense information-seeking, as both clearly share similarities with self-assessment (i.e., desire for as much information as possible), whereas guarded information-seeking shares common characteristics with self-protection (i.e., desire to protect self from potentially aversive information) and self-enhancement (i.e., seek information to maintain a positive sense of self). However, parallels between SET and the HISB patterns are less obvious for the complementary, fortuitous, and minimal patterns. For instance, in complementary information-seeking, many participants described wanting information geared towards self-improvement (e.g., diet, exercise) and self-verification (e.g., clarifying the stage and grade). This finding might further support claims that self-evaluation motives are not mutually exclusive. In addition, SET does not seem to account for minimal information-seeking behavior. Also, SET focuses on information-seeking motives and does not elaborate as much on how a particular motive might actually influence each dimension of information-seeking (i.e., type, amount, and sources of information and information management strategies used).

Implication for Measurement

Findings also have implications for the measurement of HISB. Four published scales are used to measure HISB: (a) Miller Behavioral Style Scale (MBSS) (Miller, 1987), (b) Threatening Medical Situation Inventory (TMSI) (van Zuuren et al., 1996), (c) Krantz Health Opinion Survey (KHOS) (Krantz et al., 1980), and (d) Autonomy Preference Index (API) (Ende et al., 1989). Although, these tools measure intense information-seeking and avoidance, they do not capture the other HISB patterns coined in this study.

Loiselle (2002; Loiselle & Lambert, 2008) introduced a scale designed to measure the various information-seeking motives proposed by SET: The Differential Health-Information Seeking Behavior (DHISB) scale (Figure 2). The DHISB is intended to be used with different patient populations but mainly, to date, has been used and tested with individuals diagnosed with cancer (Loiselle & Lambert, 2008). This scale is potentially the most promising tool to measure variability in information-seeking, as it is based on the strong theoretical underpinnings of SET and seeks to capture more subtle information-seeking preferences. As previously highlighted, the HISB patterns that emerged in this study share certain similarities with the description and characteristics of the self-evaluation motives. As such, the findings from this study might inform future studies aimed at refining the DHISB scale. As an example, provided that most participants in this study identified that they sought ‘all’ information because they obtained ‘all’ the cancer information they needed, the DHISB item: ‘I sought ALL available information about my general health status’ (Figure 2) designed to capture self-assessment could be reformulated to further discriminate the type and amount of information sought in intense information-seeking: ‘I sought detailed information about all the different treatment options available to me’.

In another example, the item ‘information about my illness made me feel too anxious’ (Figure 2) meant to capture self-protection could be reformulated to further emphasize the type of information that participants in guarded information-seeking reported to be most anxiety-provoking: ‘negative information about my illness made me feel too anxious’. Whilst most participants acknowledged that cancer information is anxiety-provoking, they varied in the extent to which they wanted to be confronted with ‘negative’ information.

In terms of the nature and number of subscales, two adjustments to the DHISB scale might be suggested. First, as participants in guarded information-seeking seemed to describe characteristics of both self-enhancement and self-protection, these subscales could be collapsed to avoid overlap. Second, a subscale identifying the fortuitous information-seeking pattern could be added to operationalize preference for experiential information.

Last, it may be suggested that the overall format of the DHISB scale could be revised. If the goal of the DHISB scale is to identify an individual’s main information-seeking pattern, it would be most appropriate to consider a tool format that compels the choice of one pattern over the others. For instance, a tool format such as the card sort developed by

Degner et al. (1992, 1997) to assess preference in treatment decision-making could be considered. A brief description of each HISB pattern identified in this study would be written on separate cards and participants would sort the cards according to their preferred HISB pattern. For instance, the minimal pattern could be described as: "Most of the information I wanted was provided to me by the health care professionals; I did not really seek further information." The complementary pattern as: "I did not make decisions about my treatment, but I sought information to better understand my situation and become more knowledgeable about what was going on. I did not obtain information about every single possible treatment options". In the description of a pattern it might be most important to include the main motivation underpinning the pattern and the particular type and amount of cancer information sought. Future studies might refine the DHISB scale and/or develop a card sort to measure the HISB patterns identified in this study.

Implications for Practice

Providing cancer information to patients is an integral part of oncology nursing care. However, nurses' and other health care professionals' informational interventions often do not yield the aspired benefits, and patients continue to report dissatisfaction with the information they receive (Johnson et al., 2001). Increasingly, researchers and clinicians alike advocate for the enhanced effectiveness of these informational interventions by emphasizing that the information provided to patients must match their HISB (Loiselle, 2002; van der Molen, 1999). The findings of this study provide important information that could guide health care professionals' efforts in the tailoring of these interventions. The descriptions of the HISB patterns identified the type, amount, and sources of information preferred by individuals according to their described HISB pattern. Findings might help nurses to recognize an individual's particular HISB pattern and respond accordingly. For instance, intense seekers might benefit from a list of credible and reputable websites and/or decision making aids, whereas complementary seekers might prefer references to books that best summarize different aspects of the illness experience. In addition, findings stressed the need for adequate professional informational support. Even for seemingly independent information-seekers, guidance in information-seeking was expressed as facilitating navigation through a daunting sea of cancer information.

Strengths and Limitations

The strengths of this study are many. The use of a qualitative research approach allowed for the richness of individual experience to account for variations in HISB. Particularly, the individual interviews provided an opportunity to ask a range of in-depth questions to characterize each participant's information-seeking experience. Also, variability in terms of treatment modality, stage along the illness trajectory, and age contributed to exploring the phenomenon and the fittingness of the emerging patterns in different contexts. In addition, the data in this study were triangulated by using both individual interviews and focus groups. To enhance rigor, some transcripts were coded by research assistants that were unaware of the emerging patterns and theory. In addition, 10 individual interviews were conducted by a research assistant not involved in coding and also unaware of the identified patterns.

A limitation of this study is that most interviews were retrospective. Although participants recalled the specific dates and time of different events surrounding the cancer diagnosis, they did mention forgetting certain details about their search for cancer information (e.g., not remembering specific information sources used). However, because some of the interviews were retrospective, participants also had some time to reflect on their experience and possibly provide additional insights into the different aspects of their HISB.

A second limitation is that the data collection methods relied on interviewing. In using interviewing it was assumed that if questions were formulated correctly, participants' descriptions of their information-seeking reflected what was actually done (Morse, 2000; Sandelowski, 2002; Macdonald, 2006). The assumption that words are accurate indicators of what participants' did might be problematic as participants might have chosen to withhold certain descriptions—or alternatively, embellish them—particularly if the "truth" is inconsistent with their preferred self-image or if they wanted to impress the interviewer (Fielding, 1994). In anticipation of this issue, I tried to provide an interview setting that was comfortable and nonjudgmental. In future studies, interviews could be combined with observations. For instance, interactions between patients and health care professionals could be observed.

Another limitation is that even if the study design allowed for the identification of variables that might influence preference for one pattern over another, the small number of participants precludes any statistical comparison. In addition, despite efforts to approach individuals from different ethnic backgrounds, most participants were middle-class Caucasians.

Table 1

Definitions of Health Information-Seeking Behavior

Author(s)	Definition
Lenz (1984)	Series of inter-related behaviors that can vary along two main dimensions: (a) extent and (b) method (p. 63)
Barsevick & Johnson (1990)	"Actions used to obtain knowledge of a specific event or situation" (pp. 3-4)
Corbo-Richert, Caty, & Barnes (1993)	"Verbal or nonverbal behavior seeking to attain, clarify, or confirm information" (p.30)
Baker & Connor (1994)	"Any activity undertaken to satisfy a query" (p.38)
Loiselle (1995)	"A self-regulatory strategy that patients use to organize transactions between the self and health-related settings with the goal of balancing instrumental benefits and subjective costs stemming from informational outcome" (p. 9)
Johnson (1997)	"Purposive acquisition of information from selected information carriers" (p. 4)
Conley (1998)	"Verbal or nonverbal behavior used to obtain, clarify, or confirm knowledge or information about a specific event or situation" (p. 132)
van der Molen (1999)	"Strategy that many people use as a means of coping with, and reducing, stress" (p. 239)
Rees & Bath (2000)	"Problem-focused coping strategy sometimes adopted by individuals as a response to a threatening situations" (p. 72)
Rees & Bath (2001)	Monitoring: "the urge to confront oneself with the threatening situation by means of seeking more information about it"(p. 900) Blunting: "tendency to distract from threat-relevant information" (p. 900).
Czaja et al. (2003)	Number of sources from whom an individual sought information

Table 2

Example of a Focus Group Challenging/Clarifying Interaction Emphasizing Differential Approaches to Information-Seeking about Cancer

FG7-02: There are a lot of people giving you advice as well and people trying to compare themselves to you. And saying why are you getting chemo [...] how long is your radiation treatment is it 30 seconds, is it 45, and I thought, I don't know how long is my treatment. Nobody told me how long it was. I only know that I'm going through it, like I'm not, you know, that precise. I assume the doctor knows what they are doing

FG7-03: That's quite interesting because I asked how long the [everybody laughing] and I know that I got 43 seconds from one angle and 44 seconds from another, I don't know if it's...

FG7-02: (cuts) What's the difference?

FG7-03: I wanted to know, it's a total of one minute and a half and it's a total of 4500 Grassman, they call it Grassman [...] It's just different coping strategies.

FG7-01: That's exactly it

FG7-03: What works for you ...

FG7-01: That's right, and that's amazing because like you really did what my daughter did [daughter is a medical student], you know. I can't imagine having to do that, because if she wasn't there, I would have probably done what you did [...]

FG7-02: I know a friend she had breast cancer and she's the one that called me and said how long is your radiation treatment? I don't know maybe a minute in all; I don't know [...] well you better ask him and you better find out. And I said Why? What is it going to change, well you had to know. To me it doesn't mean anything you know. Maybe to my doctors it means something but to me whether it's 30 seconds or...

FG7-04: (Cuts) If they tell 32, would you argue with 35 or 30, that's my point was [02: Yeah! Yeah!] What's the use, who am I pretending to be here. Questioning their medication, what they are giving me, I had to ask certain questions, why are you giving me this to block my hormone instead of this to eliminate them, you know. Things like that.

[FG7 = Focus group #7 with women with breast cancer n=4]

Table 3

Example of a Discussion among Focus Group Members Emphasizing the Contextual Dimension of Antecedents to Cancer Information-Seeking

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FG6-03: I guess I had to become involve in the decision-making process I guess a sense that…

FG6-02: Nothing was clear

FG6-03: I had a very small tumour but it was acting aggressively so I became atypical, what was interesting is that they didn't know how to treat me, because I didn't fit into a sort of very neat little package because they don't know what to do with me […] So what do we do? P. 7 […] Nothing was clear so therefore I felt that I just couldn't sit back and wait for somebody to say do this and this and this way. When I sensed there wasn't you know there wasn't agreement […] so you're right it's that whole notion of the…

FG6-02: Unknown

FG6-03: The unknown and then who is controlling this and how much input. Do you know what I am saying? You just put everything in the hands of the doctors. You sort of need to work with them almost like a partnership it's sort of like which is kind different when usually you go to the doctor if your arm is broken. You don't even think twice about just you arm is broken there going to fix it they're going to set it right! There is probably not many options and all of a sudden with cancer you start to realize there is not one… You know it depends on who you are, your background your this, your that there is just…

FG6-02: That's what I say I was lucky I had that…I had someone in charge right away because they knew what it was in my case. They relieved some of the feel because the doctor X took charged, the doctor X also then I said Oh! I'm in good hands. I thought both the doctors were terrific so I didn't have that unknown, I knew as much because they could tell me the rest was just things I wanted to know for myself. The unknown would have killed me.

[FG6 = Focus group #6 with women with breast cancer n=3]

Table 4

Differences between Glaserian and Straussian Grounded Theory

	Glaser & Strauss (1967)	Strauss & Corbin (1998)
Ontology	Critical realism	Social constructionist-relativism
Epistemology	Postpositivist (modified objectivist)– reality exists but incompletely measured in research	Poststructuralist (subjectivist) – reality can not be known but can be interpreted (social world is complex and ambiguous)
Theory	Emphasizes generation Discovery	Generation and testing/verification Construction
Literature	No review of the literature prior to entering the field – literature taints the researcher's view of the field and constrains the generation of categories. Literature review carried after analysis	Initial review of the literature enhances theoretical sensitivity Main literature review conducted later in the research process to support the emerging theory
Research problem	No preconceived notions about what constitutes the research problem – problem emerges as study begins	Flexibility in identifying research problem based on experiences, collegial suggestion, and literature
Data collection	Flexible	Paradigm Model Obtain multiple perspectives and recognize the contradictions inherent in them
Data analysis	Flexible Substantive and theoretical coding	Paradigm Model – provides a framework for axial coding to identify links between a category and its subcategories Open, axial, and selective coding

Note. Adapted from Annells (1996); Corbin & Strauss (2008); McCann & Clark (2003b); Mills et al. (2007)

Table 5

Participants' Demographic and Medical Data

	Individual Interviews (n=31)	Focus groups (n=31)	Intense (n=12)	Complementary (n=18)	Fortuitous (n=8)	Minimal (n=17)	Guarded (n=7)
Diagnosis (%) Prostate	39	35	50	22	63	41	14
Breast	35	45	33	61	25	29	43
Colorectal	26	20	17	17	12	30	43
Sex M	52	48	58	33	75	59	29
F	48	52	42	67	25	41	71
Age (Mean years)	59	62	55	59	69	66	54
Marital Status (%) Married	74	61	67	56	50	82	86
Common law	13	3	17	11	0	6	0
Single/divorced	13	16	16	17	38	12	14
Widowed	0	20	0	17	12	0	0
Employment (%) Full time	23	10	27	17	13	7	29
Part time	8	10	9	17	0	0	14
Unemployed	0	6	0	6	0	0	14
Sick leave	13	13	27	22	12	6	0
Retired	53	58	37	33	75	81	29
Homemaker	3	3	0	5	0	6	14
Country (%) Canada	73	74	73	83	63	88	57
Other	27	26	27	17	37	12	43
Income (%) < $10 000-29,999	21	28	18	24	43	25	25
$30,000-79,999	63	38	37	35	50	75	50
$80,000-119,999	8	24	27	29	12	0	0
> $120,000	8	10	18	12	0	0	25
Education (%) Elementary	0	3	0	0	12	0	0
High school	33	16	0	22	38	38	29
CEGEP	30	16	0	22	12	31	42
University	37	65	100	56	38	31	29
Years since diagnosis (%) < 1	21	39	37	39	12	25	29
1 – 3	41	26	27	50	12	25	23
3- 6	10	26	18	11	38	19	29
> 6	28	9	18	0	38	31	29
Treatment (%) Surgery	83	71	64	78	75	75	86
Radiotherapy	83	94	100	83	100	81	100
Chemotherapy	52	55	36	67	25	38	86
Brachytherapy	3	3	0	0	12	0	0
None	0	3	0	0	0	0	0
Other	6	13	0	6	12	0	0

Table 6

Focus Group Interaction among Women with Breast Cancer to Illustrate Individuals' Differential Approaches to Information-Seeking

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FG7-04: 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.

FG7-03: 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.

FG7-01: 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.

FG7= Focus Group #7

Table 7

Focus Group Interaction among Men with Prostate Cancer to Illustrate Difference between Intense and Complementary Information-Seeking

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FG1-02: 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 [...]

FG1-03: 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!

FG1-05: But when he [oncologist] puts on the table all the possibilities available, there are several [...] you have a choice, you can not say I abandon myself to your care, he is going to turn around and say sign here.

FG1= Focus group #1

Table 8

Quotations Depicting the Essential Characteristics of the Intense, Complementary, and Fortuitous Information-Seeking Patterns

	Intense information-seeking	Complementary information-seeking	Fortuitous information-seeking
Type and amount	#1 Prioritized, maximize: 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. #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.	#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 there were side effects. #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.	#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.
Source	#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.	#7 Books: 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	#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.
Action	#9 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.	#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.	#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.

Table 9

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
Gauging 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?
Anticipating 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).
Communicating with health care professionals and friends/family	I wanted to be able to converse on a reasonably intelligent level with physicians 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.

Table 10

Focus Group Interaction among Women with Breast Cancer

FG2-04: It's such a horrible disease. I think of it like, how awful is it to always be preoccupied by the thought of death? That to me is the worst of all this right. I will be sitting in the next room with people of my age waiting for an ultrasound for their baby. And I am waiting for an ultrasound for a… you know a CT scan […] There is not one day that goes by that I don't think that I have cancer […] I would be curious to see from you guys, if feels like retribution or punishment or something that I am getting paid back for what I ever did to deserve this.

FG2-05: There's nothing that you did wrong truthfully

FG2-04: I know, but it's just like why! Why! Does my life have to be thinking of dying on a daily basis?

FG2-03: I thought that it was like a punishment. I was thinking what did I do wrong? But then I said to myself: look it may not be a punishment; it might be an opportunity […]

FG2-05: […] There is nothing that I can blame myself for […] I don't know why we get it. But we get it.

FG2= Focus group #2

Table 11

Quotations Illustrating Variation in Minimal Information-Seeking

Quotation #1: High Interest for receiving cancer information	Quotation #2: Low interest for receiving cancer information
Because otherwise I feel like a fish out of water […] if I don't get the information. Then I feel that I don't know what to do exactly. And if I get the information, it comes from a professional person that has experience that should be able to give me information […] When I went to Doctor X, […] he explained every line of the pathology report.	I am not into the seek information thing […] I am not pro-active when it comes to that. I just figured out that I am glad to be around and aware of it […] I take everything as it comes […] I'm not a big seeker […] I know a lot of people they go nuts; you know they go online […] I'm not like, searching for the Holy Grail here. I'm just, whatever they give me, they give me, you know.

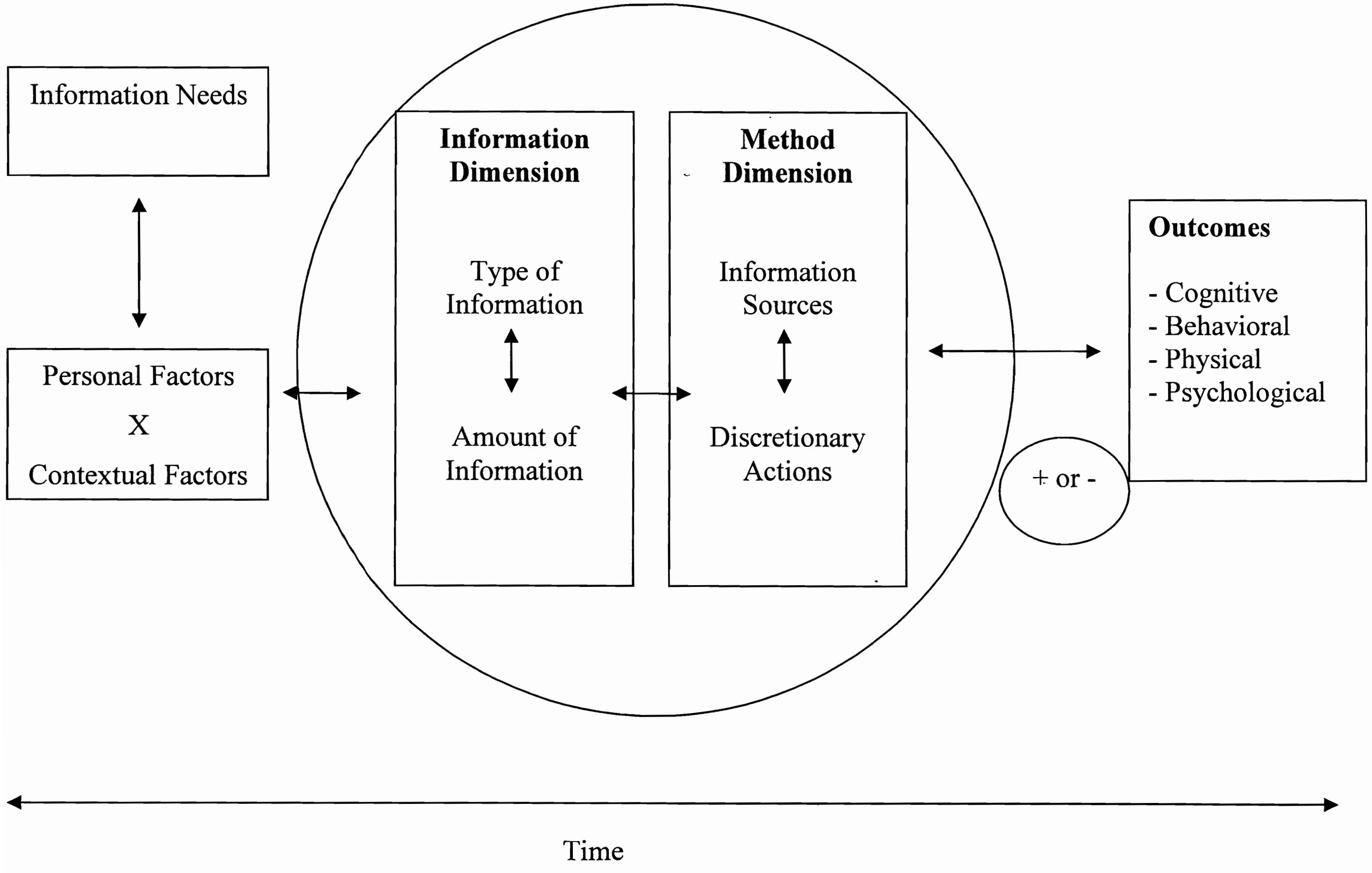


Figure 1. Schematic description of the dimensions of health-related information-seeking

The following statements describe how people may deal with information about cancer. Read each statement and decide (1) to (5) how each statement reflects how you dealt with cancer information **within the past week**. There are no right or wrong answers.

	Please place a √ in the appropriate boxes below				
This past week…	Not at all 1	Somewhat 2	Moderately 3	Very much so 4	No opinion 5
1. I only sought information about my illness related to what I thought was wrong with me					
3. I sought ALL available information about my general health status					
5. information about my illness made me feel too anxious					
13. I only sought information about my illness that was encouraging					

Figure 2. Sample items of The Differential Health-Information Seeking Behavior (DHISB) scale (Loiselle, 2002; Loiselle & Lambert, 2008).

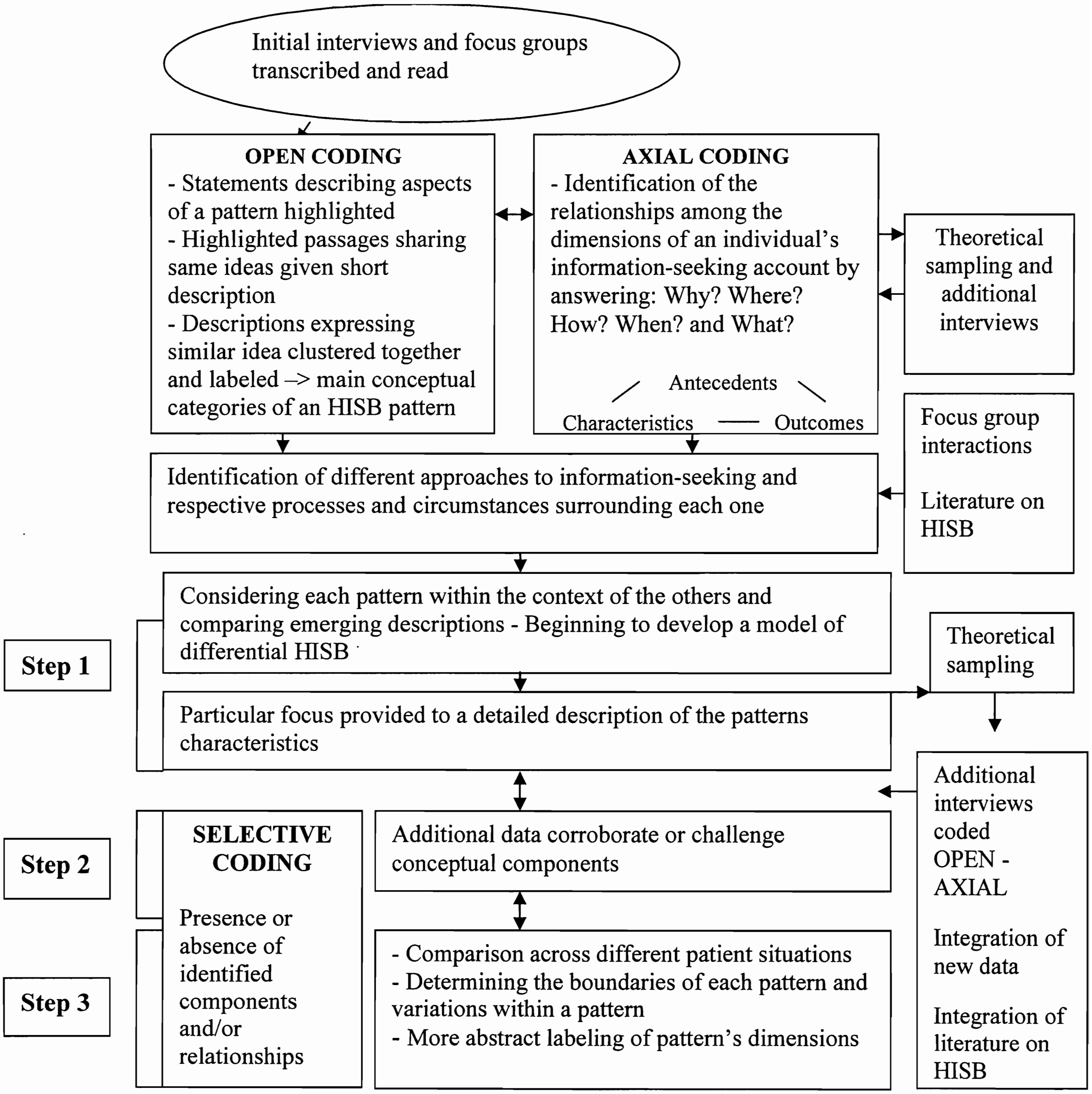
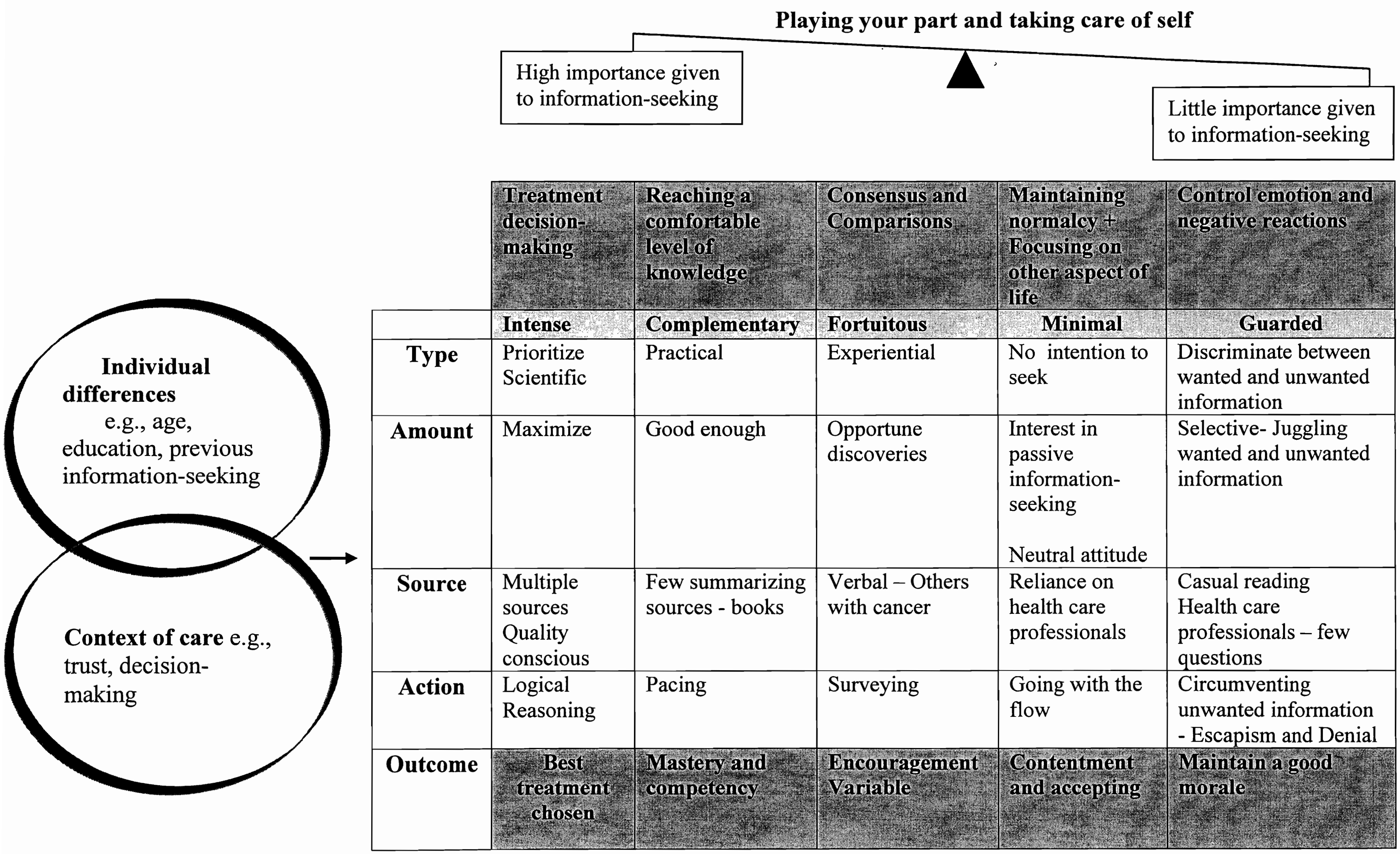


Figure 3. Steps to data analysis



	Treatment decision-making	Reaching a comfortable level of knowledge	Consensus and Comparisons	Maintaining normalcy + Focusing on other aspect of life	Control emotion and negative reactions
	Intense	**Complementary**	**Fortuitous**	**Minimal**	**Guarded**
Type	Prioritize Scientific	Practical	Experiential	No intention to seek	Discriminate between wanted and unwanted information
Amount	Maximize	Good enough	Opportune discoveries	Interest in passive information-seeking Neutral attitude	Selective- Juggling wanted and unwanted information
Source	Multiple sources Quality conscious	Few summarizing sources - books	Verbal – Others with cancer	Reliance on health care professionals	Casual reading Health care professionals – few questions
Action	Logical Reasoning	Pacing	Surveying	Going with the flow	Circumventing unwanted information - Escapism and Denial
Outcome	Best treatment chosen	Mastery and competency	Encouragement Variable	Contentment and accepting	Maintain a good morale

Figure 4. A theory of differential health information-seeking patterns in cancer. Part 1 describes patterns: Intense, Complementary, and Fortuitous. Part 2 describes patterns: Minimal and guarded

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Appendix A Ethics Approval Letters

McGill

Faculty of Medicine
3655 Promenade Sir William Osler
Montreal, QC H3G 1Y6

Faculté de médecine
3655, Promenade Sir William Osler
Montréal, QC, H3G 1Y6

Fax/Télécopieur (514) 398-3595

CERTIFICATION OF ETHICAL ACCEPTABILITY FOR RESEARCH INVOLVING HUMAN SUBJECTS

The Faculty of Medicine Institutional Review Board consisting of:

MICHAL ABRAHAMOWICZ, PHD	SARIT ASSOULINE, MD
ARTHUR CANDIB, MED	CATHERINE GARDNER, BSC
RICHARD HAMILTON, MD	LAWRENCE HUTCHISON, MD
ROBERT L. MUNRO, BCL	MARGARET SWAINE, BA

Has examined the research project **A06-B21-05A** entitled **"Refinement of a Self-Report Questionnaire Designed to Measure Individual's Different Health Information-Seeking Behaviours"**

As proposed by: Dr. Carmen G. Loiselle (Applicant) to ______ (Granting Agency, if any)

And consider the experimental procedures to be acceptable on ethical grounds for research involving human subjects.

19 August 2005
Date

Co-Chair, IRB

Dean of Faculty

Institutional Review Board Assurance Number: FWA 00004545

McGill

Faculty of Medicine
3655 Promenade Sir William Osler
Montreal, QC H3G 1Y6

Faculté de médecine
3655, Promenade Sir William Osler
Montréal, QC, H3G 1Y6

Fax/Télécopieur: (514) 398-3595

19 August 2005

Dr. Carmen G. Loiselle
School of Nursing
Wilson Hall
3506 rue University
Montreal Quebec H3A 2A7

Dear Dr. Loiselle,

The Institutional Review Board of the Faculty of Medicine, McGill University, has received documentation in support of study number A00-B21-05A entitled, "Refinement of a Self-Report Questionnaire Designed to Measure Individual's Different Health Information-Seeking Behaviours", which was initially reviewed at the IRB meeting on 13 June 2005.

The documents have been re-assessed and the submitted responses and revisions are deemed satisfactory. The IRB is pleased to inform you that final approval has been provided on *19 August 2005* for the following: the revised Research Protocol (dated August 2005); the revised Information and Consent Form – Focus Group (English and French versions, dated 15 August 2005); the Information and Consent Form – Individual Interview (English and French versions, dated 15 August 2005); the Audio Taping Consent forms for both the Group and the Individual Interviews (English and French versions, all dated 15 August 2005); the revised Socio-Demographic Questionnaires (English and French versions, dated 15 August 2005); the revised Medical Information Questionnaires (English and French versions, dated 15 August 2005) and the Recruitment Advertisements (Appendix A, English and French versions, dated June 2005). This study has been approved until **June 2006.** The Certificate of Acceptability is enclosed.

Please be aware that a review of all research involving human subjects is required on an annual basis and in accordance with the date of initial approval. If there are any modifications, or if any unanticipated developments occur to the study prior to the next review, please inform the IRB promptly.

Please note that it is the investigator's responsibility to ensure that the approved study protocol and consent documents are deposited with the Research Ethics Board of each hospital where subject recruitment will occur and/or where study data will be collected. <u>The study cannot be initiated until acceptance has been obtained from the hospitals' Research Ethics Boards. Study data may be invalidated and research funds frozen if there is a failure to comply.</u>

If you have any questions, please contact our office.

Sincerely,

J. Lawrence Hutchison, MD
Co-Chair
Institutional Review Board

Cc: Sylvie D. Lambert; Ms. F. Cantini – JGH; Ms. E. Boyle – MUHC/MGH; Ms. L. Fateen – MUHC/RVH; A06-B21-05A

Appendix H

Centre universitaire de santé McGill
McGill University Health Centre

September 7, 2005

Dr. Carmen G. Loiselle
School of Nursing
Wilson Hall
3506 reu University
Montreal, Quebec H3A 2A7

RE: McGill #A06-B21-05A (MUHC-MGH/RVH#05-071) entitled "Refinement of a Self-Report Questionnaire Designed to Measure Individual's Different Health Information-Seeking Behaviours."

Dear Dr. Loiselle:

Thank you for providing the information relating to above-mentioned research study that you wish to activate at the McGill University Health Centre (MUHC) Montreal General Hospital and Royal Victoria Hospital.

The Office of Research Ethics acknowledges the review of the McGill University Institutional Review Board, that as the Research Ethics Board (REB) of Record, has provided full approval for the following documents on 19 August 2005, valid until June 2006:

> *Study Protocol (dated August 2005); the revised Information and Consent Form – Focus Group (English and French versions, dated 15 August 2005); the Information and Consent Form – Individual Interview (English and French versions, dated 15 August 2005); the Audio Taping Consent Forms for both the Group and the Individual Interviews (English and French versions, all dated 15 August 2005): the revised Socio-Demographic Questionnaires (English and French versions, dated 15 August 2005); and the Recruitment Advertisements (Appendix A, English and French versions dated June 2005).*

Our review of the submitted documents indicates that you intend to carry out research related procedures at the MUHC sites listed above. We are pleased to inform you that the study was found within MUHC ethical guidelines for research, and according to existing agreements, you are authorized to conduct the study at the MUHC sites listed above.

We ask you to take note that it is the responsibility of the principal investigator to maintain study approval by complying with all further requests of the REB of Record, including timely submission of the application for Continuing Review to the McGill University Institutional Review Board.

The project was assigned study Number **MUHC-MGH/RVH#05-071** that will be used as the MUHC reference when communicating about the research. Should any revision to the study, or other unanticipated development occur prior to the next required review, you must advise the REB of Record without delay.

Sincerely,

Denis Cournoyer, MD
Director
Research Ethics Office
McGill University Health Centre

Cc: MUHC-MGH/RVH#05-071

McGill

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3655 Promenade Sir William Osler
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Fax/Télécopieur: (514) 398-3595

14 March 2006.

Dr. Carmen G. Loiselle
School of Nursing
Wilson Hall
3506 University Street
Montreal Quebec H3A 2A7

RE: IRB Study Number A06-B21-05A

Dear Dr. Loiselle,

The Institutional Review Board of the Faculty of Medicine has received your submission for ethics review for the study entitled, "Refinement of a Self-Report Questionnaire Designed to Measure Individuals' Differential Health Information-Seeking Behaviours".

The documents received review and full Board approval is provided on March 13, 2006 for the following:

- Study amendment as outlined in correspondence dated March 3, 2006
- Information and Consent Form – Individual Interview (English and French versions) dated March 3, 2006;
- Information and Consent Form – Focus Group (English and French versions) dated March 3, 2006;
- Socio-demographic and Medical questionnaires – English and French versions dated March 3, 2006.

Please note, it is the investigator's responsibility for ensuring that the approved consent documents are deposited at the Research Ethics Board of each hospital where subject recruitment occurs and/or where study data is collected. The investigator risks having the study's data invalidated and research funds frozen if there is a failure to comply.

Sincerely,

C. Celeste Johnston

C. Celeste Johnston, RN., D.Ed.
Co-Chair
Institutional Review Board

Cc: Ms. Sylvie D. Lambert
Ms. L. Martin – JGH
Ms. E. Boyle – MGH
Ms. L. Fateen – RVH
A06-B21-05A

Appendix B Consent Forms

"Refinement of a Self-Report Questionnaire Designed to Measure Individuals' Differential Health Information-Seeking Behaviors"

Information and Consent Form-Focus Group

Investigators

Sylvie Lambert, N., B.Sc., Doctoral Candidate
McGill University School of Nursing
(514) 298-0625
sylvie.lambert@mail.mcgill.ca

Dr. Carmen Loiselle, N., Ph.D.
Assistant Professor
McGill University School of Nursing
Nurse Scientist
Centre for Nursing Research
SMBD-Jewish General Hospital
(514) 398-4163 ou
(514) 340-8222, poste 5784
carmen.loiselle1@mcgill.ca

DATE OF I.R.B.
APPROVAL
MAR 13 2006
Faculty of Medicine
McGill University

If you have any difficulty reading this form, please let the researcher or research assistant know.

Introduction

I am a nurse completing my doctoral studies at the School of Nursing, McGill University. As part of my research training, I am conducting a research project under the direction of Dr. Carmen Loiselle. We are interested in exploring how individuals diagnosed with either breast, prostate or colorectal cancer seek information related to their health. You are being asked to participate in this study because you have been diagnosed with cancer and you are receiving medical care at the McGill University Health Centre or at the SMBD-Jewish General Hospital.

This consent form should provide you with the basic idea of what this research is about and what your participation will involve. Before accepting to participate in this study, please take time to read the information that follows. If you would like more detail about this study, please feel free to ask the researchers or research assistant. You may take this form with you and take the time necessary before making your decision to take part in this study. This document may contain terms that are unfamiliar to you. We invite you to ask the researchers or research assistant to clarify anything that is unclear to you. If you decide to participate, you will be asked to sign this form and a copy will be given to you.

Study Objective

We invite you to participate in a study that explores information-seeking behaviors in illness, in particular, how individuals diagnosed with cancer go about obtaining the information that they want about their illness. The aim of this study is to better understand how and why individuals seek and obtain this information.

We expect to recruit 30 patients for this study from the Royal Victoria Hospital, the Montreal General Hospital, and the SMBD-Jewish General Hospital.

What will happen to you if you take part in this study

Information will be gathered through face-to-face interviews with a group of individuals diagnosed with cancer (6 to 10 individuals per group). The focus of the interview will be on discussing how you seek information related to your cancer. Specifically, questions asked by the researcher or a trained research assistant will focus on the purpose of searching health-related information and the type and amount of information about your cancer that you like to seek. The interview is anticipated to last approximately 1.5 to 2 hours and will take place in a private room within the hospital. Interviews will be audio taped. The tapes will only be listened to by the researchers to help recall details of the group interviews. You can refuse to be audio taped by informing the researcher.

Following the group interview, you will be asked to complete a brief questionnaire on background information about yourself, such as your educational level, the type of work you do, and medical treatment. This will take approximately 10 minutes to complete. We may also need to review your medical record to get information on your medical history.

Risks and Discomforts

There are no foreseeable risks for participating in this study. Some individuals may find that discussions raise unpleasant thoughts or memories for them. If at any time you wish to stop the discussion, this will be accommodated. The investigators are available to discuss any concerns, and if needed, assist you in finding appropriate resources.

Potential Benefits

There are no direct benefits for participating in this study. However, some individuals may find it helpful to have the opportunity to share their experience with others. We hope that findings will inform the health care team on how to best assist individuals, in the future, in their search for cancer-related information.

Compensation

As a recognition of your involvement in this study, you will receive 20$ for participating in this study.

Confidentiality

All the information you provide remains strictly confidential within the limits set by law. Members of the McGill University (Faculty of Medicine), McGill University Health Centre, and SMBD- Jewish General Hospital Ethics Committee and authorized hospital personnel may have direct access to certain records for verification/auditing purposes. The group interview transcripts, demographic sheets, and audiotapes will be identified with a code that will be used to protect confidentiality. Your name and the names of anyone you mention will not appear anywhere to ensure anonymity. All measures will be taken to ensure that the confidentiality of your medical file, if consulted, and all information collected pertaining to yourself will remain confidential. We will keep all collected information and audio tapes in a locked filling cabinet at the Centre for Nursing Research of the SMBD-Jewish General Hospital. The researchers and research assistants are the only ones who have access to these materials. All documents and material related to this study will be destroyed after 5 years. Names or personal information will not be identifiable in any resulting publications. The findings of this study may be available to you upon request.

Voluntary Participation and/or Withdrawal

Your participation in this study is voluntary. Therefore, you have the right to refuse to participate, or to withdraw at any time, without explanation, by informing the researcher or the research assistant. Your decision not to participate in the study or to withdraw from the study will have no consequence on the present or future care you will receive at the Royal Victoria Hospital, the Montreal General Hospital, or the SMBD-Jewish General Hospital.

Contact People for the Study

Investigators:
Sylvie Lambert, N., B.Sc., Doctoral Candidate
McGill University School of Nursing
(514)-298-20625

Dr. Carmen Loiselle, N., Ph.D.
Assistant Professor
McGill University School of Nursing
Nurse Scientist
Centre for Nursing Research
SMBD-Jewish General Hospital
(514)-398-4163

Questions about your rights as a research participant and/or research related injuries please contact:

The Ombudsman Royal Victoria Hospital
Pat O'Rourke (514) 934-1934 #35655

Montreal General Hospital
Line-Marie Casgrain (514) 934-8306

The Patient Representative SMBD- Jewish General Hospital
Ms. Laurie Berlin (514) 340-8222 #5833

You do not give up any of your legal rights by signing this form

Consent

I have read this consent form and accept to be involved in the present study. I have been given sufficient time to decide whether or not to participate.

This study has been explained to me and questions that I might have were answered to my satisfaction. I know that at any time I may ask questions I have about the study or the research procedures.

I have been assured that information relating to me will be kept confidential and that no information will be released or printed that would disclose my personal identity.

By signing this consent form, I have in no way waived my legal rights, nor do I free the researchers or the hospital of their civil and professional responsibilities. I know that I am free to withdraw from this study at any time without jeopardizing the health care which I am entitled to receive. I know that my continued participation should be as informed as my initial consent, and I feel confident that I may ask at any time for clarification about the study or new information about my participation. I will be given a signed copy of this consent form.

I agree to participate in this study
Name of participant: ____________________________ (please print)
Signature ____________________________Date _________________

Name of witness: ____________________________ (please print)
Signature ____________________________ Date _________________

I have explained the nature of this study as well as the contents of this consent form to the participant. I have answered all of his/her questions and have informed the participant of his/her right to withdraw at any time. I will give a signed copy of this consent form to the participant.

Name of the researcher or the person representing her:

____

Signature ____________________________ Date _________________

Following the focus group, if you agree, the researcher may re-contact you by phone at a later time to schedule an individual interview (approximately 30-60 minutes) to further explore or clarify some aspects of the group interview. This second interview may be conducted over the phone or at a time and place that is convenient for you (e.g., home). Interviews will be audio taped. The tapes will only be listened to by the researchers to help recall details of the group interviews. You can refuse to be audio taped by informing the researcher. You can also refuse this second interview by informing the researcher and only participate in the group interview.

Do you agree to possibly be re-contacted by the researcher to schedule an individual interview:

___ Yes

___ No

Signature: ______________________________ Date: ___________

"Refinement of a Self-Report Questionnaire Designed to Measure Individuals' Differential Health Information-Seeking Behaviors"

Information and Consent Form-Individual Interview

DATE OF I.R.B.
APPROVAL
MAR 1 3 2006
Faculty of Medicine
McGill University

Investigators
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(514)-398-4163
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carmen.loiselle1@mcgill.ca

If you have any difficulty reading this form, please let the researcher or research assistant know.

Introduction

I am a nurse completing my doctoral studies at the School of Nursing, McGill University. As part of my research training, I am conducting a research project under the direction of Dr. Carmen Loiselle. We are interested in exploring how individuals diagnosed with either breast, prostate or colorectal cancer seek information related to their health. You are being asked to participate in this study because you have been diagnosed with cancer and you are receiving medical care at the McGill University Health Centre or at the SMBD-Jewish General Hospital.

This consent form should provide you with the basic idea of what this research is about and what your participation will involve. Before accepting to participate in this study, please take time to read the information that follows. If you would like more detail about this study, please feel free to ask the researchers or research assistant. You may take this form with you and take the time necessary before making your decision to take part in this study. This document may contain terms that are unfamiliar to you. We invite you to ask the researchers or research assistant to clarify anything that is unclear to you. If you decide to participate, you will be asked to sign this form and a copy will be given to you.

Study Objective

We invite you to participate in a study that explores information-seeking behaviors in illness, in particular, how individuals diagnosed with cancer go about obtaining the information that they want about their illness. The aim of this study is to better understand how and why individuals seek and obtain this information.

We expect to recruit 30 patients for this study from the Royal Victoria Hospital, the Montreal General Hospital, and the SMBD-Jewish General Hospital.

What will happen to you if you take part in this study

Information will be gathered through a face-to-face individual interview. The focus of the interview will be on discussing how you seek information related to your cancer. Specifically, questions asked by the researcher or a trained research assistant will focus on the purpose of searching health-related information and the type and amount of information about your cancer that you like to seek. The interview is anticipated to last approximately 1 to 1.5 hours and will be in a place most convenient for you (e.g., hospital, home). Interviews will be audio taped. The tapes will only be listened to by the researchers to help recall details of the interview. You can refuse to be audio taped by informing the researcher.

Following the interview, you will be asked to complete a brief questionnaire on background information about yourself, such as your educational level, the type of work you do, and medical treatment. This will take approximately 10 minutes to complete. We may also need to review your medical record to get information on your medical history.

Risks and Discomforts

There are no foreseeable risks for participating in this study. Some individuals may find that the interview raises unpleasant thoughts or memories for them. If at any time you wish to stop the discussion, this will be accommodated. The investigators are available to discuss any concerns, and if needed, assist you in finding appropriate resources.

Potential Benefits

There are no direct benefits for participating in this study. However, some individuals may find it helpful to have the opportunity to talk about their experience with others. We hope that findings will inform the health care team on how to best assist individuals, in the future, in their search for cancer-related information.

Compensation

As a recognition of your involvement in this study, you will receive 20$ for participating in this study.

Confidentiality

All the information you provide remains strictly confidential within the limits set by law. Members of the McGill University (Faculty of Medicine), McGill University Health Centre, and SMBD- Jewish General Hospital Ethics Committee and authorized hospital personnel may have direct access to certain records for verification/auditing purposes. The interview transcripts, demographic sheets, and audiotapes will be identified with a code that will be used to protect confidentiality. Your name and the names of anyone you mention will not appear anywhere to ensure anonymity. All measures will be taken to ensure that the confidentiality of your medical file, if consulted, and all information collected pertaining to yourself will remain confidential. We will keep all collected information and audio tapes in a locked filling cabinet at the Centre for Nursing Research of the SMBD-Jewish General Hospital. The researchers and research assistants are the only ones who have access to these materials. All documents and material related to this study will be destroyed after 5 years. Names or personal information will not be identifiable in any resulting publications. The findings of this study may be available to you upon request.

Voluntary Participation and/or Withdrawal

Your participation in this study is voluntary. Therefore, you have the right to refuse to participate, or to withdraw at any time, without explanation, by informing the researcher or the research assistant. Your decision not to participate in the study or to withdraw from the study will have no consequence on the present or future care you will receive at the Royal Victoria Hospital, the Montreal General Hospital, or the SMBD-Jewish General Hospital.

Contact People for the Study

Investigators:
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(514)-398-4163

Questions about your rights as a research participant and/or research related injuries please contact:

The Ombudsman Royal Victoria Hospital
Pat O'Rourke (514) 934-1934 #35655

Montreal General Hospital Line-Marie Casgrain (514) 934-8306

The Patient Representative SMBD- Jewish General Hospital
Ms. Laurie Berlin (514) 340-8222 #5833

You do not give up any of your legal rights by signing this form

Consent

I have read this consent form and accept to be involved in the present study. I have been given sufficient time to decide whether or not to participate.

This study has been explained to me and questions that I might have were answered to my satisfaction. I know that at any time I may ask questions I have about the study or the research procedures.

I have been assured that information relating to me will be kept confidential and that no information will be released or printed that would disclose my personal identity.

By signing this consent form, I have in no way waived my legal rights, nor do I free the researchers or the hospital of their civil and professional responsibilities. I know that I am free to withdraw from this study at any time without jeopardizing the health care which I am entitled to receive. I know that my continued participation should be as informed as my initial consent, and I feel confident that I may ask at any time for clarification about the study or new information about my participation. I will be given a signed copy of this consent form.

I agree to participate in this study
Name of participant: ______________________________ (please print)
Signature ______________________________Date __________________

Name of witness: ____________________________ (please print)
Signature ______________________________ Date __________________

I have explained the nature of this study as well as the contents of this consent form to the participant. I have answered all of his/her questions and have informed the participant of his/her right to withdraw at any time. I will give a signed copy of this consent form to the participant.
Name of the researcher or the person representing her:

____

Signature ______________________________ Date __________________

Following the first interview, if you agree, the researcher may re-contact you by phone at a later time to schedule a second individual interview (approximately 30-60 minutes) to further explore or clarify some aspects of the first interview. This second interview may be conducted over the phone or at a time and place that is convenient for you (e.g., home). Interviews will be audio taped. The tapes will only be listened to by the researchers to help recall details of the group interviews. You can refuse to be audio taped by informing the researcher. You can also refuse this second interview by informing the researcher and only participate in the first interview.

Do you agree to possibly be re-contacted by the researcher to schedule a second interview:

___ Yes

___ No

Signature: ______________________________ Date: ___________

"Modification d'une Échelle pour Mesurer les Comportements de Recherche D'information"

Formulaire d'information et de consentement- Entrevue Groupe

DATE OF I.R.B.
APPROVAL

MAR 13 2006

Faculty of Medicine
McGill University

Chercheures
Sylvie Lambert, N., B.Sc., Candidate au Doctorat
École des sciences infirmières - Université McGill
(514) 298-0625
sylvie.lambert@mail.mcgill.ca

Dre Carmen Loiselle, Inf., Ph. D.
Professeur adjoint - École des sciences infirmières - Université McGill
Chercheure - Centre de recherche en soins
Infirmiers - Hôpital général juif SMBD
(514) 398-4163 ou
(514) 340-8222, poste 5784
carmen.loiselle1@mcgill.ca

Si vous avez de la difficulté à lire ce document, SVP en informer l'une des chercheures ou agents de recherche.

Introduction

Je suis infirmière au doctorat à l'école des sciences infirmières de l'université McGill. Dans le cadre de ma formation en recherche, je fais une étude sous la direction du Dre Carmen Loiselle. Nous voulons explorer comment les gens, avec un diagnostic de cancer du sein, de la prostate, du colon ou du rectum, recherchent l'information qu'ils ont besoin reliée à leur cancer. Vous avez été approché(e) pour participer à cette étude parce que vous avez un diagnostic de cancer et vous recevez des soins médicaux à l'hôpital Royal Victoria, l'hôpital général de Montréal et l'hôpital général juif - SMBD.

Ce document fournit des informations au sujet de cette étude et spécifie votre engagement. Avant d'accepter de participer à cette étude, veuillez prendre le temps de lire attentivement les renseignements qui suivent. Si vous voulez davantage d'informations, SVP n'hésitez pas à poser vos questions aux chercheures ou agents de recherche. Vous pouvez apporter une copie de ce document avec vous à la maison et prendre le temps qu'il vous soit nécessaire avant de décider de prendre part à cette étude. Le présent document, peut contenir des termes que vous ne comprenez pas. Nous vous invitons à poser toutes questions que vous jugez utiles aux chercheures ou agents de recherche, ainsi qu'à leurs demander de vous expliquer les éléments qui ne vous sont pas clairs. Si vous décidez de prendre part à cette étude, nous vous demandons de signer ce formulaire, et une copie vous sera remise.

Objectif de l'Étude

Nous vous invitons à participer à cette étude qui vise à explorer les comportements des gens diagnostiqués avec un cancer du sein, de la prostate, du rectum ou du colon lors de la recherche d'information. Le but premier de cette étude est de mieux comprendre comment les gens recherchent les informations reliées à leur cancer.

Nous prévoyons recruter 30 patients pour l'étude provenant de l'hôpital Royal Victoria, l'hôpital général de Montréal et l'hôpital général juif – SMBD.

Participation à l'étude

Après avoir lu ce formulaire de consentement, si vous acceptez de participer, la chercheure ou l'agent de recherche vous invitera à participer à une entrevue avec un groupe de 6 à 10 individus diagnostiqués avec le cancer. Le but de l'entrevue, est de discuter comment vous obtenez l'information dont vous avez de besoin reliée à votre cancer. Précisément, les questions demandées par la chercheure ou l'agent de recherche focusera sur le but de vos recherches d'information, le type d'information que vous obtenez et la quantité d'information que vous préférez. L'entrevue sera d'une durée approximative de 1.5 à 2 heures et sera dans un endroit approprié de l'hôpital. Les entrevues seront enregistrées sur cassette audio. Cet enregistrement sonore aidera les chercheures à se rappeler des details de l'entrevue. Si vous ne voulez pas être enregistré, SVP en informer la chercheure ou l'agent de recherche.

Également, nous vous demanderons de compléter un bref questionnaire d'ordre général portant sur votre niveau de scolarité, votre travail et vos traitements ou soins médicaux. Ceci prendra environ 10 minutes. De plus, nous aurons peut-être besoin de consulter votre dossier médical afin d'obtenir des informations sur votre histoire médicale.

Risques

Il n'y a aucun risque connu à participer dans cette étude. Il est possible que certains des sujets abordés suscitent chez vous des sentiments, pensées ou mémoires déplaisantes. Si vous décidez de cesser l'entrevue en quelque temps que ce soit, votre volonté sera respectée. Les chercheures seront à votre disponibilité pour discuter toutes préoccupations que vous avez concernant l' étude , au besoin, seront vous référer à une ressource appropriée.

Bénéfices

Cette étude vous offrira probablement aucun bénéfice direct. Toutefois, certaines personnes peuvent trouver aidant le fait de parler de leur expérience avec d'autres individus. Par ailleurs, vos réponses nous apporterons une information précieuse sur la manière dont une équipe en soin de santé peut aider, dans le futur, les gens dans leur recherche d'information.

Compensation

En digne de reconnaissance pour votre engagement dans cette étude, vous recevrez une indemnité de $20.00 pour votre participation.

Confidentialité

Toutes les informations que vous nous fournirez demeureront strictement confidentielles dans les mesures permises par les lois et règlements applicables._Toutefois afin de vérifier les données du projet, les membres des comités d'éthique de l'université McGill (Faculté de Medicine), du centre universitaire de santé mcgill et de l' hôpital général juif SMBD et le personnel autorisé de ces hôpitaux pourront avoir accès à certains documents. Les notes et les enregistrements sonores des entrevues seront attribués un code. Pour sauvegarder l'anonymat, votre nom et celui des gens mentionés durant les entrevues n'apparaîtront pas. Toutes les mesures appropriées seront prises afin que soit préservée la confidentialité des renseignements contenus dans votre dossier médical, s'il doit être consulté, et des données recueillies à votre sujet en cours d'étude. Nous allons garder toutes les informations sous clé au centre de recherche en soins infirmiers de l'hôpital général juif SMBD. L'accès à ces documents est réservé aux chercheures et agents de recherche. Tout le matériel relié a cette étude sera détruit aprè une période de 5 ans. Les résultats de cette étude pourront être publiés. Toutefois, votre identité ne sera jamais révélée. Sur demande, les résultats de cette étude peuvent vous être disponibles.

Participation et/ou Retrait Volontaire

Votre participation est tout à fait volontaire. Vous êtes totalement libre de refuser de participer à cette étude. Vous pouvez cesser votre participation en tout temps sans explication, cependant SVP en informer les chercheures ou l'agent de recherche. Votre décision de ne pas participer à cette étude ou de vous en retirer n'aura aucune conséquence sur la qualité des soins que vous recevez ou receverez à l'hôpital Royal Victoria, l'hôpital général de Montréal et l'hôpital général juif - SMBD.

Personnes à contacter si vous le désirez :

Les chercheures principales de l'étude
Sylvie Lambert, N., B.Sc., Candidate au Doctorat
École des sciences infirmières - Université McGill
sylvie.lambert@mail.mcgill.ca

Dre. Carmen Loiselle, Inf., Ph. D.
Professeur adjoint - École des sciences infirmières - Université McGill
Chercheure - Centre de recherche en soins Infirmiers - Hôpital général juif SMBD
(514) 398-4163 ou
(514) 340-8222, poste 5784
carmen.loiselle1@mcgill.ca

À propos de vos droits en tant que participant(e) à une recherche
L' Ombudsman Hôpital Royal Victoria
Pat O'Rourke (514) 934-1934 #35655

Hôpital général de Montréal
Line-Marie Casgrain (514) 934-8306

Représentante des patients Hôpital général juif S.M.B.D.
Ms. Laurie Berlin (514) 340-8222 #5833

Vous n'abandonnez aucun de vos droits en signant ce formulaire.

Consentement

J'ai lu ce formulaire de consentement, et j'accepte de participer à cette étude. Je reconnais qu'on m'a expliqué le projet, qu'on a répondu à mes questions de façon satisfaisante et qu'on m'ait laissé le temps voulu pour prendre une décision. Je sais que je peux demander, en tout temps, aux chercheures des questions concernant cette étude.

On m'a assuré que l'information à mon égard sera gardée confidentiel et aucune information qui divulguera mon identité sera publiée.

En signant le présent formulaire, je ne renonce à aucun de mes droits légaux ni ne libère les chercheures ou l'hôpital de leur responsabilité civile et professionnelle. Je sais que je peux me retirer de l'étude en tout temps sans que cela n'influence la qualité des soins que je reçois. Je sais que je peux demander en tout temps des questions ou clarifications aux chercheures concernant l'étude et ma participation.

On me remettra une copie signée du présent formulaire.

Je consens librement et volontairement à participer à ce projet.
Nom du participant(e) : ______________________________ (en lettres moulées, s.v.p.)
Signature ______________________________ Date ___________________

Nom du témoin : ______________________________ (en lettres moulées, s.v.p.)
Signature : ______________________________ Date ___________________

Je certifie avoir expliqué au sujet la nature du projet de recherche ainsi que le contenu du présent formulaire. Ēgalement, avoir répondu à toutes ses questions et avoir indiqué qu'il/elle est libre à tout moment de mettre un terme à sa participation. Je remettrai au participant(e) une copie signée du présent formulaire de consentement.

Nom de la chercheure ou de la personne désignée par elle: _______________
Signature : ______________________________ Date ___________________

Suite à l'entrevue de groupe, si vous êtes d'accord, la chercheur vous re-téléphonera pour planifier une entrevue individuelle (30-60 minutes approximativement) pour explorer d'avantage ou pour clarifier certains points discuter durant l'entrevue de groupe. Cette seconde entrevue peut être faite au téléphone ou sera dans un endroit convenable pour vous (ex., hôpital, domicile). Cette entrevue sera également enregistrée sur cassette audio. Cet enregistrement sonore aidera les chercheures à se rappeler des détails de l'entrevue. Si vous ne voulez pas être enregistré, SVP en informer la chercheure ou l'agent de recherche. Vous pouvez choisir de participer seulement à l'entrevue de groupe, si vous ne voulez pas participer à l'entrevue individuelle, SVP en informer la chercheure.

Acceptez-vous d'être re-contacté par la chercheure pour planifier possiblement une entrevue individuelle:

____Oui

____ Non

Signature : ________________________________ Date : __________

"Modification d'une Échelle pour Mesurer les Comportements de Recherche D'information Sur ls Santé"

Formulaire d'information et de consentement- Entrevue Individuelle

DATE OF I.R.B.
APPROVAL
MAR 13 2006
Faculty of Medicine
McGill University

Chercheures
Sylvie Lambert, N., B.Sc., Candidate au Doctorat
École des sciences infirmières - Université McGill
(514) 298-0625
sylvie.lambert@mail.mcgill.ca

Dre Carmen Loiselle, Inf., Ph. D.
Professeur adjoint - École des sciences infirmières - Université McGill
Chercheure - Centre de recherche en soins
infirmiers - Hôpital général juif SMBD
(514) 398-4163 ou
(514) 340-8222, poste 5784
carmen.loiselle1@mcgill.ca

Si vous avez de la difficulté à lire ce document, SVP en informer l'une des chercheures ou agents de recherche.

Introduction

Je suis infirmière au doctorat à l'école des sciences infirmières de l'université McGill. Dans le cadre de ma formation en recherche, je fais une étude sous la direction du Dre Carmen Loiselle. Nous voulons explorer comment les gens, avec un diagnostic de cancer du sein, de la prostate, du colon ou du rectum, recherchent l'information qu'ils ont besoin reliée à leur cancer. Vous avez été approché(e) pour participer à cette étude parce que vous avez un diagnostic de cancer et vous recevez des soins médicaux à l'hôpital Royal Victoria, l'hôpital général de Montréal et l'hôpital général juif - SMBD.

Ce document fournit des informations au sujet de cette étude et spécifie votre engagement. Avant d'accepter de participer à cette étude, veuillez prendre le temps de lire attentivement les renseignements qui suivent. Si vous voulez davantage d'informations, SVP n'hésitez pas à poser vos questions aux chercheures ou agents de recherche. Vous pouvez apporter une copie de ce document avec vous à la maison et prendre le temps qu'il vous soit nécessaire avant de décider de prendre part à cette étude. Le présent document, peut contenir des termes que vous ne comprenez pas. Nous vous invitons à poser toutes questions que vous jugez utiles aux chercheures ou agents de recherche, ainsi qu'à leurs demander de vous expliquer les éléments qui ne vous sont pas clairs. Si vous décidez de prendre part à cette étude, nous vous demandons de signer ce formulaire, et une copie vous sera remise.

Objectif de l'Étude

Nous vous invitons à participer à cette étude qui vise à explorer les comportements des gens diagnostiqués avec un cancer du sein, de la prostate, du rectum ou du colon lors de la recherche d'information. Le but premier de cette étude est de mieux comprendre comment les gens recherchent les informations reliées à leur cancer.

Nous prévoyons recruter 30 patients pour l'étude provenant de l'hôpital Royal Victoria, l'hôpital général de Montréal et l'hôpital général juif – SMBD.

Participation à l'étude

Après avoir lu ce formulaire de consentement, si vous acceptez de participer, la chercheure ou l'agent de recherche vous invitera à participer à une entrevue individuelle. Le but de l'entrevue, est de discuter comment vous obtenez l'information dont vous avez de besoin reliée à votre cancer. Précisément, les questions demandées par la chercheure ou l'agent de recherche focuseront sur le but de vos recherches d'information, le type d'information que vous obtenez et la quantité d'information que vous préférez. L'entrevue sera d'une durée approximative de 1 à 1.5 heures et sera dans un endroit convenable pour vous (ex, hôpital, domicile). Les entrevues seront enregistrées sur cassette audio. Cet enregistrement sonore aidera les chercheures à se rappeler des détails de l'entrevue. Si vous ne voulez pas être enregistré, SVP en informer la chercheure ou l'agent de recherche.

À la fin de l'entrevue individuelle, nous vous demanderons de compléter un bref questionnaire d'ordre général portant sur votre niveau de scolarité, votre travail et vos traitements ou soins médicaux. Ceci prendra environ 10 minutes. De plus, nous aurons peut-être besoin de consulter votre dossier médical afin d'obtenir des informations sur votre histoire médicale.

Risques

Il n'y a aucun risque connu à participer dans cette étude. Il est possible que certains des sujets abordés durant l'entrevue suscitent chez vous des sentiments, pensées ou mémoires déplaisantes. Si vous décidez de cesser l'entrevue en quelque temps que ce soit, votre volonté sera respectée. Les chercheures seront à votre disponibilité pour discuter toutes préoccupations que vous avez concernant l'étude, au besoin, seront vous référer à une ressource appropriée.

Bénéfices

Cette étude ne vous offrira probablement aucun bénéfice direct. Toutefois, certaines personnes peuvent trouver aidant le fait de parler de leur expérience. Par ailleurs, vos réponses nous apporterons une information précieuse sur la manière dont une équipe en soin de santé peut aider, dans le futur, les gens dans leur recherche d'information.

Compensation

En digne de reconnaissance pour votre engagement dans cette étude, vous recevrez une indemnité de $20.00 pour votre participation.

Confidentialité

Toutes les informations que vous nous fournirez demeureront strictement confidentielles dans les mesures permises par les lois et règlements applicables. Toutefois afin de vérifier les données du projet, les membres des comités d'éthique de l'université McGill (Faculté de Medicine), du centre universitaire de santé mcgill et de l' hôpital général juif SMBD et le personnel autorisé de ces hôpitaux pourront avoir accès à certains documents. Les notes et les enregistrements sonores des entrevues seront attribués un code. Pour sauvegarder l'anonymat, votre nom et celui des gens mentionnés durant les entrevues n'apparaîtront pas. Toutes les mesures appropriées seront prises afin que soit préservée la confidentialité des renseignements contenus dans votre dossier médical, s'il doit être consulté, et des données recueillies à votre sujet en cours d'étude. Nous allons garder toutes les informations sous clé au centre de recherche en soins infirmiers de l'hôpital général juif SMBD. L'accès à ces documents est réservé aux chercheures et agents de recherche. Tout le matériel relié a cette étude sera détruit après une période de 5 ans. Les résultats de cette étude pourront être publiés. Toutefois, votre identité ne sera jamais révélée. Sur demande, les résultats de cette étude peuvent vous être disponibles.

Participation et/ou Retrait Volontaire

Votre participation est tout à fait volontaire. Vous êtes totalement libre de refuser de participer à cette étude. Vous pouvez cesser votre participation en tout temps sans explication, cependant SVP en informer les chercheures ou l'agent de recherche. Votre décision de ne pas participer à cette étude ou de vous en retirer n'aura aucune conséquence sur la qualité des soins que vous recevez ou recevrez à l'hôpital Royal Victoria, l'hôpital général de Montréal et l'hôpital général juif – SMBD.

<u>**Personnes à contacter si vous le désirez**</u> **:**
Les chercheures principales de l'étude
Sylvie Lambert, N., B.Sc., Candidate au Doctorat
École des sciences infirmières - Université McGill
sylvie.lambert@mail.mcgill.ca

Dre. Carmen Loiselle, Inf., Ph. D.
Professeur adjoint - École des sciences infirmières - Université McGill
Chercheure - Centre de recherche en soins
Infirmiers - Hôpital général juif SMBD
(514) 398-4163 ou
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À propos de vos droits en tant que participant(e) à une recherche

L' Ombudsman Hôpital Royal Victoria
Pat O'Rourke (514) 934-1934 #35655

Hôpital général de Montréal
Line-Marie Casgrain (514) 934-8306

Représentante des patients Hôpital général juif S.M.B.D.
Ms. Laurie Berlin (514) 340-8222 #5833

Vous n'abandonnez aucun de vos droits en signant ce formulaire.

Consentement

J'ai lu ce formulaire de consentement, et j'accepte de participer à cette étude. Je reconnais qu'on m'a expliqué le projet, qu'on a répondu à mes questions de façon satisfaisante et qu'on m'ait laissé le temps voulu pour prendre une décision. Je sais que je peux demander, en tout temps, aux chercheures des questions concernant cette étude.

On m'a assuré que l'information à mon égard sera gardée confidentiel et aucune information qui divulguera mon identité sera publiée.

En signant le présent formulaire, je ne renonce à aucun de mes droits légaux ni ne libère les chercheures ou l'hôpital de leur responsabilité civile et professionnelle. Je sais que je peux me retirer de l'étude en tout temps sans que cela n'influence la qualité des soins que je reçois. Je sais que je peux demander en tout temps des questions ou clarifications aux chercheures concernant l'étude et ma participation.

On me remettra une copie signée du présent formulaire.

Je consens librement et volontairement à participer à ce projet.
Nom du participant(e) : ____________________________ (en lettres moulées, s.v.p.)
Signature ____________________________ Date __________________

Nom du témoin : ____________________________ (en lettres moulées, s.v.p.)
Signature : ____________________________ Date __________________

Je certifie avoir expliqué au sujet la nature du projet de recherche ainsi que le contenu du présent formulaire. Ēgalement, avoir répondu à toutes ses questions et avoir indiqué qu'il/elle est libre à tout moment de mettre un terme à sa participation. Je remettrai au participant(e) une copie signée du présent formulaire de consentement.

Nom de la chercheure ou de la personne désignée par elle:_______________
Signature : ____________________________ Date __________________

Suite à la première entrevue, si vous êtes d'accord, la chercheure pourrait vous re-contacter pour planifier une seconde entrevue individuelle (30-60 minutes approximativement) pour explorer d'avantage ou pour clarifier certains points discuter durant la première entrevue. Cette seconde entrevue peut être faite au téléphone ou sera dans un endroit convenable pour vous (ex., hôpital, domicile). Cette entrevue sera également enregistrée sur cassette audio. Cet enregistrement sonore aidera les chercheures à se rappeler des détails de l'entrevue. Si vous ne voulez pas être enregistré, SVP en informer la chercheure ou l'agent de recherche. Vous pouvez choisir de participer seulement à la première entrevue individuelle, si vous ne voulez pas participer à la seconde entrevue individuelle, SVP en informer la chercheure.

Acceptez-vous d'être re-contacté par la chercheure pour planifier possiblement une seconde entrevue:

____Oui

____ Non

Signature : ________________________________ Date : __________

"Refinement of a Self-Report Questionnaire Designed to Measure Individuals' Differential Health Information-Seeking Behaviors"

Audio taping Consent Form-Group Interview

DATE OF I.R.B.
APPROVAL
AUG 19 2005
Faculty of Medicine
McGill University

Investigators

Sylvie Lambert, N., B.Sc., Doctoral Candidate
McGill University School of Nursing
sylvie.lambert@mail.mcgill.ca

Dr. Carmen Loiselle, N., Ph.D.
Assistant Professor
McGill University School of Nursing
Nurse Scientist
Centre for Nursing Research,
SMBD-Jewish General Hospital
carmen.loiselle1@mcgill.ca

If you have any difficulty reading this form, please let the researcher or research assistant know.

Purpose

You have agreed to participate in a research study that explores how individuals diagnosed with breast, prostate, or colorectal cancer seek information about their illness. You will be participating in an interview, conducted by the research or a trained research assistant, with a group of 6 to 10 individuals diagnosed with cancer. These interviews will be audio taped. The purpose of audio taping is to help the researchers recall the details of the interviews.

Confidentiality

All information collected during these interviews will be kept confidential. Although results of this study may be published, individuals will not be identified. Your name and the names of anyone you mention will not appear anywhere. Participants will be identified in the study by numeric codes. Data and audiotapes will be kept in a locked filling cabinet at the Centre for Nursing Research of the SMBD-Jewish General Hospital. Only the researchers and research assistants will have access to these materials. All audiotapes will be destroyed in 5 years.

Agreement

By signing this consent, you agree for the interviews to be audio taped.

I hereby agree to have interviews audio taped
Name of participant: ______________________________ (please print)
Signature ______________________________Date __________________

Name of Investigator/RA: ____________________________ (please print)
Signature ______________________________ Date __________________

"Refinement of a Self-Report Questionnaire Designed to Measure Individuals' Differential Health Information-Seeking Behaviors"

Audio taping Consent Form-Individual Interview

DATE OF I.R.B.
APPROVAL
AUG 1 9 2005
Faculty of Medicine
McGill University

Investigators
Sylvie Lambert, N., B.Sc., Doctoral Candidate
McGill University School of Nursing
sylvie.lambert@mail.mcgill.ca

Dr. Carmen Loiselle, N., Ph.D.
Assistant Professor
McGill University School of Nursing
Nurse Scientist
Centre for Nursing Research,
SMBD-Jewish General Hospital
carmen.loiselle1@mcgill.ca

If you have any difficulty reading this form, please let the researcher or research assistant know.

Purpose

You have agreed to participate in a research study that explores how individuals diagnosed with breast, prostate, or colorectal cancer seek information about their illness. You will be participating in an individual interview conducted by the research or a trained research assistant. These interviews will be audio taped. The purpose of audio taping is to help the researchers recall the details of the interviews.

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All information collected during the interview will be kept confidential. Although results of this study may be published, individuals will not be identified. Your name and the names of anyone you mention will not appear anywhere. Participants will be identified in the study by numeric codes. Data and audiotapes will be kept in a locked filling cabinet at the Centre for

Nursing Research of the SMBD-Jewish General Hospital. Only the researchers and research assistants will have access to these materials. All audiotapes will be destroyed in 5 years.

Agreement

By signing this consent, you agree for the interviews to be audio taped.

I hereby agree to have the interview audio taped
Name of participant: ____________________________ (please print)
Signature ____________________________Date _________________

Name of Investigator/RA: __________________________ (please print)
Signature ____________________________

"Modification d'une Échelle pour Mesurer les Comportements de Recherche D'information"

Formulaire de Consentement pour Enregistrement Audio-Entrevue Groupe

DATE OF I.R.B.
APPROVAL

AUG 19 2005

Faculty of Medicine
McGill University

Chercheures
Sylvie Lambert, N., B.Sc., Candidate au Doctorat
École des sciences infirmières - Université McGill
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Dre Carmen Loiselle, Inf., Ph. D.
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Health Information Seeking Behavior

Sylvie D. Lambert and Carmen G. Loiselle

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Health Information–Seeking Behavior

Sylvie D. Lambert
Carmen G. Loiselle
McGill University

Seeking information about one's health is increasingly documented as a key coping strategy in health-promotive activities and psychosocial adjustment to illness. In this article, the authors critically examine the scientific literature from 1982 to 2006 on the concept of health information–seeking behavior (HISB) to determine its level of maturity and clarify the concept's essential characteristics. A principle-based method of concept analysis provides the framework for exploring the nature of HISB. The authors reviewed approximately 100 published articles and five books reporting on HISB. Although HISB is a popular concept used in various contexts, most HISB definitions provide little insight into the concept's specific meanings. The authors describe the concept's characteristics, contributing to a clearer understanding of HISB, and discuss operationalizations, antecedents, and outcomes of HISB. Such an analysis of HISB might guide further theorizing on this highly relevant concept and assist health care providers in designing optimal informational interventions.

Keywords: *concept analysis; information seeking; health information*

From the late 1980s to mid-1990s, only a few seminal works addressed the concept of health information–seeking behavior (HISB) (e.g., Lenz, 1984; Loiselle, 1995; Miller, 1987). However, the advent of the information age and related increase in the amount of information potentially available (Vakkari, Savolainen, & Dervin, 1996), and an enhanced focus on self-monitoring and self-care, as well as renewed interest in predictors of health promotion and illness prevention activities, contributed to HISB's taking center stage (Johnson, 2003; Loiselle & Dubois, 2003). Since the mid-1990s, studies examining HISB abound in the health-related scientific literature. Researchers and clinicians, alike, are interested in understanding how and why individuals obtain health information, where they go to retrieve such information, what particular types of information they prefer, and how the health information sought is used. At first glance, the concept of HISB appears to be well developed and used without apparent controversies or debate about its meaning. However, on closer examination, the concept affords multiple understandings. Despite the abundant theoretical and empirical literature on HISB, no article reviewed to date critically examines the concept. Such an analysis might further clarify the concept and contribute to a more fully developed concept and more accurate assessments of HISB. Hence, the purpose of the present article is to present a comprehensive analysis of the concept of HISB.

From Wilson (1963) to the Present

One challenging and critical issue in concept analysis is the selection of the most appropriate analytical method. Traditionally, concept analysis has been addressed primarily through Wilsonian-derived methods introduced mainly by Walker and Avant (1995) and Chinn and Jacobs (1987). These methods are widely used, as they offer structure and guidance for concept analysis. However, the end product of such analysis often lacks depth, with resulting concept attributes that are vague and of limited utility. An additional criticism is that these methods are based on demised positivist philosophy (Hupcey, Morse, Lenz, & Tason, 1996; Morse, Hupcey, Mitcham, & Lenz, 1996). For these reasons, authors have recommended alternate methods, such as critical analysis of the literature and the use of qualitative approaches (Hupcey, Morse, et al., 1996; Morse, Hupcey, et al., 1996; Rodgers, 1989; Schwartz-Barcott, 2003).

Rodgers (1989) proposed an evolutionary method for concept analysis that moves away from a static view of concepts to a more fluid one and overcomes some of the aforementioned weaknesses (Hupcey, Morse, et al., 1996; Morse, Hupcey, et al., 1996). However, certain aspects of the evolutionary method remain disputable. The analysis still focuses mainly on the linguistic aspect of the concept (Morse, Hupcey, et al., 1996) and is often limited to a single exemplar (limiting the richness of the data obtained) (Hupcey, Morse, et al., 1996; Morse, 1995; Morse, Hupcey, et al., 1996). Furthermore, the selection of one exemplar that encompasses all contexts contradicts Rodgers's statement that concepts are context bound. In addition, Rodgers's recommendation that data analysis be delayed until last violates standards of qualitative inquiry (Hupcey, Morse, et al., 1996).

Morse and colleagues have contributed a criteria- or principle-based method to concept analysis (Morse, 1995; Morse, Hupcey, et al., 1996; Morse, Mitcham, Hupcey, & Tason, 1996; Penrod & Hupcey, 2005). Morse et al.'s (Morse, Hupcey, et al., 1996; Morse, Mitcham, et al., 1996) method is selected for the present analysis, as it promotes the use of rich data sources and provides clear criteria on which to base the analysis and it is more flexible and less decontextualizing than the abovementioned methods (Penrod & Hupcey, 2005). According to Morse, Hupcey, et al. (1996), concept analysis "refers to a process of inquiry that explores concepts for their level of development or maturity as revealed by their internal structure, use, representativeness, and/or relations to other concepts" (p. 255). The initial phase focuses on analyzing extant literature on the concept and determining its level of maturity. Maturity is a criteria-based determination of the concept's clarity from epistemological (i.e., definitions), linguistic (i.e., contexts within which the concept is used), logical (i.e., boundaries and theoretical integration with other concepts), and pragmatic (i.e., operationalization) perspectives (Hupcey, Penrod, Morse, & Mitcham, 2001; Morse, Hupcey, et al., 1996; Morse, Mitcham, et al., 1996; Penrod & Hupcey, 2005). Each criterion "contributes to an understanding of the strengths and limitations of the present state of the concept in the scientific literature" (Penrod & Hupcey, 2005, p. 403). A concept is mature if it is well defined; it has distinct characteristics, delineated boundaries, and well-described preconditions and outcomes; and a consensus exists on its use (Morse, Mitcham, et al., 1996). For the concept of HISB, an exploration of the literature reveals that the concept is partially developed. The second part of the analysis clarifies HISB by delineating its conceptual components, including its antecedents, characteristics, and outcomes.

Sample for Data Collection

The literature reviewed for this analysis includes book chapters, theoretical and empirical articles on HISB, instruments that attempt to measure the concept, and review articles. The inclusion criteria for the chosen literature were (a) works written in English or French, (b) those with a focus on actual behaviors of individuals when seeking health-related information, (c) the inclusion of "information seeking" in the title or the text, and (d) scholarly works published in a peer-reviewed journal. A computer-generated search was performed using OVID software, accessing the Medline, CINAHL, psychINFO, HEALTHSTAR, Web of Science, and Health and Psychosocial Instruments databases. The search was conducted in various disciplines to obtain a broad perspective on the concept (Morse, 2000; Penrod & Hupcey, 2005). The period from 1982 to 2006 was retained, as it represents a period long enough to detect seminal work undertaken on HISB. Examples of terms (used alone or in combination) included *information-seeking behavior*, *information needs*, *health information*, *coping*, *decision making*, *information services* (*use*), and *health education* (use). In addition, a perusal of the reference lists of each article was conducted to retrieve potentially relevant work not initially identified. Five books and approximately 100 published articles were reviewed. Of the articles, approximately 60% were quantitative studies (e.g., information-seeking styles, correlates of information seeking), 15% were qualitative studies (e.g., type and sources of information preferred), 15% were reviews (e.g., information needs), and 10% were theoretical papers (e.g., model or theories of information-seeking behavior). The references were organized using Reference Manager.

Data Analysis

Analysis was carried out according to an in-depth content analysis of each source (Morse, 2000). First, we read each article and book chapter two to three times to identify general content and to gain a sense of the overall meaning given to HISB. Analysis then proceeded inductively; within each article, statements or paragraphs providing information on some aspect of the concept (i.e., components, maturity) were identified and noted. The following questions guided the analysis: Is the concept clearly defined? Is the concept used consistently and appropriately within context? Does the concept hold its boundaries? Has the concept been theoretically integrated with other concepts? Has the concept been appropriately operationalized? What are the key characteristics of HISB? What are the relationships among the characteristics? Is HISB treated as a fixed personality characteristic or as a behavioral, context-bound strategy? What are the antecedents to HISB (e.g., is an information need sufficient to enact

Table 1
Definitions of Health Information–Seeking Behavior

Author(s)	Definition
Lenz (1984)	Series of interrelated behaviors that can vary along two main dimensions: (a) extent and (b) method (p. 63)
Barsevick & Johnson (1990)	"Actions used to obtain knowledge of a specific event or situation" (pp. 3-4)
Corbo-Richert, Caty, & Barnes (1993)	"Verbal or nonverbal behavior seeking to attain, clarify, or confirm information" (p. 30)
Baker & Connor (1994)	"Any activity undertaken to satisfy a query" (p.38)
Loiselle (1995)	"A self-regulatory strategy that patients use to organize transactions between the self and health-related settings with the goal of balancing instrumental benefits and subjective costs stemming from informational outcome" (p. 9)
Johnson (1997)	"Purposive acquisition of information from selected information carriers" (p. 4)
Conley (1998)	"Verbal or nonverbal behavior used to obtain, clarify, or confirm knowledge or information about a specific event or situation" (p. 132)
van der Molen (1999)	Strategy use as a means of coping with, and reducing, stress
Rees and Bath (2000)	"Problem-focused coping strategy sometimes adopted by individuals as a response to a threatening situations" (p. 72)
Rees and Bath (2001)	Monitoring: "the urge to confront oneself with the threatening situation by means of seeking more information about it" (p. 900). Blunting: "tendency to distract from threat-relevant information" (p. 900).
Czaja, Manfredi, and Price (2003)	Number of sources from whom an individual sought information

HISB)? What are some of the outcomes or consequences of HISB? Detailed analysis and interpretation of notes resulted in our identifying main themes related to HISB. We described each aspect of the concept further by continually organizing and reorganizing key points in the literature until cohesive and comprehensive descriptions were obtained. Articles reviewed were constantly compared and contrasted with each other, and similarities and differences among authors were identified. Rigor was supported by our reviewing a large amount of the literature on HISB from the various disciplines (Morse, 2000; Penrod & Hupcey, 2005). In addition, findings were discussed between the authors until a consensus was reached.

Findings

Maturity of the Concept

Is the Concept Clearly Defined?

Explicit definitions of HISB are difficult to locate, and there is no apparent dominant definition. Typically, definitions are inferred by the purpose or focus of the article. The meaning of HISB is often thought to be obvious, and what individuals do to obtain information taken for granted (Case, 2002). The broad sense attributed to HISB relates to the ways in which individuals go about obtaining information, including information about their health, health promotion activities, risks to one's health, and illness.

Few authors use the complete label health information–seeking behavior (e.g., Baker & Pettigrew, 1999; Gollop, 1997; N. Gray, Klein, Noyce, Sesselberg, & Cantrill, 2005; Kakai, Maskarinec, Shumay, Tatsumura, & Tasaki, 2003). Most authors of articles reviewed use the term *information seeking behavior*. The word *health* is implied by the type of information sought (i.e., individuals seek "health"-related information) and/or the context (i.e., information sought within a health-related context) (e.g., Beisecker & Beisecker, 1990; Borgers et al., 1993; Czaja et al., 2003; Szwajcer, Hiddink, Koelen, & Van Woerkum, 2005). Others use the term *health information seeking* or simply *information seeking*. Authors imply that "behaviors" or "actions" to obtain information are an inherent component of information seeking (e.g., Meischke, Eisenberg, Rowe, & Cagle, 2005; Shi, Nakamura, & Takano, 2004). For the purpose of the present analysis, the comprehensive label of health information–seeking behavior (HISB) is used.

Various definitions of HISB found in the literature are presented in Table 1. Most authors have proposed that HISB entails the use of specific actions and/or strategies by individuals to acquire information. However, little insight or description is provided as to what those behaviors or actions consist of (circular definitions). Lenz (1984) appears most informative in her treatment of the concept by specifying that HISB varies along two main dimensions: extent (scope and depth of search) and method (information source used). Czaja et al. (2003) and Johnson (1997) have focused primarily on the method dimension of HISB in their definition.

The definitions proposed by van der Molen (1999) and Rees and Bath (2000, 2001) suggest an antecedent, or cause (i.e., stress or threat), and/or a purpose (i.e., coping) to HISB. These definitions limit HISB to situations of threat; one of several possible situations where individuals would seek health-related information. Other authors are less prescriptive and more general about the situations in which the information is sought (e.g., Barsevick & Johnson, 1990; Conley, 1998; Loiselle, 1995) or the antecedents to HISB (e.g., Baker & Connor, 1994).

Is the Concept Used Consistently and Appropriately Within the Context?

Overall, HISB is studied within the context of (a) coping with a health-threatening situation, (b) participation and involvement in medical decision making, and (c) behavior change and preventive behavior. Each context as related to HISB is reviewed in turn.

HISB in the context of coping with a health-threatening situation. Processes related to HISB are becoming increasingly central to how individuals cope with health-threatening situations (Davison et al., 2002; Garvin et al., 2003; Hoskins & Haber, 2000; Ransom, Jacobsen, Schmidt, & Andrykowski, 2005; Rees & Bath, 2000). Within this context, researchers have identified the type of information individuals seek to cope with stressful situations, the amount of information sought, how the information is obtained, and when or under what circumstances the information is needed (Loiselle, 1995; Rees & Bath, 2001; van der Molen, 1999). HISB is typically referred to as a problem-focused coping strategy (or monitoring) and implies that individuals focus their attention on the threatening situation and direct their efforts at becoming more engaged with and aware of stressors (Livneh, 2000; Rees & Bath, 2001; Shiloh, Sinai, & Keinan, 1999). Information seeking is suggested to enhance coping by helping individuals understand the health threat and the associated challenges that it brings (Clark, 2005; Davison et al., 2002; Flattery, Pinson, Savage, Salyer, & Virginia, 2005; Henman, Butow, Brown, Boyle, & Tattersall, 2002), help to evaluate what is at stake (Flattery et al., 2005; van der Molen, 1999), contribute to attaching appropriate meanings to events (Rees & Bath, 2001; Rees, Sheard, & Echlin, 2003; Shiloh, Mahlev, Dar, & Ben-Rafael, 1998), help individuals rehearse or work through their experiences (Rees, Sheard, et al., 2003), provide ways of managing the stressors (Davison et al., 2002; Feltwell & Rees, 2004; Huber & Cruz, 2000), determine what resources are available to manage the stressors (van der Molen, 1999) and make informed decisions (Henman et al., 2002; Loiselle, 1995; Rees & Bath, 2001), and increase predictability and feelings of control over situations (Andreassen, Randers, Naslund, Stockeld, & Mattiasson, 2005; Case, Andrews, Johnson, & Allard, 2005; Flattery et al., 2005; Henman et al., 2002; Rees, Sheard, et al., 2003). HISB is also argued to have emotion-focused coping functions, in that information reduces negative reactions linked to uncertainty (e.g., anxiety) and provides reassurance, which might account for the observation that information seeking is often positively related to both problem-focused and emotion-focused coping (Shiloh, Sinai, et al., 1999). Overall, information seeking efforts serve to manage or alter the relationship between an individual and the source of stress, potentially contributing to positive health outcomes and psychosocial adjustment (van der Molen, 1999). Although, many individuals choose to cope with a health-related threat by seeking information, others are found to purposefully avoid such information. Information avoidance, also referred broadly as denial, blunting, or repression, emphasizes that some individuals choose to divert their attention from the perceived threat (Feltwell & Rees, 2004; Livneh, 2000; Loiselle, 1995).

HISB in the context of participation and involvement in medical decision making. As the trend toward shared or collaborative medical decision making between health care professionals and patients continues (Warner & Procaccino, 2004), much attention is given to individuals' preferred role in medical decision making (Beaver et al., 1996; Davison et al., 2002; Hack, Degner, & Dyck, 1994; Hashimoto & Fukuhara, 2004). Individuals' preferences for medical decision making range from wanting to be able to understand health care professionals' decisions about care, to wanting their views to be heard and considered, to making the final decision (Beaver et al., 1996; Hack, Degner, Watson, & Sinha, 2006; Henman et al., 2002). HISB is conceptualized as a means of obtaining the type and amount of information needed to participate in medical decision making. In general, studies have shown that individuals who prefer an active or collaborative role when making decisions with health professionals are also more active in their search for health-related information (Davison et al., 2002; Hack, Degner, & Dyck, 1994). Seeking information contributes to participation in medical decision making by helping individuals identify possible options, weigh and evaluate the different options, reduce uncertainty and doubt about alternatives, and decide whether a particular option is appropriate (J. Brown, Carroll, Boon, & Marmoreo, 2002; Budden, Pierce, Hayes, & Buettner, 2003; Huber & Cruz, 2000; Johnson, 1997). The assumption is that individuals who seek out information might be better prepared to engage in medical decision making (Beaver et al., 1996; J. Brown et al., 2002; Hashimoto & Fukuhara, 2004; Radecki & Jaccard, 1995; Shuyler & Knight, 2003). However, individuals seeking large amounts of health-related information do not consistently play an active role in decision making (Czaja et al., 2003; Hashimoto & Fukuhara, 2004; Henman et al., 2002). Here, information might be sought for other purposes, such as anticipating the sequence of events or evaluating appropriateness of treatment proposed (Czaja et al., 2003; Hashimoto & Fukuhara, 2004).

HISB in the context of behavior change and preventive behavior. HISB is often perceived as a crucial step in the enactment of discretionary health-related and preventive behaviors (Budden et al., 2003; Fahrenwald & Walker, 2003; Shi et al., 2004; Shuyler & Knight, 2003; Warner & Procaccino, 2004; Yu & Wu, 2005). Theoretically and empirically, information seeking is identified as a significant factor influencing the extent to which individuals decide to engage in healthy lifestyles and/or preventive behaviors (e.g., Burbank, Reibe, Padula, & Nigg, 2002; Fahrenwald & Walker, 2003; Yu & Wu, 2005). Although information alone does not guarantee healthy behaviors, acquiring adequate information might motivate individuals to make positive changes in their health practices (Loiselle & Delvigne-Jean, 1998; Meischke et al., 2005; Shi et al., 2004; Szwacjer et al., 2005). Individuals' specific HISB might influence the scope and nature of the information on which judgments, beliefs, and attitudes toward the health behavior are based, the number of alternative courses of action known to individuals, and knowledge about the pros and cons of different actions (risk perception) and resources available to carry out the different behaviors (Burbank et al., 2002; Griffin, Dunwoody, & Neuwirth, 1999; Holmes & Lenz, 1997; Huber & Cruz, 2000; Johnson, 1997).

Does the Concept Hold Its Boundaries, and Has it Been Theoretically Integrated With Other Concepts?

The boundaries of a concept are traditionally identified by what is and what is not part of the concept (Morse, Mitcham, et al., 1996). One commonality across several authors is that HISB is an intentional, overt action; individuals make a conscious choice to seek health-related information (Case, 2002; Johnson, 1997; Lenz, 1984; Longo, 2005; Rees & Bath, 2001; Warner & Procaccino, 2004). This intentionality is suggested to be related to the accomplishment of some particular information-related goal (Johnson, 1997). HISB does not include instances in which individuals are being exposed to health-related information without a specific request (passive receipt of information) (Barsevick & Johnson, 1990; Lenz, 1984; Loiselle, 1995; Longo, 2005) or when information is retrieved from memory (Johnson, 1997). For instance, if information is acquired, but not purposefully sought, while the individual is engaging in another activity such as watching television, this is not considered to be HISB (Lenz, 1984). Furthermore, HISB does not include information received from health professionals unless this information was specifically requested (Barsevick & Johnson, 1990). However, passive acquisition of information can occur during active information seeking (Lenz, 1984; Longo, 2005). Case (2002) has used the term *information behavior* to encompass information seeking or avoidance as well as unintentional or passive behaviors.

A concept often found to be used interchangeably with HISB is preference for information within health-related contexts. A review of authors using this term revealed that it is most often used to emphasize the extent to which an individual reports a desire, from an affective perspective, to seek or receive specific types of health information (e.g., Garvin, Moser, et al., 2003; Hack, Degner, & Dyck, 1994; Loiselle, 1995). Individuals with high preference for information wish to seek or receive as much health information as possible; however, this high preference does not ensure that they will subsequently carry out their information search (Garvin & Kim, 2000; Loiselle, 1995). Other factors, such as the complexity of the situation or individuals' physical or psychological health, might influence whether a high preference for information will translate into actual behavior (Harrison, Galloway, Graydon, Palmer-Wickham, & Rich-Van, 1999).

Theoretical Underpinnings of HISB

Although the majority of empirical studies reviewed do not specify a formal model or theoretical framework for HISB, six models or theories related to HISB are found in the health-related literature. These include (a) Lazarus and Folkman's (1984) stress, appraisal, and coping theory; (b) Miller's (1987, 1989) monitoring and blunting hypothesis; (c) Lenz's (1984) information-seeking model; (d) the health information acquisition model (Freimuth, Stein, & Kean, 1989); (e) the comprehensive model of information seeking (Johnson, 1997, 2003); and (f) the expanded model of health information–seeking behaviors (Longo, 2005). Lazarus and Folkman's (1984) theory and Miller's (1987) framework are most frequently referenced. Both authors focus primarily on individuals' differential responses to stress. Although, Lazarus and Folkman (1984) did not expand on HISB, Miller (1987) provided specific characteristics that differentiate an information seeker (i.e., monitor) from an information avoider (i.e., blunter). Although the concept of monitoring/blunting is popular, it is suggested that this concept is not specific to information seeking and, rather, mingles different types of coping strategies (Ransom et al., 2005). Therefore, the concept of monitoring/blunting may not best capture individuals' HISB. Neither of these specifically describes the process of HISB.

The other four models are, in essence, flowcharts that describe a series of steps through which individuals progress to seek information (information-seeking process) and identify the underlying factors that might explain HISB. One appealing aspect of these models is their simplicity. However, some models appear to oversimplify HISB and represent the information-seeking process as linear (e.g., Johnson, 1997); no feedback loops are included, overlooking the iterative nature of HISB. A more fluid and nonlinear model (e.g., Freimuth et al., 1989) is suggested to be more appropriate (Case, 2002; Foster, 2004). Although most models have some theoretical and/or empirical justifications, some provide little evidence to support their depiction of HISB and the associated variables.

Typically, the models or theories reviewed specify several background, personal, and/or contextual factors that motivate a person to seek information (or not) and attempt to predict HISB (Case, 2002). Some authors, particularly Lenz (1984) and Freimuth et al. (1989), have focused on a conception of HISB as a process initiated by a stimulus. The key role of a stimulus or a recognized information need in initiating HISB is empirically reported by several authors (e.g., Griffin et al., 1999; Szwajcer et al., 2005; Warner & Procaccino, 2004). Johnson (1997) acknowledged the critical role of a stimulus; however, this variable is not explicitly depicted in the model. Lenz and Freimuth et al. also called attention to intermediary steps following the stimulus, particularly the perception of a positive cost-benefit ratio, which influence an individual's search for information.

Although these models move away from conceptualizing HISB as a simple stimulus-response reaction and include cognitive activities, the need for a positive cost-benefit ratio can be challenged. Some authors have contended that most individuals seek information that is relevant to them regardless of the potentially negative or positive implications (Dauenheimer, Stahlberg, Spreeman, & Sedikides, 2002). Lenz (1984) and Freimuth et al. (1989) also provided the most comprehensive understanding of the different dimensions of HISB: extent and method, as defined earlier. Longo (2005) and Johnson (1997) focused primarily on the method dimension. Johnson provided an extensive description of the method dimension and emphasized that information sources are selected on the basis of their match with individuals' information needs. Although Johnson did not exclude the extent dimension, it is not explicitly depicted in the model (Johnson, Andrews, & Allard, 2001). Most models or theories reviewed focus merely on whether individuals seek information or not and do not take into consideration the possible variability contained within these extreme HISB. Longo's (2005) is the only model reviewed that considers different information-seeking outcomes (e.g., a patient might access the information but be unable to use it). Together, all models provide important insights into the study of HISB and increase our understanding of why certain individuals might choose to seek available information whereas others do not to the same extent.

Has the Concept Been Appropriately Operationalized?

Most often, authors operationalize the concept of HISB in terms of (a) type of health-related information sought, (b) amount of health-related information sought, (c) information sources used, or (d) discrete actions implemented (e.g. Loiselle, 1995). Some authors have captured HISB by examining the specific kinds of health-related information sought (e.g., information about disease and disease process, information on self-care and self-management strategies) (e.g., Borgers et al., 1993; Butow, Maclean, Dunn, Tattersall, & Boyer, 1997; Szwajcer et al., 2005). Individuals have also been asked about the general type of information sought. For example, are individuals seeking all possible information, most pertinent information, or only "good news" or "bad news"? Amount of information sought is most often documented by asking individuals about the extent of details sought (e.g., Butow et al., 1997; Hack et al., 1994; Loiselle, 1995). HISB is also frequently operationalized through descriptions of sources used (type and number, frequency of use) (e.g., Gollop, 1997; Loiselle, Edgar, & Batist, 2002; McGuffin & Wright, 2004; Rees & Bath, 2001). Some authors have focused on surveying individuals' discrete behaviors when seeking information, such as how frequently they ask questions to HCPs or initiate discussions about specific issues (e.g., Borgers et al., 1993).

Authors have also used various scales to measure HISB. Four relevant published scales have been identified: (a) the Miller Behavioral Style Scale (MBSS) (Miller, 1987), (b) the Threatening Medical Situation Inventory (TMSI) (van Zuuren, deGroot, Mulder, & Muris, 1996), (c) the Krantz Health Opinion Survey (KHOS) (Krantz, Baum, & Wideman, 1980), and (d) the Autonomy Preference Index (API) (Ende, Kazis, Ash, & Moskowitz, 1989). Although most of these scales have been used in several studies for their ease of administration and acceptable reliability and validity, several shortcomings are noted. For instance, the MBSS measures individuals' tendency either to seek or to avoid information within hypothetical threatening situations; the MBSS items are not specific to health-related contexts (Garvin & Kim, 2000). In an effort to design a scale that would be more relevant to health contexts, van Zuuren et al., inspired by the MBSS, designed the TMSI and included health-related hypothetical scenarios. The use of hypothetical scenarios, by both the MBSS and TMSI, might lead to discrepancies between how individuals think they might behave in a particular situation and their actual HISB (Garvin & Kim, 2000; Loiselle, 1995). As such, the MBSS and TMSI appear to be measuring preference for information rather than HISB. The KHOS focuses mainly on individuals' preferences for asking questions directed at health professionals when undergoing medical treatments but provides little information on the type or amount of health-related information individuals seek. The API appears to measure what individuals think others should provide them with in terms of health-related information rather than the actual search for information. One of the most significant criticisms of the scales reviewed is that HISB is conceptualized primarily as an all-or-nothing phenomenon; that is, individuals either seek or avoid health-related information. Such a dichotomous operationalization of the concept has often been identified as insufficient; individuals' HISB are actually found to be more variable on a continuum from avoidance and selectivity to complete search (Johnson, 1997; Loiselle, 1995; Szwajcer et al., 2005).

Concept Clarification: Key Components of HISB

Based on the above analysis of the concept's maturity, HISB is partially developed, and further concept clarification is needed. One of the main weaknesses of the concept is that its essential characteristics are not clearly delineated. Despite the popularity of the concept and its extensive use, much about the essence of HISB remains implicit. Based on the literature reviewed, key components of HISB were extracted. These include the concept's characteristics, antecedents, and consequences.

Characteristics of HISB

Essential characteristics of HISB are those that are present in all instances in which the concept appears, but they can vary in strength of association and be present in different forms (Morse, Mitcham, et al., 1996). Throughout the literature, two main dimensions of HISB emerge: (a) the information dimension, and (b) the method dimension. The information dimension emphasizes the characteristics of the information sought, particularly in terms of type and amount. The type refers to the content and diversity of the search. The amount refers to how much information (details) about a given topic one seeks, underlining the depth of the search. Individuals have been found to vary greatly along this dimension: Some might search a lot of health-related information on a wide array of topics (Clark, 2005; Echlin & Rees, 2002; Leydon et al., 2000; Szwajcer et al., 2005); whereas others might choose to seek little or no health-related information (Case et al., 2005; Echlin & Rees, 2002; Longo, 2005; Szwajcer et al., 2005). Some individuals might seek health-related information only on a particular issue but avoid other types of health-related information (Friis, Elverdam, &

Schmidt, 2003; Leydon et al., 2000; Loiselle, 1995), or some might seek general information, whereas others prefer details or specifics (Ford, Wilson, Foster, Ellis, & Spink, 2002).

The method dimension of HISB focuses on the discretionary actions individual use to obtain health-related information and sources of information used. Discrete information seeking activities or strategies include direct and indirect questioning (e.g., Borgers et al., 1993; Brashers, Goldsmith, & Hsieh, 2002; Feltwell & Rees, 2004; Johnson, 1997), asking for clarifications (e.g., Beisecker & Beisecker, 1990), discussing and exchanging information with others (e.g., Beisecker & Beisecker, 1990; Friis et al., 2003; Matthews, Sellergren, Manfredi, & Williams, 2002), reading (e.g., Brereton & Nolan, 2002; Feltwell & Rees, 2004), observing (e.g., Brereton & Nolan, 2002), use of a third party (e.g., Johnson, 1997), browsing (e.g., Johnson, 1997), and listening (e.g., Brereton & Nolan, 2002).

Most often, individuals seek health-related information, at any given time, from a combination of personal (e.g., self, friends, family) and impersonal (e.g., book, Internet) sources. The use of multiple sources might reflect individuals' desire to acquire as much information as possible (J. Brown et al., 2002; Shuyler & Knight, 2003) and/or to validate (R. Gray et al., 1998; Muha, Smith, Baum, Maat, & Ward, 1998) or complement information received from a prior source (Brereton & Nolan, 2002; Fleming, Goodman, Geraghty, West, & Lancaster, 2002; Muha et al., 1998). Johnson (1997) referred to the sources of information an individual consults to obtain information as their information field. Most individuals indicate a preference for health professionals when seeking medical facts (Andreassen et al., 2005; J. Brown et al., 2002; Johnson, 1997; Loiselle, Semenic, Côté, Lapointe, & Gendron, 2001; Warner & Procaccino, 2004). This might reflect individuals' belief that professionals can provide unbiased, reliable information that is in their best interest (J. Brown et al., 2002; Gollop, 1997; James, James, Davies, Harvey, & Tweddle, 1999). Individuals also report a preference for other sources of information, such as friends or others experiencing the same health issue, when seeking psychosocial information (Beresford & Sloper, 2003; Dunne, 2002) or the Internet when seeking sensitive information (anonymity provided) (N. Gray et al., 2005). As such, the type and amount of information desired influence which source(s) of information one will consult (Beresford & Sloper, 2003; N. Gray et al., 2005; Griffin et al., 1999; Johnson, 1997; Szwajcer et al., 2005). General properties of information sources that influence their use include accessibility, credibility, and accuracy of the source (N. Gray et al., 2005; Johnson, 1997), and the style and comprehension of information presented (Johnson, 1997; Szwajcer et al., 2005). Other frequently stated sources of information are television (e.g., Carlsson, 2000; McGuffin & Wright, 2004), magazines or newspapers (e.g., Andreassen et al., 2005; Feltwell & Rees, 2004; McGuffin & Wright, 2004; Shi et al., 2004), pamphlets and/or books (e.g., Loiselle, Edgar, et al., 2002; Szwajcer et al., 2005; Warner & Procaccino, 2004), and support groups (e.g., Rees & Bath, 2001).

In sum, HISB is characterized by the type and amount of health-related information sought, the specific actions implemented to obtain the information, and the sources individuals use. Although authors have reported that individuals might have a general or stable tendency to either seek or avoid information (Butow et al., 1997; Echlin & Rees, 2002; Garvin & Kim, 2000), actual HISB are dynamic and might be expected to vary according to changing personal and contextual variables and time (Garvin & Kim, 2000; Szwajcer et al., 2005).

Antecedents

Typically, individuals' HISB are recognized as initially motivated by an information need (Dunne, 2002; Griffin et al., 1999; Holmes & Lenz, 1997; Johnson, 1997; Szwajcer et al., 2005; Warner & Procaccino, 2004), generally defined as a perceived gap between what an individual knows and what he or she wants to know to achieve a certain goal (Case, 2002; Griffin et al., 1999; Johnson, 1997; Loiselle, 1995; Szwajcer et al., 2005). However, several authors have reported that even if an individual has a need for information, he or she might not actually seek the information (Loiselle, 1995; Matthews et al., 2002; Rees & Bath, 2001; Szwajcer et al., 2005). Although significant, an information need is not sufficient to prompt HISB; rather, several personal and contextual factors influence whether and how an individual responds to an information need (Allen, 1996; Case et al., 2005; Czaja et al., 2003; Loiselle, 2001; Loiselle & Delvigne-Jean, 1998; Shiloh, Sinai, et al., 1999). Personal and situational factors are reported to influence what type of and how much information is sought, what sources are used, and how the information is obtained. Personal factors include individuals' sociodemographic characteristics as well as psychosocial variables such as personality traits and individuals' expectations, goals, beliefs, values, attitudes, emotions and moods, skills, and/or resources (Borgers et al., 1993; Loiselle, 2001; Matthews et al., 2002). For example, women (Czaja et al., 2003; Johnson, 1997) and educated and younger individuals (Czaja et al., 2003; Johnson, 1997; Muha et al., 1998) are often reported to be active information seekers. Personality characteristics such as high internal locus of control (Hashimoto & Fukuhara, 2004; Johnson, 1997), self-esteem (Radecki & Jaccard, 1995), a preference for involvement in health-related decision making (Czaja et al., 2003; Davison et al., 2002), and self-efficacy (Brown, Ganesan, & Challagalla, 2001; Griffin et al., 1999; Johnson, 1997) are shown to contribute positively to information seeking. Other individuals' reactions are found to limit HISB, such as feelings of guilt (Dunne, 2002), fear of social stigma regarding certain type of information (Matthews et al., 2002), and concern that information will contribute to more worry and anxiety (Borgers et al., 1993; Case et al., 2005).

Contextual or situational factors emphasize the characteristics of individuals' environment, source of information, and information seeking context (Allen, 1996; Czaja et al., 2003; Dunne, 2002; Loiselle, 2001; Matthews et al., 2002). For example, an accessible information source might be more likely to be used than one perceived to be difficult to access (Gollop, 1997). Furthermore, trust in HCPs is shown to contribute to asking questions and seeking more information from HCPs (Borgers et al., 1993; Czaja et al., 2003). Individuals' social network and the informational support received from family and friends are also found to affect their HISB (Brashers et al., 2002; Czaja et al., 2003; Johnson, 1997; Loiselle, Lambert, & Cooke, 2006). Family members and partners' contribution to individuals' HISB appear dependent on whether the information needs coincide with those of their family members (Brashers et al., 2002; Loiselle, Lambert, & Cooke, 2006). For example, if both family members and individuals desire information, family members are often found to aid individuals in their search (Brashers et al., 2002; Echlin & Rees, 2002; Johnson, 1997; Loiselle, Lambert, & Cooke, 2006). Conversely, a "mismatch" between individuals' HISB and those of their family members is shown to limit individuals' HISB. For example, individuals might seek as much information as possible and wish to share it with their partners, whereas partners might decide to avoid discussion on information-related issues; this pattern of communication might, in turn, lead individuals to refrain from seeking and/or disclosing further information (Brashers et al., 2002; Loiselle, Lambert, & Cooke, 2006).

Findings from these studies particularly emphasize the importance of considering the interaction among personal (i.e., individual information preference) and situational factors (i.e., family members' HISB) in predicting individuals' HISB (Loiselle, 2001; Loiselle & Delvigne-Jean, 1998). In most studies reviewed, the influences of personal and contextual factors were analyzed independently, and the main effect of each variable on HISB was determined separately. An interactional approach ("person × context") focuses on relationships among personal and contextual factors and how these, together, determine HISB (Loiselle, 2001). Although few researchers have carried out interactional analyses, this approach is suggested as most promising to evaluate the predictive value of specific personal and contextual antecedents on individuals' HISB (Loiselle, 2001).

Outcomes

Several studies reviewed measured the influence of HISB on individuals' health-related outcomes. Commonly, outcomes or consequences of seeking information include (a) cognitive outcomes, such as increase knowledge (Andreassen et al., 2005; Muha et al., 1998), informed decision making (Davison et al., 2002; Muha et al., 1998; Warner & Procaccino, 2004), increase perception of control (Echlin & Rees, 2002), and coping (Edgar, Remmer, Rosberger, & Fournier, 2000); (b) behavioral outcomes, including discussing information obtained with health care professional (Andreassen et al., 2005; Czaja et al., 2003; Muha et al., 1998), increased self-care abilities and adherence to treatment (N. Gray et al., 2005), and change in health behavior (Shi et al., 2004; Szwajcer et al., 2005; Warner & Procaccino, 2004); (c) physical outcomes, such as increase physical quality of life (Ransom et al., 2005); and/or (d) affective outcomes, including decrease anxiety, fear, and distress (Brereton & Nolan, 2002; Huber & Cruz, 2000) and increase hope (Huber & Cruz, 2000) and empowerment (N. Gray et al., 2005).

Although outcomes of seeking information are generally reported as positive, in some instances information seekers experience more negative outcomes (e.g., feeling overwhelmed, more worry) than information avoiders (Clark, 2005; Echlin & Rees, 2002; Feltwell & Rees, 2003; Garvin et al., 2003; Loiselle, Lambert, & Boisclair, 2003; Miller, 1995). It appears that when determining outcomes of individuals' HISB, the congruence between the information individuals wanted and what they obtained needs to be taken into consideration. In general, HISB outcomes are reported to be more positive when individuals sought or received the information desired (Butow et al., 1997; Garvin et al., 2003; Loiselle, 2001; Miller, 1995; Shiloh, Mahlev, et al., 1998). For example, information seekers who obtain the information they want report less anxiety than those that do not, and information avoiders who obtain more information than they desire report more anxiety than information avoiders who do not receive voluminous amount of information (Garvin et al., 2003; Miller, 1995). Therefore, empirical studies emphasize that an interactional analysis of the person and the context is also most predictive for determining not only individuals' HISB but also its outcomes (Loiselle, 2001).

Conclusion and Implications

Findings of this concept analysis provide up-to-date conceptual and operational foundations for clinicians, researchers, and theorists interested in the concept. To our knowledge, this is one of the first articles exploring in such depth the concept of health information–seeking behavior (HISB). This analysis initially examined the definitions of and contexts related to HISB and the concept's boundaries and operationalizations. This section of the analysis was challenging primarily because of the large amount of literature available and lack of clear definitions and/or theoretical frameworks, and consensus on the meaning of HISB. It is apparent that the concept of HISB is used within many contexts, particularly in relation to illness-related coping, and has great appeal to multiple disciplines. Together, researchers have attempted to understand, explain, or predict individuals' quests for health-related information, with an underlying assumption that seeking information is often desirable and central to health and illness behaviors. In addition, insights into whether HISB is a trait (i.e., a relatively stable characteristic) or a state (i.e., according to the particular circumstance) has been provided, which, in turn, is important to consider when measuring HISB.

In the second part of the analysis, we focused on clarifying and offering additional insights into the concept's key components, including its antecedents, characteristics, and outcomes. Although HISB has received considerable attention in the literature, there has been less focus on examining the concept's key dimensions. Identification of the two main dimensions of HISB (information and method dimension) clarifies the core meaning of the concept. Using these key dimensions affords a more throughout identification and discussion of individuals' actual HISB. The degree to which emphasis has been put on each dimension of HISB varies among authors. Most researchers have examined either dimension of HISB, but rarely have they attended to both despite suggestions that HISB is best understood as a composite of information and method-related behaviors (Lenz, 1984). Therefore, a more comprehensive understanding of HISB might lie in examining individuals' patterns of HISB, that is, the particular ways in which individuals sequence components of the information and method dimensions within a given situation (and over time) to satisfy their information needs (Dunne, 2002; Echlin & Rees, 2002; Huber & Cruz, 2000; Szwajcer et al., 2005). Patterns of HISB reflect individuals' selectivity in the type and amount of information needed and sources and actions used, and best capture the uniqueness of each individual search for information. As such, HISB might best be reconceptualized from an either/or single behavior to an agglomeration of information and method behaviors. Such a reconceptualization further challenges traditional operationalization of HISB as categorically seekers or avoiders (Loiselle, Lambert, & Dubois, 2006). General definitions of seekers and avoiders focus on whether the information is sought or not, with little consideration of the individual's overall information environment. Typical categorizations of seekers or avoiders do not optimally capture differential patterns of HISB and might contribute to the misclassification of individuals' HISB. For example, if a pregnant woman does not want to be told the sex of her fetus as it might appear on the ultrasound but might be opened to "folk" tales about how to tell whether the fetus is a girl or a boy (Loiselle, Lambert, & Dubois, 2006), how should these HISB be categorized?

Findings from this concept analysis can be used to theorize on HISB. Particularly, a fine-grained analysis of HISB requires attention to individuals' patterns of HISB, its situational and personal antecedents, and their interaction effects. Some of the following questions could be considered: What differentiates individuals' patterns of HISB? How do patterns of HISB vary across context and time? What are the consequences of different patterns? Such an analysis would further document individuals' selectivity and variability when seeking information and can be integrated into current models to explain HISB beyond the mere seeker-versus-avoider dichotomy. In addition, much of the research on HISB centers on illnesses, such as cancer, HIV, and heart disease, there is a need also to understand patterns of HISB in a variety of other contexts and in various stages of health and illness. How patterns of HISB differ in different groups, such as across cultures and within different age groups, also needs to be explored further. All of these questions indicate further areas in which to develop and clarify the concept of HISB and demonstrate the need to collect new data using qualitative methods. We have recently undertaken a qualitative study to explore further patterns of HISB among individuals diagnosed with breast, prostate, or colorectal cancer (Lambert & Loiselle, 2005). This exploration is contributing to a better understanding of the complexities and subtleties of HISB, such as the Differential Health Information Seeking Behavior (DHISB) scale (Loiselle & Lambert, 2007).

HISB is of interest to health professionals because of its potential influence on the process and outcome related to psychosocial adjustment to illness. In addition, the concept of HISB as presented herein might be most relevant to practice as key dimensions are clearly outlined; making its assessment accessible and comprehensive. Such a clear and precise definition of HISB will also assist researchers and clinicians in tailoring their informational interventions to individuals' needs and preferences.

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Appendix E Manuscript #2

Lambert, S. D., & Loiselle, C. G. (2007). Combining individual interviews and focus groups to enhance data richness. *Journal of Advanced Nursing, 62*(2), 228-237.

JAN RESEARCH METHODOLOGY

Combining individual interviews and focus groups to enhance data richness

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Abstract

Title. Combining individual interviews and focus groups to enhance data richness.

Aim. This paper is a presentation of the critical reflection on the types of findings obtained from the combination of individual interviews and focus groups, and how such triangulation contributes to knowledge production and synthesis.

Background. Increasingly, qualitative method triangulation is advocated as a strategy to achieve more comprehensive understandings of phenomena. Although ontological and epistemological issues pertaining to triangulation are a topic of debate, more practical discussions are needed on its potential contributions, such as enhanced data richness and depth of inquiry.

Method. Data gathered through individual interviews and focus groups from a study on patterns of cancer information-seeking behaviour are used to exemplify the added-value but also the challenges of relying on methods combination.

Findings. The integration of focus group and individual interview data made three main contributions: a productive iterative process whereby an initial model of the phenomenon guided the exploration of individual accounts and successive individual data further enriched the conceptualisation of the phenomenon; identification of the individual and contextual circumstances surrounding the phenomenon, which added to the interpretation of the structure of the phenomenon; and convergence of the central characteristics of the phenomenon across focus groups and individual interviews, which enhanced trustworthiness of findings.

Conclusion. Although the use of triangulation is promising, more work is needed to identify the added-value or various outcomes pertaining to method combination and data integration.

Keywords: cancer information-seeking behaviour, focus groups, grounded theory, individual interviews, qualitative approaches, research methods

Introduction

The purpose of this paper is to discuss the implications of combining qualitative methods within a single study. In the nursing literature, the combination of multiple methods to study the same phenomenon is most often designated as triangulation (Loiselle *et al.* 2007). Although, the triangulation of qualitative methods continues to be advocated as a strategy to increase understanding of a phenomenon, little attention is given to the types of data each method provides and the impact of subsequent data combination on knowledge generation. Failure to recognize the implications of combining methods can lead to research resource misuse and methodological chaos (Morse 1999).

Recently we conducted individual interviews and focus groups to explore people's patterns of information-seeking behaviour (ISB) in cancer (Lambert & Loiselle 2005). During the initial analysis, we began to reflect critically on the use of these methods separately and in combination. In this paper we present the outcomes of this reflexive analysis to further stimulate discourse on the use of these methods and their contribution to knowledge acquisition. The discussion moves beyond the nature of knowledge generated to include pragmatic issues of method triangulation. It is based on an epistemological position that underscores the importance of various types of knowledge to obtain a comprehensive understanding of complex nursing phenomena.

Background

Individual interviews as a data collection method

Individual interviews are the most widely-used data collection strategy in qualitative research (Sandelowski 2002, Nunkoosing 2005). Researchers typically choose individual interviews to collect detailed accounts of participants' thoughts, attitudes, beliefs, and knowledge pertaining to a given phenomenon (Fielding 1994, Speziale & Carpenter 2003, Loiselle *et al.* 2007). This approach assumes that if questions are formulated correctly, participants' expressions of their experiences will reflect their reality (Morse 2000, Sandelowski 2002, Macdonald 2006). There is also the presupposition that participants will be able to formulate answers to the questions (Macdonald 2006).

Although assumed to be a 'generic' data collection method, individual interviews come in a variety of forms (e.g. structured, semi-structured) (Bernard 2002). Each interviewing approach assumes a philosophical orientation and may be more or less appropriate according to context and the qualitative methodology retained (Fielding 1994). For instance, grounded theory's underlying philosophical assumption (i.e. symbolic interactionism) implies reliance on semi-structured rather than structured interviews (Fielding 1994, Duffy *et al.* 2004). Ethnographic studies, on the other hand, use informal interviews (Macdonald 2006).

Although individual interviews contribute in-depth data, the assumption that words are accurate indicators of participants' inner experiences may be problematic. Interviewees may choose to withhold certain descriptions–or alternatively, embellish them–particularly if the 'truth' is inconsistent with their preferred self-image or if they wish to impress the interviewer (Fielding 1994). Such considerations raise the issue of whether interviewee-interviewer characteristics (e.g. demographics) should, at times, be matched (Fielding 1994). Also, although interviewers may wish to adopt a rather neutral role, they may inadvertently demonstrate a preference for a particular perspective and, in the process, bias the findings.

Focus groups as a data collection method

Focus groups are used by researchers worldwide to explore a range of phenomena (e.g. Brajtman 2005, Oluwatosin 2005, van Teijlingen & Pitchforth 2006). The primary goal of this method is to use *interaction data* resulting from discussion among participants (e.g. questioning one another, commenting on each others' experiences) to increase the depth of the inquiry and unveil aspects of the phenomenon assumed to be otherwise less accessible (Freeman *et al.* 2001, van Eik & Baum 2003, Duggleby 2005). Group interactions may accentuate members' similarities and differences and give rich information about the range of perspectives and experiences. However, regrettably, more often they are used as an 'inexpensive' substitute for individual interviews (Hollander 2004, Barbour 2005), and group transcripts are analysed for the content of 'individual' discussion (Hydén & Bütow 2003). Increased attention to interaction analysis and the unique insights obtained about the phenomenon in this process are critical to reach the full potential of this method (Freeman 2006).

Focus group data are the product of context-dependent group interactions (Hollander 2004, Duggleby 2005, Lehoux *et al.* 2006). Hollander (2004) discusses four types of social contexts that may be created within a group and influence members' interactions (type and amount): (1) associational context (i.e. a common characteristic that brings the participants together), (2) status context (i.e. positions of participants in local or societal status hierarchies), (3) conversational context (i.e. flow of the discussion and types of discussion within the group), and (4) relational context (i.e. degree of prior acquaintance with participants). According to the contexts created within a particular group, participants may or may not disclose certain information (Kidd & Parshall 2000, Hollander 2004). If focus groups are seen as a 'social space' where participants construct their experiences based on how the discussion evolves and how participants interact, then an additional layer of data may be obtained (Lehoux *et al.* 2006). Stevens (1996) suggests a series of analytical questions to identify the nature of group interactions. These include: 'How closely did the group adhere to the issues presented for discussion? Why, how, and when were related issues brought up? What statements seemed to evoke conflict?' (p. 172). Similarly, Lehoux *et al.* (2006) propose an analytical template to understand group interactions and ask, for instance: To what extent do the interactions among participants represent broader social contexts (e.g. age, gender)? How do dominant participants affect the contribution of other participants? How do participants respond to passive participants? Also, Hydén and Bütow (2003) suggest conducting an interaction analysis by examining whether an individual is interacting as a member of the group or as an individual in a group context and how these interactions may shift throughout the session. Therefore, rather than labelling certain interactions among participants as group consensus, a finer-grained analysis might reveal important aspects of the phenomenon of interest (Stevens 1996, Lehoux *et al.* 2006).

Integrating focus group and individual interview data

Although attention is increasingly placed on the combination of quantitative and qualitative methods, fewer authors (Barbour 1998, Morse 1999) have explicitly addressed the implications of combining qualitative data collection methods. The disproportionate number of methodological papers addressing qualitative–quantitative triangulation vs. qualitative–qualitative triangulation may be due to a misperception that combining methods within the same research paradigm is less paradoxical than integrating methods across paradigms (Barbour 1998). However, researchers also need to be explicit about the reasons for combining qualitative methods, as these can involve potentially divergent epistemological assumptions (Barbour 1998) and an *ad hoc* combination of methods may threaten the trustworthiness of findings (Morse 2003).

A search of the CINAHL database (1984–2007) using the keywords 'focus group' and 'individual interview' reveals that many researchers favour the combination of these methods. Although focus groups and individual interviews are independent data collection methods; their combination can be advantageous to researchers as complementary views of the phenomenon may be generated. A reading of nursing studies reveals three broad rationales for this combination: (1) pragmatic reasons, (2) the need to compare and contrast participants' perspectives (parallel use), and (3) striving toward data completeness and/or confirmation (integrated use).

Some researchers combine both methods for practical or pragmatic considerations. For instance, individual interviews may be offered to participants unable or unwilling to attend a focus group (e.g. Rees *et al.* 2003, Taylor 2005). This type of combination may lead to fewer refusals or withdrawals, as individuals can choose the method that is most convenient for them. However, each method's particular contribution to the understanding of the phenomenon is often not explicitly analysed – similar, dissimilar or complementary data are not taken into account. Also, consideration should be given to whether individuals participating in one type of interview are any different in relation to the phenomenon of interest than those participating in the other method.

Others use focus groups and individual interviews in parallel to explore the phenomenon of interest. Each method is used with a different group of participants, and the data from one method do not influence the implementation of the other. For example, if the aim of a study is to evaluate the process and outcomes of a health education programme, focus groups may be used with nurses who implemented the programme and programme participants may be interviewed individually (e.g. Leung *et al.* 2005). Although data source triangulation may provide different views about the same phenomenon and contribute to the credibility of the findings (Loiselle *et al.* 2007), the rationale for selecting a particular method for a sub-group of participants is often not explicit. For instance, why is a sub-group of participants interviewed individually and not invited to take part in a focus group (or vice versa)? In addition, it may be challenging to determine if disparate views are expressed because different sources of data are used or because different methods are implemented.

Individual interviews and focus groups also may be combined for the purposes of data completeness and/or confirmation (Adami 2005, Halcomb & Andrew 2005). When seeking data completeness, it is assumed that each method reveals different parts of the phenomenon of interest (complementary views) and contributes to a more comprehensive understanding (expanding the breadth and/or depth of the findings). For example, individual interviews may be used to explore personal experiences, whereas focus groups may be used to examine opinions and beliefs about the phenomenon (Molzahn *et al.* 2005). Sandelowski (1995) argues that triangulation with the intention of completeness in fact defies the original metaphor of a triangle. The term 'triangulation' should be reserved for when methods are combined for the purpose of confirmation. Rather, the metaphor of a 'crystal' better represents the integration of a phenomenon's multiple dimensions. A crystal is three-dimensional, changes and has multiple facets and angles, whereas a triangle is two-dimensional, fixed and rigid (Sandelowski 1995, Tobin & Begley 2004).

When authors combine individual interviews and focus groups for confirmation, the data obtained by one method are anticipated to corroborate those acquired with the other.

Some authors first obtain individual interview data and then carry out focus groups to confirm the findings (e.g. Plack 2006). Alternatively, others initially implement focus groups and later verify these findings with individual interview data (e.g. Dick & Frazier 2006). However, combining methods for confirmatory purposes may inadvertently lead to an erroneous hierarchy of evidence, where one data collection method is judged to yield more 'accurate' findings than the other (Barbour 1998). Also, combination for confirmation assumes that there is a 'reality on which it is possible to converge' (Sandelowski 1995, p. 572), an assumption that is typically challenged within the qualitative paradigm.

Overall, when integrating focus group and individual interview data, the trustworthiness of the findings may be threatened if each method's particular methodological underpinnings are overlooked and the data sets are assumed to be equivalent (Barbour 1998, Tobin & Begley 2004). To increase the rigour of method combination, consideration should be given to the correspondence of the study aims with the data collection methods, the rationale underpinning the combination of methods, and the epistemological assumptions of each method and their compatibility. Also, authors need to specify the relative weight of each data set (e.g. hierarchical, equal value) and identify the particular insights into the phenomenon obtained from each method and the added-value of the combination.

The study

Aim

We undertook a grounded theory study (Lambert & Loiselle 2005) to explore the ISB patterns of individuals diagnosed with breast, prostate or colorectal cancer.

Method

Consistent with grounded theory methodology, we conducted semi-structured interviews and focus groups. Participants were recruited from two ambulatory oncology clinics of a university-affiliated public teaching hospital in Montreal, Canada. All individual interviews were conducted between November, 2005 and September, 2007 and lasted from 20 minutes to 2·5 hours. Individual interviews and focus groups ($n = 31$) were not conducted in a predetermined sequence. That is some interviews were conducted prior to focus groups, others took place iteratively with focus groups, and approximately half of the interviews were conducted after the focus groups. Eight focus groups were conducted from January to June 2006: four with women diagnosed with breast cancer, two with men diagnosed with prostate cancer, one with men diagnosed with colorectal cancer, and one with men and women diagnosed with colorectal cancer. A moderator (the first author) and a co-moderator were present for each focus group. The focus groups lasted for 1·5–2·5 hours. Informed by our previous work on ISB (Loiselle 1995, Loiselle *et al.* 2006, Lambert & Loiselle 2007), a semi-structured interview guide was developed for use with both focus groups and individual interviews. The questions explored different aspects of ISB, including the motivation to seek cancer-related information and the type of information sought. All interviews were tape-recorded with participants' permission and transcribed verbatim. Ethics approval was obtained from the university and hospital ethics review boards. All participants in the study signed an informed consent.

Methodological observations

Initially, we combined individual interviews and focus groups for pragmatic reasons. Simply, participants who refused or were unable to participate in a focus group were invited to take part in individual interviews. However, as we proceeded with data analysis we noted that different types of data were collected according to the method, and their combination contributed to a more nuanced understanding of the phenomenon than initially anticipated. The focus then became to investigate how the combination of methods enhances our understanding of ISB patterns. In this particular context, data triangulation led to: (1) a productive iterative process whereby an initial model of the phenomenon guided the exploration of individual accounts and successive individual data further enriched the conceptualisation of the phenomenon, (2) identification of the individual and contextual circumstances surrounding the phenomenon, which added to the interpretation of the structure of the phenomenon, and (3) convergence of the central characteristics of the phenomenon across focus groups and individual interviews, which enhanced the trustworthiness of findings.

Iterative process guiding the exploration of the phenomenon

When comparing the transcripts from the focus groups and individual interviews, two levels of understandings of the phenomenon were noted. The focus group data reflected a general understanding of the range of ISB patterns and contributed to developing an initial model of the phenomenon. This model was subsequently used to guide the exploration of the phenomena as the study progressed. The individual interviews supplied detailed descriptions of how individuals proceeded through a particular ISB pattern, and further enriched the initial conceptualisation of the phenomenon. Thus, the separate data sets were mutually informative.

At the outset of the study, we assumed that participants would describe variability in information-seeking. However, we did not know how many ISB patterns would emerge. The second or third focus group led to the formulation of a general model pertaining to ISB pattern and substantiated the claim that 'differential ISB patterns' were present within this group. In fact, this initial model contained most of the patterns that emerged throughout the study. Many follow-up individual interviews were required before a similar range of ISB patterns was identified. During individual interviews, the interviewer used this model as a guide by considering whether and how an individual ISB pattern was embedded in the overall model or context of 'differential ISB patterns'. In this way, individual patterns were not explored in isolation.

Focus group findings helped to determine the most pertinent questions to be further explored during an individual interview. For instance, choosing the 'best' treatment was identified in the first few focus groups as a key motivation to pursue information-seeking intensely. According to the pattern identified in an individual interview, this motivation was more or less explored – the interviewer pursued in-depth exploration of this motivation only if pertinent for the pattern described. By concentrating only on the relevant aspects of a pattern, the interviewer optimized the time spent in the interviews. The data from individuals were found to be particularly important when fine-tuning the descriptions of a pattern. They allowed us to zero-in on a particular ISB pattern and further differentiate it from others. From the general model of ISB patterns, we were able to move back and forth between individual and group data, putting forward hypotheses about the phenomenon that were further explored through either individual or group interactions.

Interactions among focus group participants were key in developing the initial model of the phenomenon. As the focus group discussions progressed, participants were more likely to associate with members of the group sharing similar ISB, while differentiating from those who described disparate approaches to information-seeking. Also, we found that some types of interactions were more likely to occur among individuals sharing the same approach to information-seeking, while other interactions occurred among individuals thought to be different. Thus, considering the specific types of interactions among participants served to further delineate ISB patterns. The types of interactions identified across the focus groups included: validating or challenging interactions (e.g. argumentation, agreement), clarifying interactions (e.g. asking others to explain their opinion), criticizing interactions (e.g. lack of informational support), contrasting interactions (e.g. comparing experiences with cancer information), supporting interactions (e.g. commendation), venting interactions (e.g. expression of frustration), and information exchanging interactions (e.g. seeking/giving advice). Figure 1 gives an example of a challenging/clarifying interaction among women with breast cancer and underscores the importance of interaction analysis. Here, participant FG7-03 was most pro-active in seeking information about cancer. Both FG7-01 and FG7-02 showed a middle-ground approach to information-seeking, whereas FG7-04 sought information the least in comparison to the other group members.

Context as adding further structure to the phenomenon

Combining individual interview and focus group data also contributes to an enhanced understanding of the structure of the phenomenon. Structure is defined within the context of grounded theory analysis as 'the circumstances in which problems, issues, happenings, or events pertaining to a phenomenon are situated or arise' (Strauss & Corbin 1998, p. 127). Although within both data sets similar antecedents to a pattern of ISB were identified, the extent to which these factors were delineated or interpreted by participants differed. An individual account typically offered a concrete perspective or narration of the antecedents that motivated a pattern – participants clearly described how they proceeded through a set of circumstances contributing to information-seeking. Although during focus groups similar antecedents were mentioned, these were not necessarily described with the same level of detail. Rather, the animated discussions among group members exposed the contextual dimension of antecedents and provided a wider-angled lens to interpret individual-level data. For example, across methods, treatment-related decision-making was identified as an important antecedent to seeking cancer information. The analysis of individual data showed how participants might have proceeded through the decision-making process (procedural description) and how this was related to cancer information-seeking. Focus group discussions did not emphasize the actual process of decision-making, but rather broad contextual factors that might have been involved (e.g. physicians' preferences for patient involvement). Figure 2 provides a concrete example of the discussion that occurred in the focus groups about decision-making. Here, participant FG6-03 sought intense information as the oncologist did not give clear indications as to the best treatment, whereas participant FG6-02 did not experience the same context of care and was identified as describing an intermediary

FG7-02: There are a lot of people giving you advice as well and people trying to compare themselves to you. And saying why are you getting chemo [...] how long is your radiation treatment is it 30 seconds, is it 45, and I thought, I don't know how long is my treatment nobody told me how long it was. I only know that I'm going through it, like I'm not you know that precise. I assume the doctor knows what they are doing

FG7-03: That's quite interesting because I asked how long the [everybody laughing] and I know that I got 43 seconds from one angle and 44 seconds from another I don't know if it's...

FG7-02: (cuts) What's the difference?

FG7-03: I wanted to know it's a total of one minute and a half and it's a total of 4500 Grassman, They call it Grassman p. 9-10 [...] It's just different coping strategies.

FG7-01: That's exactly it

FG7-03: What works for you ...

FG7-01: That's right and that's amazing because like you really did what my daughter did [daughter is a medical student], you know. I can't imagine having to do that because if she wasn't there and I would have probably done what you did. P. 11 [...]

FG7-02: I know a friend she had breast cancer and she's the one that called me and said how long is your radiation treatment? I don't know maybe a minute in all, I don't know [...] well you better ask him and you better find out. And I said Why? What is it going to change, well you had to know. To me it doesn't mean anything you know, maybe to my doctors it means something but to me whether it's 30 seconds or...

FG7-04: (Cuts) If they tell 32 would you argue with 35 or 30 that's my point was [02: Yeah! Yeah!] What's the use who am I pretending to be here. Questioning their medication, what they are giving me, I had to ask certain questions, why are you giving me this to block my hormone instead of this to eliminate them, you know. Things like that P.18

[FG7 = Focus group #7 with women with breast cancer n=4]

Figure 1 Example of a focus group interaction emphasizing different approaches to information-seeking about cancer.

approach to information-seeking. FG6-03 did not give an actual description of her decision-making process, however much information was obtained about the context of care that 'obliged' her to participate in decision-making and why these factors were not as relevant for FG6-02. Overall, this interaction further contributed to a contextualized description of the process of decision-making.

Characteristics of the phenomenon further delineated across focus groups and individual accounts

Analysis of the focus group data led to the identification of a model for the phenomenon, which was substantiated by individual interview data. However, as the essential characteristics of the various ISB patterns were compared across data sets, some discrepancies arose. This instigated further analysis of the process to elucidate the nature of each ISB pattern. Particularly, certain characteristics were prominently identified from the individual interview data and not mentioned or elaborated upon by participants of the focus groups who were thought to share the same pattern. The focus group findings seemingly provided a 'partial' picture of each pattern when compared to what appeared to be the pattern's equivalent description obtained from individual interviews. It was unclear how these discrepancies should be interpreted and whether similar patterns were in fact captured by each method. Such considerations were particularly important when determining how many patterns were described by the participants and whether certain descriptions should be collapsed into the same pattern.

Apparent variations in meaning were better understood when we further attended to the process by which the patterns' descriptions emerged according to each method. The individual interview context allowed most questions included in the interview guide to be systematically explored. That is, each dimension of the concept that the interviewer hoped to address was explored. Obviously, focus groups did not allow the exploration of all questions included in the interview guide. Rather, focus group participants spontaneously discussed dimensions of the concepts relevant to the group conversation and according to the specific type of ISB patterns discussed; the group progressively co-constructed the various components and meaning of the phenomenon. Each focus group elucidated particular characteristics of a pattern

FG6-03: I guess I had to become involve in the decision making process I guess a sense that...

FG6-02: Nothing was clear

FG6-03: I had a very small tumour but it was acting aggressively so I became atypical, what was interesting is that they didn't know how to treat me, because I didn't fit into a sort of very neat little package because they don't know what to do with me [...] So what do we do? P. 7 [...] Nothing was clear so therefore I felt that I just couldn't sit back and wait for somebody to say do this and this and this way. When I sensed there wasn't you know there wasn't agreement [...] so you're right it's that whole notion of the...

FG6-02: Unknown

FG6-03: The unknown and then who is controlling this and how much input. Do you know what I am saying? You just put everything in the hands of the doctors. You sort of need to work with them almost like a partnership it's sort of like which is kind different when usually you go to the doctor if your arm is broken. You don't even think twice about just you arm is broken there going to fix it they're going to set it right! There is probably not many options and all of a sudden with cancer you start to realize there is not one... You know it depends on who you are, your background your this, your that, there is just...

FG6-02: That's what I say I was lucky I had that...I had someone in charge right away because they knew what it was in my case. They relieved some of the feel because the doctor X took charged; the doctor X also then I said Oh! I'm in good hands. I thought both the doctors were terrific so I didn't have that unknown, I knew as much because they could tell me the rest was just things I wanted to know for myself. The unknown would have killed me.

[FG6 = Focus group #6 with women with breast cancer n=3]

Figure 2 Example of a discussion among focus group members emphasizing the contextual dimension of antecedents to information-seeking about cancer.

and discussed 'a' version of the phenomenon as relevant in that group context. As a result, a characteristic of a pattern might or might not have been discussed by all members of a group or might not even have been raised by a particular group. Therefore, it was not optimal to initially consider participants' group conversations separately – assuming that interview questions had been explored – and compare these with individual interview data. However, when all focus group data were taken together and summarized, we did obtain a more 'complete' picture of each pattern as discussed across groups. When this alternate approach to analysis was adopted, most pattern characteristics were corroborated across methods and data convergence became appropriate as a mean to increase the trustworthiness of findings.

Discussion

The main challenge addressed in this paper pertains to the optimal integration of individual interview and focus group data. In the examples given, side-by-side and non-hierarchical comparisons of the data sets revealed overlapping and rich complementary findings that contributed to a coherent and more nuanced understanding of ISB patterns.

Morse (1999, 2002) emphasizes that the qualitative 'tool box' offers multiple methods to choose from to enhance the exploration of complex phenomenon, and she advocates for the competent use of multiple qualitative methods within a single study and within a programme of research. Researchers are encouraged to use multiple qualitative methods to enhance the analysis of a phenomenon and to broaden its conceptualization (Morse 1999, 2002). However, the unskilful mixing and matching of methods may threaten the trustworthiness of findings (Morse 1999, Tobin & Begley 2004, Rolfe 2006). Although authors may contend that multiple methods were used to obtain a more in-depth understanding of the phenomenon, the essence of that enhanced understanding is rarely explicitly presented. Hence, the practical discussion about the added-value of the integration of multiple qualitative methods presented in this paper is timely.

Even if few papers explicitly elaborate on the combination of qualitative methods, there are many papers in the nursing literature discussing the epistemological and methodological benefits and potential drawbacks of triangulation (e.g. Breitmayer *et al.* 1993, Sandelowski 1995, Tobin & Begley 2004). These are useful to guide a reflection on approaches to method combination and to avoid common methodological mistakes. For instance, we avoided claiming that one method might be better at uncovering the essence of the phenomenon, that convergent findings supported the validity of methods used, or that the 'strengths' of one method offset the weaknesses of the other (Massey 1999). Although we do not claim that triangulation may be used as a form of validity,

What is already known about this topic

- Whereas individual interviews are often the undisputed 'gold standard' of qualitative data collection methods, focus groups are increasingly favoured by nurse researchers to explore participants' experiences in an interactive format.
- Triangulation of qualitative methods is a research strategy generally anticipated to contribute to a more thorough exploration of complex phenomena, but limited consideration has been given to the process, function, and outcome of such activities.

What this paper adds

- Main considerations when integrating individual interview and focus group data include the purpose of data integration, the types of data collected through each method, and the insights into the phenomenon obtained across data sets.
- Data integration also involves moving back and forth between the data sets to discover data convergence, divergence and complementarity.
- During this process, to promote methodological integrity, recognition of the epistemological underpinnings of method triangulation is key (e.g. convergence and implications for the validity of methods).
- When performed rigorously, the integration of individual interview and focus group data is a productive strategy that leads to an enhanced description of the phenomenon's structure and its essential characteristics.

we acknowledge that the data may be similar, different or complementary, and that the combination of methods is useful to understand the different representations of the phenomenon. Findings from this study were integrated into a workable model to account for diverse ISB patterns, such that similar or complementary findings increased our level of confidence in some of the concepts and areas of disagreement were further interpreted.

In research environments where resources are increasingly scarce, researchers need to be explicit about the added benefits of investing resources in the use of multiple data collection methods within a single study. In our study, the integration of data sets led to an iterative process of data collection and analysis and enhanced understanding of the structure and essential characteristics of the phenomenon within the context of cancer. Moezzi (2007) also found that focus groups were particularly useful at cataloguing the range of participants' experiences and that individual interviews contributed to a detailing of these experiences. In addition, we note that for this type of combination to be fruitful, attention must be given to the nature and context of focus groups that are more productive (e.g. that facilitate and enhance interactions among participants and that create a context encouraging the sharing of similar or differing views). Moreover, individual interviews should build on the information gathered through focus groups. Hall and Rist (1999) did not find their focus groups to be particularly useful in answering the research questions and, therefore, additional qualitative methods were used. However, the authors acknowledged some limitations in the implementation of the focus groups (e.g. type of participants, timing) which may have contributed to their unproductiveness.

Sands and Roer-Strier (2006) identify five types of data obtained in their study through data triangulation (i.e. different data sources): (1) same story, same meaning (when similar interpretations of the phenomenon are provided); (2) same story, different interpretations (when similar answer to questions are provided but a different meaning to the phenomenon is ascribed); (3) missing pieces (when information is provided by one participant but not another); (4) unique information (when some information is only reported by one participant); and (5) illuminating (when data are different but not contradictory). Although the focus of Sands and Roer-Strier (2006) is on data triangulation and not on method triangulation, we have documented similar findings. For instance, our discussion about the different levels of interpretations of the phenomenon (individual vs. contextual) bears some resemblance to what Sands and Roer-Strier (2006) describe as 'same story, different interpretations' or 'illuminating'. In addition, Pamphilon (1999) contributes The Zoom Model, which can be applied to the combination of methods discussed in this paper. The Zoom Model underscores that three levels of meaning may be found in participants' narrations of a phenomenon: macro-zoom (corresponding to the socio-historical dimension, collective meanings), meso-zoom (reflecting personal level of values), and micro-zoom (which examines emotions and characteristics of voice). The combination of these three levels of meaning reveals the complexity of the phenomenon better than any one level of meaning alone (Pamphilon 1999). These types of data were also identified in our study across methods. For instance, the focus groups were particularly useful at uncovering macro-level data. In combination with the findings presented in this paper, the findings of Sands and Roer-Strier (2006) and the model by Pamphilon (1999) are helpful tools to guide the identification and categorization of the different data obtained through each method and their combination.

Vandermause (2007) raises challenges, comparable to those identified in this paper, to consider when using multiple methods, including identification of a method fitting the question and the intended study outcome(s) and the combination of methods while maintaining methodological rigour. Furthermore, Vandermause (2007) emphasizes that the complexity of healthcare phenomena calls for innovative combinations of qualitative methods that include multidisciplinary – different methods implemented by researchers from several disciplines – and multi-media research – integrating, for instance, poetic interpretation with theatrical or photographic interpretation. This type of research raises additional challenges, including the coordination of a process that permits different researchers to work together effectively and to arrive at a consensus for data interpretation (Vandermause 2007). Hence, methodological discussion providing guidelines for the rigorous combination of qualitative methods is needed to further address such complex, yet increasingly common, research designs.

Conclusion

Future discussion about method triangulation may be most productive when efforts are directed towards the identification of the various types of knowledge obtained (Foss & Ellefsen 2002, Jones & Bugge 2006). Future studies could benefit from the development of a matrix of findings that would identify the data obtained by each method across themes and categories. The visual depiction of a matrix can assist researchers in systematically comparing the data sets, thereby enhancing the identification of the various levels of data and their mutual contribution to an enhanced understanding of the phenomenon (Averill 2002, Farmer *et al.* 2006).

Author contributions

SL and CL were responsible for the study conception and design. SL and CL were responsible for the drafting of the manuscript, SL performed the data collection and data analysis. SL and CL obtained funding and CL also provided administrative support. SL and CL revised the paper. CL supervised the study.

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Appendix F Manuscript #3 and #4 Confirmation of Acceptance to Cancer Nursing

Sylvie Lambert

From: "Cancer Nursing" <editor@gator.net>
To: <sylvie.lambert@mail.mcgill.ca>
Sent: June 1, 2008 9:45 AM
Subject: CN Decision

Jun 1 2008 9:42AM

RE: CN-D-08-00040R1, entitled "An in-depth exploration of information-seeking behavior among individuals with cancer: Part 1 Understanding differential patterns of active information-seeking"

Dear Ms. Lambert,

I am most pleased to inform you that your work has now been accepted for publication in CANCER NURSING: An International Journal for Cancer Care. I shall forward all of your manuscript materials to our production staff for placement in an upcoming issue. I am not sure as of yet which issue your work will be a part of but we shall be sure to share that with you in a very timely fashion.

I want to thank you for your responsiveness to our reviewers' comments in both of your linked manuscripts. In order to pubish them together, I shall be placing them in our online component of the journal. This component of our journal is very strong and in fact, the majority of nominees for our annual research award were from the online component.

Thank you for submitting your interesting and important work to the journal.

http://cn.edmgr.com/

Slambe
lambert

With Kind Regards,

Pam

Dr. Pamela Hinds
Editor-in-Chief
CANCER NURSING: An International Journal for Cancer Care

Sylvie Lambert

From: "Cancer Nursing" <editor@gator.net>
To: <sylvie.lambert@mail.mcgill.ca>
Sent: June 2, 2008 8:51 AM
Subject: CN Decision

Jun 2 2008 8:50AM

RE: CN-D-08-00041R1, entitled "An in-depth exploration of information-seeking behavior among individuals with cancer: Part 2 Understanding patterns of information disinterest and avoidance"

Dear Ms Lambert,

Last evening I recevied the final reviewer comments on this manuscript and I am most pleased to inform you that your work has now been accepted for publication in CANCER NURSING: An International Journal for Cancer Care. All manuscript materials will be forwarded immediately to the production staff for placement in an upcoming issue. The reviewers commented upon your responsiveness to their comments and to the added clarity that resulted from your additions. Special thanks for this added effort.

Thank you for submitting your interesting and important work to the journal.

http://cn.edmgr.com/

Slambe
lambert

With Kind Regards,

Pam

Dr. Pamela Hinds
Editor-in-Chief
CANCER NURSING: An International Journal for Cancer Care

Appendix G Interview Guide and Socio-Demographic and Medical Information Sheets

I would first like to thank you for participating in this study.

The purpose of the interview today is to learn more about how you go about seeking the information about your illness that you want.

When we will begin the interview I will start the tape-recorder, however if at any time during the interview you want me to stop it, let me know.

Do you have any questions or concerns before we start?

1. Before discussing specifically how you sought (or not) information about cancer, can you provide a summary of the events you have experienced since the diagnosis?

2. What did you know about cancer when you were diagnosed?

3. What importance do you give to seeking information about cancer?

4. What are some reasons that lead you to seek information?

What are the reasons that lead you to seek information the way you did?

Probes:
- What was your motivation to seek information?
- What was your goal to seek information?
- How did you use the information that you sought?
- What are the benefits of seeking information?
- What are the costs of seeking information?
- How are you planning to use the information? How did you decide on what treatment to have?

5. How do you obtain the information about cancer that you need?

Probes:
- Who or what is your best information resource?
- Who or what has been least helpful in obtaining the cancer-related information you are seeking?
- What aspect of seeking information, if any, do you find to be a problem?
- Could you describe a situation that most represent how you went about obtaining the information that you needed/wanted?
- What are some **strategies** you use to obtain information?
- How did you determine that the information you obtained was pertinent?
- Do you think sometimes it is better to avoid information? Why or Why not?
- Did you sometimes feel overwhelmed by information? What were you trying to understand?

6. What type of information related to your cancer have you been searching or wanting to obtain since your diagnosis?
Different type of information at different moments?

Probes:
- Which type of information do you prefer: factual information versus life experiences (testimonials); factual information versus sensory information?
- How do you want the information about cancer to be presented (written, oral, both, other? Why?
- Could you give me an example, typically, what type of information you prefer to search for?
- Could you give me an example, typically, what type of information you prefer to avoid?
- What type of information about your illness do you think is necessary to search for?
- Who or what influences the type of information that you search for?
- Do you prefer certain kind of information over other ones? Why?
- If there is some type of information related to your illness that you don't want to have, but it is offered to you, what do you do?
- What type of information related to your illness do you think has been most important for you to search for?
- What influences the type of information you seek?
- Are there some types of information more then others? Why?

7. Did you obtain all the information you were seeking for?
Probes:
- What information did you receive after your diagnosis?
- Looking back, what information do you wish you had received?

8. Did you compare yourself to others diagnosed with cancer?
Probes:
-How was this useful? Or not?

9. Did any experienced side effects lead you to seek information?

10. How much information related to your illness do you prefer to search for?
Probes:
- How much detail about a particular topic did you seek to obtain? Very detailed, much technical detail, superficial, overviews, just enough…. Clarify what is meant by expressions 'just enough', 'not much'
- Could you give me an example of the amount of information you sought?
- Do you feel you limit the amount of information that you search or accept? If yes, How do you limit the information sought?
- What influences how much information you will search for?

11. Overall, do you feel that the information that you search for (or have been searching for) is helpful?
Probes:
- Could you give me an example of how the information you have sought has been useful?
- Could you give me an example of how the information you have sought has not been useful?
- How was the information sought helpful?
- How was the information sought not helpful?
- Was the information sought what you desired?
- Was the information sought satisfactory?

12. Has the way in which went you about searching for information changed since you've been diagnosed (or since you've begun treatment)?
Probes:
- Has the amount of information changed? The type of information changed?
- How have you changed how you search for information?
- What advice would you give to those newly diagnosed with cancer regarding seeking information related to their illness?
- If you could turn back time, would you go about searching for information related to your illness differently?

13. Did how you went about searching for information (or not searching for information) affect your interactions with your family or the health care team?
Probes:
-Can you give me an example of how it has affected your interactions with your family?
- Can you give me an example of how it has affected your interactions with the health care team?
- Have these interactions changed how you go about searching for information?
- What kind of advice have you received from your family or the health care team regarding obtaining information related to your illness?
- If I would ask your family to describe how you go about searching for information related to your illness, what would they say?
- If I would ask members of the health care team to describe how you go about searching for information related to your illness, what would they say?

14. In general, do you have a tendency to always seek information?
Probes
- Could you describe a situation when you decided not to search or receive any information related to your illness?
- If yes, could you give me an example? Were the reasons for seeking information similar or different?
- If no, could you give me an example? Why do you think your approach to information-seeking was different?

Additional interview questions to explore information disinterest or avoidance

**** Important to differentiate whether participant simply <u>not interested</u> in information (and why) (e.g., all information needed provided by MD) <u>versus</u> <u>Avoidance</u> (e.g., not wanting to seek information because of fear or too distressed…)**

1. What importance do you give to seeking information about cancer?

2. In what ways do you think that you avoid certain types of information about cancer?

3. Are there certain types of information you are (were) more likely to avoid then others?

4. Can you give me some specific reasons why you may avoid information about cancer?

5. When do you tend to avoid information about cancer (e.g., when stressed..)?

6. What would you say are the main <u>benefits</u> of <u>not</u> seeking information about cancer?

7. According to you, what may be the <u>disadvantages</u> of <u>not</u> seeking information about cancer?

8. For you, what may be the drawbacks of <u>seeking too much information</u>?

9. Some people say that they want to know as much as possible about their cancer and treatment, why do you think it may be helpful, on some occasions, to seek a lot of information about cancer?

10. Sometimes people find it useful to seek information to help them reduce their uncertainties, anxieties or stress, what do you do to help you with feelings of anxiety/stress?

11. How do you react to information presented to you (e.g., media)? (e.g., if a friend or family member talks to you about cancer?)

12. In general, would you say that you're the type of person that has a tendency to not seek information?
    If yes, could you please give me an example?
    If no, could you give me an example?

13. What kind of information did you receive from the oncologist, nurse or others regarding diagnosis? treatment? side effects? sexuality? spirituality?

Tout d'abord, merci de participer à notre étude

Chaque personnes recherche l'information sur le cancer différemment, aujourd'hui j'aimerais apprendre comment vous recherchez l'information sur le cancer.

Lorsque nous allons débuter l'entrevue, je vais démarrer le magnétophone, toutefois si à n'importe quel moment durant l'entrevue vous voulez que je l'arrête, dites-le moi.

Avez-vous des questions avant que nous commencions?

1. Avant de discuter comment vous avez recherché l'information, est-ce que vous pouvez décrire les événements qui se sont produits depuis votre diagnostique?

2. Qu'est-ce que vous saviez sur le cancer quand vous avez été diagnostiqué?

3. Quelle importance avez-vous attribué à la recherche d'information sur le cancer?

4. Quelles sont les raisons qui vous ont amenées à rechercher de l'information?
- Qu'est-ce qui vous a motivé à rechercher de l'information sur le cancer?

- Quel était le but de votre recherche d'information?

- Comment avez-vous utilisé l'information que vous avez obtenue?

- Quels sont les <u>bénéfices</u> de rechercher de l'information?

- Quels sont les <u>inconvénients</u> ou points négatifs de rechercher de l'information?

5. Comment avez-vous obtenu l'information que vous aviez besoin sur le cancer?
- Quel était votre source d'information préférée?
- Qu'est-ce qui a été moins utile dans votre recherche d'information?
- Quel(s) aspect(s) de votre recherche avez-vous trouvé problématique?
- Pouvez-vous me décrire une situation qui représente le mieux comment vous avez recherché l'information?
- Quels sont les stratégies que vous avez utilisées pour obtenir de l'information?
- Comment avez-vous déterminé que l'information que vous avez recherchée était pertinente pour vous?
- Est-ce que vous croyez qu'il est parfois mieux d'éviter l'information? Pourquoi?
- Parfois, est-ce que vous vous sentiez inondé par l'information recherchée?

6. Quel genre d'information liée au cancer avez-vous recherché?
Est-ce que vous avez préféré différent genre d'information à différents moments?
- Quel genre d'information préférez-vous? (information factuelle, statistique, témoignage)?
- Comment préférez-vous que l'information vous soit présentée (écrite, orale, les deux)? Pourquoi?

- Pouvez-vous me donner un exemple du genre d'information que vous préférez rechercher?
- Pouvez-vous me donner un exemple de genre d'information que vous préférez éviter?
- Quel genre d'information liée au cancer croyez-vous était le plus important pour vous de rechercher?
- Qu'est-ce qui influence le genre d'information que vous recherchez?
- Est-ce que vous préférez certains genres d'information plus que d'autre? Pourquoi?
- S'il y a un genre d'information que vous ne voulez pas, mais qu'on vous l'offre, comment réagissez-vous?
- Quel genre d'information reliée au cancer pensez-vous est nécessaire de rechercher?
- Qu'est-ce qui influence comment vous recherchez l'information?

7. Est-ce que vous avez obtenu toute l'information que vous vouliez ?
- Quel genre d'information avez-vous reçu après votre diagnostique ?
- En rétrospective, quel genre d'information auriez-vous aimé recevoir ?

8. Est-ce que vous vous comparez à d'autres personnes avec le cancer ?
- Est-ce que vous avez trouvé ça utile ? Pourquoi ?

9. Est-ce que vos symptômes vous ont incité à rechercher de l'information ?

10. Quelle est la quantité d'information que vous avez recherchée?
- Comment décririez-vous la quantité d'information que vous avez recherchée?
- Pouvez-vous me donner un exemple d'une situation qui décrit le mieux comment vous avez obtenu l'information dont vous aviez besoin?
- Pouvez-vous me donner un exemple d'une situation où vous avez décidé d'éviter de l'information sur le cancer?
- Comment limitez-vous l'information que vous recherchez?
- Qu'est-ce qui influence la quantité d'information que vous recherchez?

11. En général, est-ce que l'information que vous avez recherchée a été utile?
- Pouvez-vous me donner un exemple d'une situation où l'information recherchée vous a été utile?
- Pouvez-vous me donner un exemple d'une situation où l'information recherchée ne vous a pas été utile?

12. Est-ce que la manière dont vous recherchez de l'information a changé depuis votre diagnostique? Ou depuis le début de votre traitement?
- Est-ce que la quantité d'information recherchée a changé?
- Est-ce que le genre d'information recherchée a changé?
- De quelle façon vos recherches d'information ont-elles changées?
- Quel(s) conseil(s) concernant la recherche d'information sur le cancer donneriez-vous à des gens nouvellement diagnostiqués avec un cancer?
- Si vous pouviez retourner en arrière, est-ce que vous rechercheriez l'information différemment?

13. Est-ce que vos recherches d'information ont affecté vos interactions avec votre famille ou les professionnels de la santé?
- Pouvez-vous me donner un exemple de comment votre recherche d'information a affecté vos interactions avec votre famille?
- Pouvez-vous me donner un exemple de comment votre recherche d'information a affecté vos interactions les professionnels de la santé?
- Est-ce ces interactions ont influencé comment vous recherchez de l'information?
- Quel(s) conseil(s) concernant la recherche d'information sur le cancer avez-vous reçu de votre famille ou des professionnels de la santé?
- Si vous demandiez à un membre de votre famille de décrire vos recherches d'information, que diraient-ils?
- Si vous demandiez à un professionnel de la santé de décrire vos recherches d'information, que diraient-ils?

14. En général, est-ce que vous avez tendance à rechercher de l'information?
- Est-ce que vous pouvez me décrire une situation où vous n'avez pas recherché de l'information?
- Pourquoi pensez-vous que vous n'avez pas recherché d'information dans cette situation?

Questions supplémentaires pour explorer la recherche minimale d'information ou l'évitement d'information.

1. De quelle façon avez-vous évité certaines informations liées au cancer?

2. Est-ce que vous avez une tendance à éviter certains types d'information plus que d'autres?

3. Quel genre d'information êtes-vous porté à éviter?

4. Pourquoi avez-vous décidé d'éviter de l'information sur le cancer?

5. Est-ce qu'il y a eu des moments ou des situations ou vous étiez plus porté à éviter de l'information (ex. moment plus stressant…)?

6. Selon vous quelles sont les <u>bénéfices</u> de ne <u>pas</u> rechercher de l'information?

7. Est-ce que pour vous il y avait des <u>désavantages</u> à ne <u>pas</u> rechercher de l'information?

8. Selon vous quelles sont les <u>désavantages</u> de rechercher <u>trop</u> d'information?

9. Certaines personnes préfèrent rechercher le plus d'information possible lié au cancer, pourquoi pensez-vous que dans certaines situations il peut être aidant de rechercher beaucoup d'information?

10. Parfois certaines personnes recherchent de l'information pour diminuer leur anxiété, stress ou incertitude face au cancer, vous qu'est-ce qui vous a aidé à diminuer ces sentiments?

11. Comment réagissez-vous lorsque qu'on vous donne de l'information? (ex. un membre de votre famille vous donne de l'information liée au cancer)

12. En général, est-ce que vous avez tendance à ne pas rechercher de l'information?
    Si oui, est-ce que vous pouvez me donner un exemple?
    Si non, est-ce que vous pouvez me donner un exemple?

13. Quel genre d'information avez-vous reçu de l'oncologiste, de l'infimière ou autres personnes concernant votre diagnostique? traitement? sexualité? spiritualité?

Socio-Demographic Information

1. Today's Date: ____/_____/_____
Day Month Year

2. Your date of birth: ____/_____/_____
Day Month Year

3. Age: _______

4. (a) **What is your m**arital Status:
Check only the category that applies to you

(1) Single ____
(2) Married ____
(3) Common law ____
(4) Separated/divorced ____
(5) Widowed ____

(b) **What is your current living situation?**
Check only the category that applies to you

(1) Alone ____
(2) With spouse/important other ____
(3) With children ____
(4) With other family ____
(5) With other non-family ____
(6) With spouse and children ____

(c) **Do you have any children?** (1) Yes ___ (2) No ___

If yes, how many children do you have? _________

How old are your children? __________

How many of your children live with you? ________

5. Work status:
Check only the category that applies to you

(1) Full time in the paid work force ____
(2) Part time in the paid work force ____
(3) Unemployed ____
(4) Disability/sick leave ____
(5) Homemaker ____
(6) Retired ____
(7) Other (specify) ___________________________________

6. In which country were you born? ___________________________________

If other than Canada, when did you move to Canada? _____ / _____
Month Year

7. **What is your ethnic background?**
Check only the category that applies to you

(1) Caucasian ____
(2) Hispanic/Latina ____
(3) Asian ____
(4) African ____
(5) Other (please specify) ______________

8. What language(s) do you speak most at home? _________________________

9. What is your religious background?
Check only the category that most applies to you

(1) Buddhist ____
(2) Christian ____
(3) Greek or Eastern Orthodox ____
(4) Hindu ____
(5) Jewish ____
(6) Muslim ____
(7) Not applicable ____
(8) Other (specify) ________________

10. What is your total household income before taxes?
Check only the category that applies to you

(1) Less than $ 10, 000 ____
(2) $10,000-$29,999 ____
(3) $30,000-$49,999 ____
(4) $50,000-$79,999 ____
(5) $80,000-$99,999 ____
(6) $100,000-$119,999 ____
(7) More than $120,000 ____
(8) I don't know ____

11. What is the highest level of education that you have completed?
Check only the category that applies to you

(1) Elementary school ____
(2) High school ____
(3) CEGEP: Technical ____
(4) CEGEP: General ____
(5) Bachelors ____
(6) Masters ____
(7) Doctorate ____

12. How many years of education does this represent? ___________

13. What is (was) your primary occupation?

____

Medical Information

1. When were you diagnosed with cancer? ____/_____/_____
day month year

2. Have you already had surgery for this cancer?
(1) Yes ___ (2) No ___

→ If yes, what type of surgery? ____________________________ Date of surgery:
_____/_____

Month Year
→ If no, has surgery been planned?
(1) Yes ___ (2) No ___ (3) I don't know ___

3. Are you receiving or have you received any of the following treatment?
Check all that apply

(1) Chemotherapy ____ Beginning: ______/______ End: ______/______
Month Year Month Year
(2) Radio-therapy ____ Beginning: ______/______ End: ______/______
Month Year Month Year
(3) Other (specify): _____________________

4. Have you used other types of treatments or approaches for your cancer?
(1) Yes ___ (2) No ___

If yes, check all that apply:
(1) Acupuncture ___
(2) Special diet ___
(3) Exercise ___
(4) Herbs ___
(5) Medication from other countries ___
(6) Relaxation ___
(7) Visualisation ___
(8) Vitamins ___
(9) Other (specify): ______________________________________

5. Do you have any other health-related problems?
(1) Yes ___ (2) No___

If yes, please specify: ______________________________

6. Are you participating in any other study related to cancer?
(1) Yes (please indicate the name of the study):
____

(2) No ______

(3) I don't know _______

Source. Adapted from Loiselle, Edgar, & Batist (2002)

Questionnaire Socio-Démographique

1. Date d'aujourd'hui : ____/____/____
Jour Mois Année

2. Votre date de naissance: ____/____/____
Jour Mois Année

3. Âge : ________

4. (a) **Quel est votre statut civil** :
Cochez seulement la catégorie qui s'applique à vous

(1) Célibataire ____
(2) Mariée ____
(3) Union de fait ____
(4) Séparée/divorcée ____
(5) Veuve ____

(b) **Demeurez-vous avec quelqu'un?**
Cochez seulement la catégorie qui s'applique à vous

(1) Seul(e) ______
(2) Avec époux/épouse/conjoint ______
(3) Avec enfant(s) ______
(4) Avec autre membre de la famille ______
(5) Avec autre non membre de la famille ______
(6) Avec époux/épouse et enfants(s) ______

(c) **Avez-vous des enfants?** (1) Oui ____ (2) Non _____

Si oui, combien d'enfants avez-vous ? __________

Vos enfants (votre enfant) a (ont) quel âge ? __________

Combien d'enfant(s) vit (ent) avec vous ? __________

5. Statut d'emploi:
Cochez seulement la catégorie qui s'applique à vous

(1) Plein temps ____
(2) Temps partiel ____
(3) Sans emploi ____
(4) Absence/congée de maladie ____
(5) Travail à la maison (ménagère) ____
(6) Retraitée ____
(7) Autre (spécifiez) ___________________________________

6. Pay de naissance (specifies)? ___________________________________

Si autre que le Canada, depuis quand restez-vous au Canada? _____ / _____
Mois Année

7. Quelle est votre origine ethnique?

(1) Caucasien ____
(2) Hispanique/Latine ____
(3) Asiatic ____
(4) Africain ____
(5) Autre (SVP spécifiez) _____________

8. Language parlée à la maison (spécifiez)? _______________________

9. Dans quelle religion avez-vous grandi?
Cochez seulement la catégorie qui s'applique à vous

(1) Bouddhist ____
(2) Chrétienne ____
(3) Grecque ou Orthodoxe orientale ____
(4) Hindouiste ____
(5) Juive ____
(6) Musulmane ____
(7) Ne s'applique pas ____
(8) Autre (spécifiez) _______________

10. Quel a été votre revenu familial total avant impôts ?
Cochez seulement la catégorie qui s'applique à vous

(1) Moins de $ 10, 000 ____
(2) $10,000-$29,999 ____
(3) $30,000-$49,999 ____
(4) $50,000-$79,999 ____
(5) $80,000-$99,999 ____
(6) $100,000-$119,999 ____
(7) Plus de $120,000 ____
(8) Je ne sais pas ____

11. Quel est le plus haut niveau de scolarité que vous avez complété?
Cochez seulement la catégorie qui s'applique à vous

(1) École primaire ____
(2) École secondaire ____
(3) CEGEP: Techniquel ____
(4) CEGEP: Général ____
(5) Université : Baccalauréat ____
(6) Étude post- baccalauréat : Maîtrise ____
(7) Étude post- baccalauréat : Doctorat ____

12. Combien d'année de scolarité cela represente-t-il ? __________

13. Quelle est (était) votre occupation principale?

____

Information Médicale

1. Quand avez-vous eu votre diagnostic de cancer? ____/_____/_____
Jour Mois Année

2. Avez-vous déjà subi une chirurgie pour ce cancer ?
(1) Oui ___ (2) Non ___

→ Si oui, quel genre de chirurgie? ____________________ Date de la chirurgie:
_____/_____

Mois Année
→ Si non, une chirurgie est-elle prévue?
(1) Oui ___ (2) Non ___ (3) Je ne sais pas ___

3. Recevez-vous (ou avez-vous reçu) le (les) traitement(s) suivant ?
Cochez la(les) catégorie(s) qui s'applique(nt) **à vous :**

(1) Chimiothérapie ____ Début: ______/______ Fin: _____/_____
Mois Année Mois Année
(2) Radio-thérapie ____ Début: ______/______ Fin: _____/_____
Mois Année Mois Année

(3) Autre (spécifiez): ___________________

4. Avez-vous utilisé d'autre(s) traitement(s) ou approche(s) pour votre cancer?
(1) Oui ___ (2) Non ___

Si oui, cochez la(les) catégorie(s) qui s'applique(nt) **à vous:**
(1) Acupuncture ___
(2) Diète spéciale ___
(3) Exercise ___
(4) Plantes médicinales ___
(5) Médicaments provenant d'autres pays ___
(6) Relaxation ___/
(7) Visualisation ___
(8) Vitamines ___
(9) Autre (specifiez): __________________________________

5. Avez-vous d'autres problèmes de santé?
(1) Oui ____ (2) Non ____

Si oui. SVP spécifiez : _______________________________

6. Participez- vous à une autre étude en lien avec le cancer?
(1) Oui (SVP, indiquez le nom de l'étude):
____

(2) Non ______

(3) Je ne sais pas _______

Source. Loiselle, Edgar, & Batist (2002)