University of Alberta

Breast Cancer Patients' Acquisition and Evaluation of Information Relevant to Treatment Decision-making

By

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Abstract

An understanding of the factors influencing information acquisition by patients is needed to design dissemination strategies that are effective in providing high quality information for treatment decision making. I conducted two studies to explore factors influencing information acquisition for early-stage breast cancer patients facing surgery. Study 1: An integrative review of information needs, information sources used, and outcomes associated with the use of decisional support interventions. Several personal and contextual factors influenced needs and sources, and decisional support interventions had some limited benefits. Study 2: A focused ethnography examining the evaluation and utilization of information sources by breast cancer patients prior to treatment. Findings included patient preference for interpersonal sources, the need for both technical and experiential information, and the role of trust in source choice. Six source characteristics were identified. Better knowledge of patient information use patterns will help to devise more effective information dissemination strategies by healthcare providers.

Dedication

"Ohne Fleiß, kein Preis"

(Without industriousness, there is no reward.)

German Proverb

I dedicate my thesis to my first teachers, my parents Erna & Joe Walder, who taught me that great efforts reap great rewards, and to always take pride in everything I do.

I also dedicate this thesis to my children—Susannah, Thomas & Michael, who are my greatest treasures, and whose enthusiasm for life and learning continues to inspire me in countless ways. Finally, to my husband Dennis—my greatest supporter, whose unwavering belief in my abilities buoyed my spirits and kept me striving towards my goal.

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I would like to acknowledge the contribution of 14 amazing women who shared their breast cancer treatment experiences with me. I was humbled by the dignity and courage with which they faced their challenges.

I would like to express appreciation to my thesis committee members—Dr. Ceinwen Cumming and Dr. Karin Olson. I am grateful for their insightful advice and intellectual generosity. Their guidance and support was very much appreciated, particularly with recruitment.

Finally, I would like to thank Dr. Carole Estabrooks, my thesis supervisor. Dr. Estabrooks has consistently believed in my abilities and has provided challenge and encouragement throughout my entire academic career. She is an excellent researcher and I feel very fortunate to have been under her mentorship. A sincere thanks Carole.

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Chapter 1: Introduction

Breast Cancer Patients' Acquisition and Evaluation of Information Relevant to Treatment Decision-making

This thesis is an outcome of my masters program of research in information transfer to healthcare consumers. The purpose of my research was to investigate the ways in which early-stage breast cancer patients acquire and evaluate information relevant to treatment decision making. The findings from this thesis provide the groundwork for development of information transfer interventions that will appropriately meet the information and supportive needs of breast cancer patients. I undertook the research as two projects which led to the development of two manuscripts for publication. This 'paper-based' thesis document consists of four chapters. In Chapter 1, I review the relevant literature in order to provide a frame of reference for the two papers that follow (in manuscript format) in Chapters 2 and 3. In the final chapter (Chapter 4) I discuss the findings and how they contribute to existing research. In this thesis, I will use 'I' in the first and last chapters to indicate authorship. While chapters 2 & 3 are the products of my own research, I have used 'we' to indicate the contribution of my colleagues as is appropriate for published articles (or articles to be submitted for publication).

1. Background

1.1. The context of the studies

Breast cancer is the most common female cancer in the world. According to the most recent Canadian statistics, one in nine women will be diagnosed, and one in 27 will die of breast cancer in their lifetime [1]. While the incidence of breast cancer has been slowly increasing over the years, the mortality rates for this disease have been declining [2]. Due to the effectiveness of mammography screening programs, there has been a shift towards the detection and diagnosis of breast cancer at an earlier stage of disease [1]. Disease prognosis improves with earlier diagnosis, which means that more women are living longer with breast cancer. It also means that more women are undergoing treatment for *early stage* breast cancer, a treatment that primarily involves the surgical removal of the cancerous tissue with or without radiation as an adjuvant treatment [3].

The two main treatment options for early stage breast cancer are mastectomy, surgical removal of the entire breast and the axillary lymph nodes, and lumpectomy (sometimes called breast conserving therapy or BCT) the removal of the cancerous tumor along with a margin of normal tissue surrounding the tumor. Radiation therapy is always recommended as an adjuvant therapy to lumpectomy in order to ensure all of the cancerous cells have been destroyed. Prognosis for each of the treatments is the same [4], which means that treatment choice can be based on the patient's circumstances and personal preferences [3]. Patients are encouraged to take an active role in treatment decision making, but in order to do so, they require knowledge of the risks and benefits of both treatment options.

Not all cancer patients want to take part in decision making, some prefer to leave the final decision to someone else, usually their physician [5-7]. However, most individuals who defer decision making to someone else, still want as much information as possible about potential treatments [8,9]. The majority of patients prefer to share decision making with a healthcare professional, and a few prefer to make the decision wholly on their own [10]. Preferred role in decision making does not always match the actual role played [5] and concordance between these roles is associated with improved patient satisfaction and clinical outcomes [11,12].

Regardless of a patient's role in decision making, in order to make a truly *informed* choice, they require clear, unbiased, evidence based information. Deciding on a treatment involves looking at the differences between the two procedures, keeping in mind personal preferences and values. Women who value survival over body image may tend to lean towards mastectomy because ensuring that the surgeon has 'gotten it all' is of more importance to them than keeping their breast intact. Women who value maintaining body integrity may choose differently. Whatever decision is made, a 'good' decision will be one where the individual has improved knowledge and realistic expectations, lowered decisional conflict, reduced indecision, and improved agreement between the individual's values and choice made [13].

Decision aids are tools that are used by healthcare professionals to convey information relevant to specific healthcare decisions. Though they may take different forms (e.g., workbook, pamphlet, CD, video, or decision 'board'), their purpose is the same: to assist in eliciting patient values and preferences, and in communicating to patients the alternative treatments available, the relative risks and benefits of each treatment, and the probability of different outcomes occurring [14]. Decision aids are particularly helpful in situations where, as with the choice between mastectomy and lumpectomy, different treatment options have the same prognostic outcome but may have different effects on the patient's quality of life. For decision aids in general, the most consistent benefits have been better knowledge of options and outcomes, and more realistic expectations of the benefits and harms of options [15]. More specifically, decision aids designed to assist women in choosing surgical treatment for early-stage breast cancer have been shown to increase knowledge, reduce decisional conflict, and increase satisfaction with the decision making process [16].

Not all patients are aware of, have access to, or choose to use these decision making tools, and most treatment decisions are made without their benefit. Patients must rely on whatever information they are provided with or are willing to seek out themselves (or by others on their behalf). People seek out information as a way to manage the immediate threat of disease [7,17]. Those who are active information seekers cope better with the disruption of quality of life associated with cancer diagnosis and treatment [18]. Information seeking is also associated with positive health outcomes and psychosocial adjustment [19].

Many health information seeking behaviour studies are conducted within the context of cancer (screening, prevention or treatment). Because of the considerable number of treatment options that exist, and the fact that roughly 40% of the population in Canada will develop cancer sometime during their lives (based on current incidence rates) [1], cancer patients contribute significantly to the population of individuals seeking health information. Breast cancer patients make up a sizable proportion of this group. Understanding the information acquisition process for this population will not only contribute to improvements in the dissemination of breast cancer information, but may be relevant to other populations as well.

1.2. Information-seeking models/theories

Researchers have developed several models and theories describing the information seeking process. While some of the models focus on the content aspects of information seeking (i.e., the types and amount of information), others focus more on the method aspects of this behaviour (source choice and use) [20]. Lazarus and Folkman's [21] stress/appraisal/coping theory and Miller's [22] monitoring and blunting theory both centre on the individuals response to a stressful situation. Information seeking is viewed as a way of coping with the immediate threat of illness. While these two constructs centre on the antecedents to information seeking and the seekers response to stress, neither attempts to explain the process of information seeking.

The other models depict information seeking in a flow-chart form, showing the various steps individuals progress through and identify factors thought to influence information seeking behaviour [20]. Lenz's information seeking model [23] and the health information acquisition model [24] are very similar, both describing a six-step process: reacting to a stimulus, goal setting, deciding whether an active search has merit, the actual search behaviour, evaluation of the information, and an assessment of whether the information gathered is sufficient. The latter model differs in that it shows the process as a more iterative one, with the individual restarting the search for information if previous searches have yielded inadequate results.

The final two models focus primarily on the process of information seeking rather than on the depth or kind of information sought. The comprehensive model of information seeking [7] describes the antecedents (background and personal relevance factors) to information seeking and how they impact searching behaviour. It also describes the information ‘channel’ characteristics that are thought to be relevant to channel selection, such as social presence and uncertainty reduction. Information ‘channels’ are described as conduits of information, with ‘sources’ being specific locations within the channel, and ’messages’ being words, symbols, or signals representing specific content that emanate from a source. While Johnson’s model admirably represents the complexity involved in the search for information, it fails to represent the iterative nature of information seeking [20]. Longo’s expanded model of information seeking [25] differentiates active seeking from passive reception of information. This is the first model that I located in the literature to specifically acknowledge that information may be acquired without the intention to do so. It lacks, however, any appreciation for the role that the sources themselves play in the equation.

The variety and extent of the models presented help to illustrate the inherent complexity of the information seeking process. In their concept analysis of health information seeking behaviour, Lambert and Loiselle [20] differentiated between two dimensions of the concept of information seeking behaviour. First they identified an *information dimension* concerned with the characteristics of the information sought in terms of type (content and diversity of the search) and amount (detail and depth), and secondly, a *method dimension* that contends with how individuals seek out and retrieve information, and the sources they use to satisfy information needs. While the former deals with the attributes of the information itself, the latter deals with the actions involved in obtaining the information. A large part of the health information behaviour research has been descriptive (i.e., a listing the kinds of information, the methods and sources used etc. for a specific population), with some attempts to uncover influencing factors.

Generally, personal and situational factors influence what *kind* of information, the *amount* of information, what *sources* are used, and *how* the information is acquired. Personal variables such as age and education have been shown to influence the type [26-28] and amount [29,30] of information and types [30-32] of sources accessed. There is also evidence to suggest that contextual and situational variables such as type or stage of disease [7,33] or size and composition of an individual's social network [7,9] influence health information seeking behaviour. Researchers have not for the most part considered the interrelationships *among* variables in predicting health information seeking behaviour [20]. Also, there have been no studies that examine the role of information source characteristics, or what potential effect the interplay between individual, situational and source characteristics have on seeking behaviour.

1.3. Information provision

The information seeking behaviour literature looks at the acquisition of information from the information *receivers* vantage point. Another way of looking at this phenomenon is to view it from the *providers* perspective. Countless strategies (e.g., decision aids, pamphlets, telephone helplines etc.) are employed by healthcare professionals to inform patients and encourage greater involvement in health decision making. Outcomes of interest that have been evaluated have come from one or more of the following categories: (1) patient knowledge (e.g., recall of information, knowledge of treatment outcomes and likely outcomes), (2) patients' experience (e.g., patient satisfaction, quality of life), (3) use of services and costs (e.g., hospital admission rates, cost effectiveness), and (4) health behaviour/status (e.g., physical or mental functioning). Coulter & Ellins [34] in their systematic review suggested that strategies for informing, educating and involving patients regarding their care are effective and result in improved outcomes in the four categories above. Despite the effectiveness of these interventions, evaluations of the information materials themselves by patients and professionals suggest that these materials often fall short in terms of completeness, accuracy and relevance [35].

1.4. Knowledge translation

Within the healthcare field, the term 'knowledge translation' is most often talked about in terms of the translation of research findings into a form that can be used by clinicians, and/or other decision-makers. The underpinning assumption is that healthcare practice based on the best available science will result in more effective and efficient patient care. Most of the focus to date in the knowledge translation field has been on providers of care, with less attention having been paid to those *receiving* care.

1.5. Knowledge to action (KTA) framework

Graham and colleagues [36] proposed a knowledge translation framework in 2006 (see **Fig1-1**) that describes the concept of moving knowledge into action. In this framework, 'knowledge' consists of *all forms* of knowing (including research), and 'action' is meant to not only to refer to the use of knowledge by practitioners and policy makers, but by patients and the public as well. Recently, Tugwell and colleagues [37] applied Graham's Knowledge-To-Action (KTA) framework more specifically to the creation and application of research findings to a population of healthcare consumers with musculoskeletal conditions. I have used Graham's KTA framework to organize my thesis work and illustrate how this work on information fits into a larger knowledge translation program – in this case one focused on early-stage breast cancer patients.

The Graham framework consists of two phases: a 'knowledge creation' phase, and an 'action' phase. The knowledge creation phase begins with determining what knowledge is important to the end user, tailoring that information into a useable format, and then creating knowledge tools or products using appropriate language. An example of a knowledge tool that can be used to inform patients would be a decision aid. The action phase involves the application of the knowledge within the context of a specific health problem. Tugwell et al. [37] describe the process of applying the action cycle to a *specific patient population* as beginning with the identification of a problem that needs addressing, then searching for and separating out the appropriate information which is then reviewed and selected based on its quality and relevance to the problem of interest. Then, the information is adapted to the local context and the barriers to knowledge use are assessed. The final three steps of the action cycle are to monitor knowledge uptake, evaluate the outcomes of the intervention, and to sustain knowledge use. Examples of the framework's application to the treatment of early-stage breast cancer are provided in **Table 1-1.**

The framework illustrates the iterative nature of the knowledge creation and dissemination process. Graham and associates stress that the framework is 'fluid' in nature, with the phases of the 'action' cycle influencing each other and in turn influencing and being influenced by knowledge creation. This allows for the 'back and forth' nature of the consultative process that occurs between the producers and consumers of knowledge in order to ensure that the final product is acceptable to the user. Lastly, this framework includes an 'monitoring' phase, an 'evaluation' phase and a 'sustaining' phase. The responsibility of the knowledge producer/disseminator does not end with simply handing out the information. Information uptake is scrutinized and appraised so that problems can be identified and adjustments made. The sustainability phase involves making sure that a plan for assessing and evaluating changes in the action cycle are detected and managed.

I have located the findings from the two studies that comprise the substantive portion of this thesis within the KTA framework (**Figure 1-1**). The integrative review (paper #1) is a summary of the literature in the area of information needs and the sources of information used by breast cancer patients, and the outcomes associated with a specific kind of knowledge dissemination intervention (CDA). The findings of this paper correspond to the 'knowledge inquiry' and 'knowledge synthesis' portions of the framework. Determining the relevant knowledge needs and sources used by this population contribute to a better targeted knowledge product. The evaluation of CDA outcomes (paper #1) corresponds to the evaluation phase of the action cycle. Based on the results of the review, the success of the dissemination strategy is assessed and reworked as necessary. The focus of the qualitative paper (paper #2) was on the evaluation of information sources used by breast cancer patients. Understanding how individuals evaluate sources of information will contribute to better tailoring of knowledge dissemination interventions. For example, source characteristics that patients judge to be important (e.g., accessibility) would need to be considered when developing knowledge dissemination strategies.

2. Purpose

The purpose of my thesis was to explore which early stage breast cancer patients access, evaluate and use information to inform their treatment decision making.

3. Research Questions

The research questions guiding this thesis are as follows:

1. What are the expressed information needs of early-stage breast cancer patients and what sources of information are used to fill these needs within the context of a treatment decision between mastectomy and lumpectomy?
2. What effects do women identify as a result of using research evidence to support a treatment decision between mastectomy and lumpectomy?
3. Can they describe how they *weight* these sources in terms of importance?
4. What is the relative contribution of each source in terms of its influence on the decision making process?

4. Design

I designed and conducted two independent studies with the intention of answering the questions listed above. Both were written as manuscripts for a paper-based master's thesis. The purpose of the first study, an integrative review , was to answer the first two questions. The second study , a secondary analysis of a qualitative data set, was conducted in order to answer the last two research questions.

5. Overview of Studies 1 and 2

Study 1: Information acquisition for women facing surgical treatment for breast cancer: influencing factors and selected outcomes.

The objective of the first paper was to examine, summarize, and critically assess the literature focusing on information use by early-stage breast cancer patients. I used empirical articles that reported the information needs, sources used, sources preferred, and intervention-related outcomes experienced by patients in the context of making a treatment choice. I discussed the findings using Longo's [25] expanded conceptual model of information seeking. The need to determine, a) which qualities of information sources make them attractive to patients and, b) why some sources are preferred over others, were identified as areas for further study.

The paper has been published in *Patient Education and Counseling*[1].

Study 2: A qualitative examination of how early-stage breast cancer patients evaluate sources of information relevant to treatment decision making.

In the second paper my object was to investigate how newly diagnosed breast cancer patients find, use and weigh evidence in the context of making treatment decisions between mastectomy and lumpectomy. I conducted a secondary analysis of a qualitative data set that had been collected several years previously. In order to validate the analysis and to augment theory development, primary data collection was conducted using focus group interviews. Analysis yielded a list of sources used as well as the six characteristics by which the sources were evaluated.

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[1] O'Leary, K.A., Estabrooks, C.A., Olson, K., & Cumming, C. (2007). Information acquisition for women facing surgical treatment for breast cancer: Influencing factors and selected outcomes. *Patient Education and Counseling, 69*(1-3), 5-19.

The paper will be submitted to *Patient Education and Counseling* for publication.

6. Method

Study 1: Information acquisition for women facing surgical treatment for breast cancer: influencing factors and selected outcomes.

I conducted a review of the literature published in English over the last 20 years (January 1, 1986-March 31, 2006). In order to find the literature relevant to the two research questions guiding the review, two separate searches were conducted using the following data bases: CINAHL, Medline, PsychINFO, Science Citation Index Expanded, Social Sciences Citation Index, and the Arts and Humanities Citation Index. The first search used the key words: information seeking, information sources, information seeking behaviour, information needs, decision-making, information resources, oncology, cancer, and neoplasm. The search was further refined using the terms breast conserving therapy, lumpectomy, mastectomy and surgery. A review of the articles determined that eight articles fit the criteria and were relevant to the topic of the review. The second search utilized the keywords: decision making, treatment choice, oncology, cancer, and neoplasm. The search was further refined using the terms breast conserving therapy, lumpectomy, mastectomy and surgery. Only three articles fit the criteria, and were relevant to the review. Ancestry searches and hand searches yielded an additional 14 articles for both searches. The disparate nature of the methods used precluded any *systematic* quality assessment, so an assessment of the methodological rigor was presented in narrative form.

Study 2: A qualitative examination of how early-stage breast cancer patients evaluate sources of information relevant to treatment decision making.

I conducted a secondary analysis of qualitative data that had been collected in 1999-2000 from one surgeon's practice at a tertiary Health Sciences Centre in central Canada. Inclusion criteria included: a) being within one week of diagnosis of Stage I or Stage II breast cancer, and b) facing a decision between mastectomy and lumpectomy. Part of the original study involved the evaluation of the consumer decision aid (CDA) that was given to each of the women following their surgical consultation with the surgeon. Two separate interviews were conducted, one as soon as possible after they received the decision aid, and one at approximately six months post-diagnosis. Six women were eventually recruited for the study.

In order to validate the analysis and to enhance theory development, I collected additional qualitative data using focus group interviews. Participants had to have: a) been diagnosed with either Stage I or Stage II breast cancer, b) faced a treatment choice between mastectomy and lumpectomy, and c) completed their surgical treatment no more than 4 years previously. Two focus group interviews were conducted with eight women in total participating.

I conducted a content analysis of both data sets [38] examining the sources of information access, evaluated and used to inform the women's decision making for breast cancer treatment. The analysis of the six individual interviews was completed before data were collected from the focus group interviews. Analysis was conducted in three steps: data reduction (simplifying, abstracting, focusing, transforming the raw data), followed by data display (organization of the data in order to draw conclusions) and finally, conclusion drawing /verification (confirming that the conclusions are valid). Transcribed data were managed using N6™ software.

7. Summary

In this research I focused on the information behaviour of early-stage breast cancer patients in the context of a decision between two surgical treatments. While not all individuals wish to be involved in decision making, most would like to have as much information as possible about their disease and its treatment. Clear, unbiased, evidence based information is essential for those who wish to make an informed decision regarding treatment, and one intervention that has been developed for that purpose is the consumer decision aid. Health information-seeking models have been developed to describe and explain the ways in which individuals locate, evaluate and acquire information about their health. While collectively these models provide a comprehensive picture of information seeking behaviour, no one model captures the complexity inherent in this activity.

The information-seeking literature explores the receiver's point of view, but another way of looking at this transaction is to view it from the *providers* perspective. The Knowledge to Action (KTA) framework provides a useful means of organizing research findings, and planning and evaluating dissemination interventions. The two manuscripts contained within this paper-based thesis will contribute to the creation of better knowledge tools and enhanced dissemination strategies.

Table 1-1: Information provision to early-stage breast cancer patients by researchers/providers to inform a treatment decision: Application of the Graham et al. (2006) Knowledge-To-Action (KTA) framework [2]

Knowledge Creation

Knowledge to Action Process	*Application to Early-Stage Breast Cancer Treatment Decision*
Knowledge Inquiry	Determining priority issues and concerns (e.g., chances for a cure, possible treatments)
Knowledge Synthesis	Gathering information (highest level of evidence possible, e.g., locating systematic reviews regarding prognostic outcomes of mastectomy vs. lumpectomy)
Knowledge Tools/Products	Development of a Consumer Decision Aid for treatment of early-stage breast cancer

Action Cycle or Application of Knowledge

Knowledge to Action Process	*Application to Early-Stage Breast Cancer Treatment Decision*
Identify problem	Determine specific information needs—where are the knowledge gaps? (survey, focus group interview, etc.)
Identify, review, select knowledge	Locate required information, evaluate in terms of credibility, completeness etc., select knowledge
Adapt knowledge to local context	Ensure information is relevant to the individual's specific situation
Assess barriers to knowledge use	Accessibility, emotional state, cognitive abilities, language issues etc.
Select, tailor, implement interventions	Delivery of information should be based on the individual's needs, desires, preferences (be aware of potential barriers above)
Monitor knowledge use	Survey the population (early-stage breast cancer patients) to ensure that information needs are being met
Evaluate outcomes	Research study evaluating outcomes such as level of knowledge, decisional regret, satisfaction with decision making process etc.
Sustain knowledge use	Establish and maintain funding for specialized information delivery programs/tools

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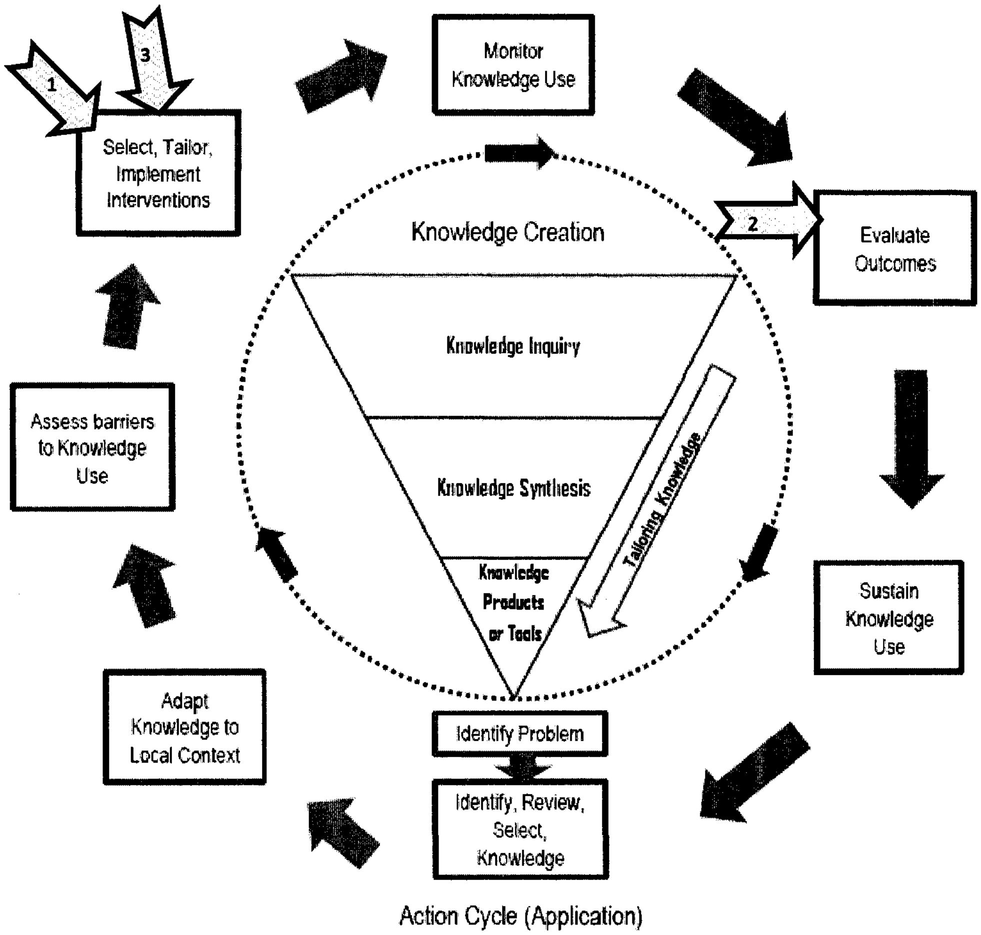
[2] Graham, I.D., Logan, J., Harrison, M.B., Straus, S.E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: Time for a map? The Journal of Continuing Education in the Health Professions, 26(1), 13-24.

Figure 1-1: Knowledge to Action Process[3]



How papers 1 & 2 are situated within the KTA process:

1 Determining information needs/sources (Paper #1)

2 The evaluation of the CDA (Paper #1)

3 Determining reasons for source preference, types of knowledge desired (Paper #2)

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[3] Graham, I.D., Logan, J., Harrison, M.B., Straus, S.E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: Time for a map? The Journal of Continuing Education in the Health Professions, 26(1), 13-24.

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Chapter 2: Information acquisition for women facing surgical treatment for breast cancer: Influencing factors and selected outcomes.

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Information acquisition for women facing surgical treatment for breast cancer: Influencing factors and selected outcomes.

1. Introduction

For more than a decade now, evidence-based decision-making has been a major trend in healthcare. Rather than relying on unsystematic clinical experience, healthcare professionals are encouraged to base their clinical decision-making on the findings of scientific studies [1]. The 'evidence' in evidence-based decision-making is usually understood to be empirically based, with the findings of randomized clinical trials (RCTs) being considered one of the most robust forms of evidence [2] because it has the most objective way of eliminating bias. However, other form of evidence, where bias is more difficult to control (e.g. observational or case studies), may be more appropriate for answering certain kinds of research questions. Regardless of what research design is used, careful, systematic scientific scrutiny is used to determine effective diagnostic procedures and treatments. Optimal patient care is then limited to these practices in order to minimize unnecessary treatment and control costs [3].

While there is an expectation that healthcare providers will incorporate evidence into decision-making involving patient treatments, until relatively recently, there was no such expectation of the patients themselves. In the past, treatment decisions were entrusted to the professional healthcare provider [4–7]. More recently, trends within healthcare are transforming the patient role in treatment decision-making from one of passive recipient, to one of more equal partner [5]. An increase in 'consumerism,' an expansion in the number of viable treatments options available, and the exponential growth of the Internet and availability of health information have all contributed to greater patient involvement in healthcare decisions [8,9].

Evidence-informed patient choice (EIPC) is a concept that is rooted in the principle of informed choice [10]. In order to uphold the principle, healthcare providers are obligated to ensure that patients are reasonably informed of the risks and benefits of a procedure prior to the patient giving or withholding consent, and are afforded the opportunity to have their concerns and questions addressed [11]. Scientific studies determine the risks and benefits of different avenues of treatment (or non-treatment). In order for patients to be informed regarding treatment choices, they require a reasonable understanding of both the advantages and disadvantages of available treatments.

There is increased opportunity for oncology patients in particular to become involved in decision-making because of the variety of therapeutic options that are available for different cancers. Most oncology patients want to be involved in decision-making and attaining their preferred role in decision-making leads to better quality of life [12,13]. Despite this, patients do not always assume their preferred role in decision-making [14,15]. Not all cancer patients wish to be involved in decision-making, despite having more opportunity to do so. Several studies have reported that the degree to which patient wish to participate in decision-making varies widely [15–17], and that a patient's level of involvement in decision-making is not indicative of their desire for information. Many patients who undertake a passive role in decision-making still want to be well informed. Increases in knowledge, satisfaction, treatment compliance, and quality of life have been reported as positive outcomes of adequate information provision [18–20]. Not having enough information has been linked to dissatisfaction with care and reduced wellbeing [17,21].

Investigators have found that the desire for information is temporal in nature, with different kinds of information being requested at different times throughout the disease trajectory [22,23]. Generally, the information cancer patients say that they require most is the information about survival and staging of the disease, and about treatment options and related side effects [22,24]. While the literature widely refers to the desire for information exhibited by a patient as information need, we acknowledge that the term 'need' inappropriately describes what is occurring. Using the term 'need' implies that there is an objective standard by which the need can be assessed. What is actually being determined is the patients' expressed desire for information. For the sake of simplicity, however, we will use the term need in order to be in agreement with the existing literature.

Overwhelmingly, healthcare practitioners are the most widely used and the most preferred source of information for cancer patients [25], although there is evidence that the use of electronic and media sources for cancer information has increased significantly [26,27]. Patients may also use specially designed interventions called consumer decision aids (CDAs) that provide information relevant to a specific decision regarding treatment options. CDAs, used prior to or during a physician consultation, are one way of engaging patients in a meaningful discussion of their treatment options. In addition to providing relevant information, the patient is led through the decision process. Risks and benefits of the treatment options are presented in a format that is easy to understand along with a values clarification exercise meant to elicit the patient's personal preferences regarding different treatment options. CDAs are an increasingly common method of supporting a treatment choice and are often used to facilitate the decision process. However, not all patients may have access to or choose to use decision aids prior to making a treatment choice.

Pierce [28] studied the unaided decision-making process in women with a diagnosis of early-stage breast cancer or a diagnosis of cardiovascular disease and found several problematic aspects of decision behaviour. Decision aids are designed, in part, to counteract faulty decision behavior. Pierce also asserted that the majority of women in her study made satisfactory decisions without the benefit of a decision aid. This unaided decision must be based on some type of information or 'evidence'. As was mentioned previously, healthcare practitioners are the most preferred sources of information for patients facing a treatment choice; however, other sources such as families, friends, the media, and the Internet are also widely used. Researchers examining the sources used by breast cancer patients have reported inconsistent results, with some investigators reporting that 'people' sources are favored over documentary sources [29,30] and others reporting the reverse [22].

Other factors may come into play when patients make decisions about which treatment to choose other than the simple provision of information. Researchers examining how decisions are actually made in the real world (descriptive theory) rather than how they ought to be made (normative theory) have discovered that people often make decisions that do not appear to be rational. How a choice is 'framed' [31], which outcomes a patient values [32], and whether the patient has the ability or motivation to understand the intricacies of the scientific information [33] may all play a role in how a decision is made. Decisional heuristics, adaptive 'short-cuts' in the decision process are used to make decisions in complex situations where information may be incomplete or difficult to understand. Also, the emotional impact of being diagnosed with cancer may lead patients to base decisions on fear rather than scientific evidence [34].

In terms of theoretical research, two particularly informative models of how oncology patients seek out healthcare information exist in the literature. Johnson [35] produced the comprehensive model of information seeking (CMIS) which focuses on characteristics and utility of information channels (sources) as well as factors antecedent to information seeking (personal relevance and background factors). More recently, Longo [36] developed a conceptual model, which identifies several personal and contextual factors thought to influence information seeking and use; factors that are roughly equivalent to Johnson's personal relevance and background factors. But instead of focusing on the characteristics of the sources, the Longo model describes the actual process of information seeking and information use (see **Figure 2-1**). Two kinds of information use are identified: one resulting from active information seeking and one resulting from the passive receipt of information. In each of these two categories, several phases of information use are identified according to the level of the patient's involvement. For example, in phase 1, the patient is not aware of or does not receive the available information. In phase 2, the patient is aware of the information but does not attempt to access it, or passively receives it and so on. Longo identifies satisfaction, health outcomes, activities of daily living (ADLs), and empowerment/locus of control as relevant patient outcomes.

Conceptual models are helpful in identifying key variables that are to be studied, and can help in organizing the findings of related research [37]. Evidence obtained from empirical research or systematic review of the existing literature either refute or confirm the models proposed relationships, thus either challenging or strengthening the model. The ultimate goal is to produce the most accurate and parsimonious representation of the 'truth'. The Longo model is useful in that it synthesizes and integrates the concepts surrounding information seeking and use by cancer patients, however, the relationships proposed need to be tested and refined. It is our intention to determine whether or not the influencing factors and relationships presented in the Longo model are supported by the existing literature. In order to resolve this, we have sought out empirical articles that explore the ways in which breast cancer patient's acquire and utilize information for treatment decision-making.

In this paper, the authors survey the existing literature relating to the expressed information needs of early-stage breast cancer patients facing a treatment choice between mastectomy and lumpectomy, the information sources used to satisfy these needs, and the outcomes related to decisional support interventions. Specifically, we summarize research related to the following questions:

Question 1: What are the various expressed information needs of early-stage breast cancer patients (in terms of type, range, quality, and quantity) and what sources of information are used to fill these various needs within the context of a treatment decision between mastectomy or lumpectomy?

Question 2: What effects do women identify as a result of using research evidence, specifically decision aids used to support a treatment decision between mastectomy and lumpectomy?

2. Methods

Broadly speaking, the aim of a systematic review is to synthesize the findings of several studies that address the same topic or problem, using strategies that limit bias and random error. Studies are put through a rigorous critical appraisal process and findings are combined and interpreted [38]. When findings are too diverse to be compared statistically or when the research methods used are dissimilar, a more narrative approach must be undertaken. The research questions guiding this review cast a broad net into the literature resulting in the capture of a diverse set of studies. It was evident early in our process that an integrative review was a more appropriate strategy to assimilate the findings. Integrative reviews allow for the inclusion of a diversity of literature, both empirical and theoretical and ''. . .can contribute to a comprehensive portrayal of the topic of interest'' [39, p. 57].

2.1. Procedures

A review of the literature published over the last 20 years was conducted using the following databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, PsychINFO, Science Citation Index Expanded, Social Sciences Citation Index, and the Arts and Humanities Citation Index (the last three through the Web of Science). The search was limited to articles published in English between January 1, 1986 and March 31, 2006. In order to adequately cover the topic under review, we conducted two searches, with each relating to one of the guiding questions.

The first search used the terms information seeking, information sources, information seeking behaviour, information needs, decision-making, information resources, oncology, cancer, and neoplasms and yielded 557 hits. The search was further refined using the limiting terms breast conserving therapy, BCT, lumpectomy, mastectomy and surgery. This resulted in a substantial narrowing of the focus of the search and consequently the number of hits was reduced to 64. The abstracts of these articles were reviewed and it was determined that only eight articles were relevant to the topic of review. In conducting the second search, the key search terms used were decision-making and treatment choice in combination with oncology, cancer, or neoplasm and yielded a combined total of 1922 hits. The search was further refined using the limiting terms decisional support, decision aids, CDA, and consumer decision aids. This resulted in a substantial narrowing of the focus of the search and consequently the number of hits was reduced to 63. The abstracts of these articles were reviewed and it was determined that only three of the articles were relevant to the topic of review. Acceptance or rejection of an article was based on the inclusion/exclusion criteria listed in Fig. 1. A complete list of excluded articles (127) is available from the authors.

Combined, the relevant articles from the two searches numbered 11. A search of the reference lists (ancestry search) of the retained articles yielded another 11 articles. Hand searching of the following journals yielded the final three articles: Psycho-Oncology, European Journal of Cancer Care, Medical Decision Making, Oncology Nursing Forum, Cancer Nursing, and Patient Education and Counseling. In all, 25 articles met the inclusion/exclusion criteria. We determined that a methodological evaluation was not feasible, given the disparate research methods used among the included articles.

3. Results

The retrieved articles were sorted into three broad categories. In all of the articles, the study participants were early-stage breast cancer patients within the context of having to make a treatment decision between mastectomy or lumpectomy. Investigators in the first group reported on studies examining information needs (**Table 2-1**), the second group on the sources of information preferred and/or used (**Table 2-2**), and the third group on the effectiveness of a specific decisional support intervention (**Table 2-3**). The first two groups provided a potential answer to Question 1, and the third group of articles provided a potential answer to Question 2.

3.1. Information needs studies

There were eight articles [17,40–46] in which authors discussed the expressed informational needs of early-stage breast cancer patients within the context of choosing between mastectomy and lumpectomy (**Table 2-1**). Despite the variety of methods used by this group of investigators, their findings were consistent. All of the articles reported that overall desire for information was high. The majority of patients wanted as much information as possible. The most requested information was about chances of a cure, followed (in order) by stage of the disease, treatment options, family risk, and side effects. 'Stage of disease' is related to 'chance for a cure' in that the stage of the cancer is an indication of the severity of the illness and consequently, how 'curable' it is.

The next greatest desire was for treatment information. While having information available to help in decision-making was important, it was not the only reason for satisfying an information need, as was reported in the article by Henman et al. [44]. There were a number of factors found to be associated with the type and degree of information need, and these are summarized in **Table 2-4**.

3.2. Information sources studies

Investigators in 11 studies [34,40,47–55] explored the sources of information that breast cancer patient's access in order to support a choice between two forms of surgical treatment (**Table 2-2**). Preferred sources were ranked either by the participants directly, or the rankings were determined based on mean scores from Likert-like evaluative scales. Overall, in all but one study [54], physicians were the most preferred source, followed closely by other healthcare providers. In the single study that mentioned the Internet, the World Wide Web was ranked fifth behind newspapers and magazines [54]. Of the studies that ranked the actual sources used, participants were asked either to pick from a list which sources they used, to rate the degree of influence (Likert-like scale) the choice had on their treatment decision, or to simply list the sources they used. Again, healthcare professionals were the most frequently identified sources or had the greatest influence on decision-making. Family and friends were also highly ranked. In one study [54], participants were asked to list which sources they accessed first after receiving their diagnosis and, in this case, the top three sources (in order) were physicians, books, brochures and pamphlets, and the Internet.

Age and the type of surgery chosen were found to influence source choice (**Table 2-4**). Findings from one of the studies that used qualitative methods included two themes that were consistent with what the quantitative studies found: trusting in the advice and opinion of physicians about treatment decisions, and appreciating the importance of support from family and friends in decision-making [49]. Both themes support the notion that interactive 'human' sources of information are preferred over static 'paper-based' or electronic sources.

3.3. Decision aid studies

While there were several well-known evaluative studies of decisional support interventions that included a mixture of decision aids [56–58] (in terms of purpose, patient population, or diagnoses), there were only six studies that focused on women making the treatment choice between lumpectomy or mastectomy [59–64]. Quantitative findings were equivocal. Statistically significant differences were found between intervention and control groups in some studies, while other studies found no differences (**Table 2-5**).

Qualitative findings were more definitive. Patients appreciated the clarity of information, the use of diagrams and pictures, and the fact that information that the physician provided was reinforced. Overall, both patient and physician reaction to the interventions was positive.

3.4. Methodological rigor

The disparate nature of the research methods used among the included articles precluded any systematic quality assessment from being performed. Articles using similar methods were grouped together for a narrative assessment of research rigor.

The most common research design used to investigate information needs and sources was a descriptive cross-sectional design. Methods of data collection included self-report questionnaire, card-sorts, and interviews (both individual and focus group). Questionnaires about source use/preference and information needs were able to elicit the degree of use or preference by using a Likert-like scale. However, a 'ceiling' effect was noted especially in the information need studies, with patients designating every kind of information as being important. The card-sort technique used in four of the studies eliminated this problem and allowed information needs to be measured relative to each other.

The use of consecutive and convenience sampling in the quantitative studies, while understandable given the difficulty in randomizing patients and the vulnerability of the population under study, does introduce potential sampling bias. Samples used in the majority of studies were predominantly white, well educated, middleclass women. Attempts to attain a more balanced sample by using quota sampling for example, may have led to a more representative sample, and therefore, to a greater ability to generalize to the population at large. The one study that focused on ethnicity [54] did find some subtle differences in source use (higher %use of written materials) suggesting that more heterogeneous sampling may produce slightly different results. Purposive sampling was used for the qualitative studies, which is entirely appropriate given that the goal of this kind of sampling is to ensure that those informants with a 'special knowledge' of a phenomenon are chosen.

Another factor, the time between diagnosis and data collection, varied substantially among the studies. Anywhere from ‘0’ (i.e. at the time of diagnosis) to 119 months passed between the diagnostic consultation and data collection making recall bias a considerable threat. Given that information needs were found to change over time in one study [17], it is quite likely that information needs at 18 months post-diagnosis will not be comparable to information needs at time of diagnosis. None of the studies examined source use over time.

Data analysis consisted of either simple reporting of frequencies/rankings or the use of various statistical methods to determine if differences in rankings according to a specific variable (age, education, choice of surgery, degree of decisional control, etc.) were statistically significant. All the analysis was done at the individual level. Articles reporting the results of decisional support interventions used various experimental and quasi-experimental designs to determine the effectiveness of different decision aids. Three of the articles reported on the development and pilot testing of decisional support tools [59,61,63]. Two of the studies [60,62] used a randomized controlled trial design (cluster randomization with physicians randomized) and, one study [64] used a pre-test/post-test longitudinal design with data collection occurring at three points. ‘Control’ groups received either the ‘usual’ practice or a significantly scaled down version of the decisional support intervention. Statistical tests used to determine if differences between groups were statistically significant were the t-test, Chi-square test, and MANOVA. Power calculations were reported for all three of the studies that were not pilots. One of the three non-pilot studies was underpowered [60].

In summary, the information needs and the sources accessed to satisfy these needs have been explored in several studies, but mainly on a descriptive level. Additionally, the sampling methods used in these studies may limit the generalizability of the results. The studies that examined decision aid outcomes, while methodologically more rigorous, found only very modest differences between the intervention groups and the 'usual practice'.

4. Discussion and conclusion

4.1. Discussion

This review focused on the information needs identified by early-stage breast cancer patients in the context of making a treatment choice and the sources of information they access to satisfy those needs. Investigators have conducted systematic reviews of the literature examining the information and support needs of breast cancer patients [23] and cancer patients in general [22], but none have focused specifically on information needs in the context of making a treatment choice. Only one systematic review of the sources of information used by cancer patients could be located [65]. One review [22] examined information needs and sources use in tandem. Systematic reviews of decisional support interventions for cancer treatment decision-making exist [66,67], however, none were restricted to examining the use of consumer decision aids (CDAs) with breast cancer patients specifically. This review then, is unique in that it links together these three different but related aspects of information seeking behavior, and examines them within the context of a specific patient population at a particular juncture of their disease trajectory.

Based on this review, the relationship between information needs, information sources, and decisional supports can be described in the following way. Most, but not all patients wish to be involved in treatment decision-making [68]. Those who take part in planning their treatment need to base decisions on some sort of information. This requirement for information is expressed as an information need. How this need is satisfied determines the sources accessed. CDAs are interventions designed by healthcare professionals to help patients and their physicians choose among two or more sound clinical options [69]. However, patients may not be aware of, have access to, or have the desire or need to use a CDA. A decisional support intervention is only one of any number of information sources on which a patient may base her treatment decision. As well, several factors such as age, education, and health status may influence which information needs have priority and which information sources are accessed.

4.2. Information needs

The overall ranking of information needs was fairly consistent with 'chances for a cure' and 'stage of disease' taking precedence over 'treatment information'. This is not surprising since the question (in most cases) was asked relatively close to the time of diagnosis. Cancer is seen as a threat to life and being able determine the extent of that threat would likely be a priority. Information needs were found to be influenced by several factors, albeit not consistently, over the eight articles reviewed. Age, education, time since diagnosis, and degree of participation in decision-making were all found to influence information need priority rankings. For example, older women ranked information about sexuality lower, and information about self-care higher than younger women. This could be explained in a number of ways. Older women are more likely to be single and therefore, may lack a sexual partner or they may have increased sexual dysfunction due to postmenopausal hormonal changes [70]. Women already coping with age-related functional changes may be concerned that disease-related changes may threaten their ability to maintain independence. As a result, information needs regarding self-care took precedence over sexuality. An alternate explanation may be that older women have more sexual experience to draw from than do younger women, and therefore, have fewer information needs. Another factor found to influence information needs was time since diagnosis. Information concerning chances of a cure and stage of disease were the most important needs for all breast cancer patients, but they took on a higher priority closer to the time of diagnosis. This is not surprising, since the degree of threat and feelings of vulnerability would be heightened at the time of diagnosis and would dissipate somewhat over time [71].

4.3. Information sources

The choice of sources of information used by early-stage breast cancer patients to inform their treatment choice was consistent in that 'people' sources were ranked higher than media or documentary sources in almost all of the studies, with physicians being the most preferred/used source overall. The use of family and friends as an information resource was also a prevalent finding. Patients appreciated human sources of information for their interactive nature—information could be tailored to their specific situation, misunderstandings could be rectified, questions answered, and information gaps filled. Human sources, however, differ in terms of their knowledge domains. A physician, a nurse, and a family member would each have a different kind of expertise, but in the studies examined here, they were not differentiated. It would be helpful to know what 'kind' of information is being sought from family and friends, and what kind is being sought from health professionals, and what the relative importance in the decision-making process each has.

Factors found to be associated with the kind of source used were chiefly age, education, degree of involvement in decision-making, income, and eventual surgical choice. For example, older women were found to be more satisfied with the information they received from their physician, while younger women wanted more information and sought it out from a greater variety of sources. There was speculation that this was due to a change in attitude towards the medical profession, and that older patients would be more familiar or comfortable with a physician–patient relationship where the physician had a larger decision-making role, and therefore, would trust that what information the doctor gave them was 'good enough'. Income and education impacted sources use in predictable ways. In the two minority groups studied, higher income was associated with computer ownership and consequently with the higher ranking of web-based sources. Higher education was associated with the use of medical journals in one study. As would be expected, the overall use of traditional research dissemination vehicles (i.e. peer-reviewed healthcare journals) by patients was very low. For those patients with considerable education, however, it was a source that was accessed. More highly educated subjects may have more positive attitudes towards research and may be better able to understand and assess research findings.

4.4. Decision aids

The CDA studies examined in this review showed mixed findings. Some decreased decisional conflict and increased satisfaction with the decision and increased knowledge scores. While qualitatively the comments regarding the decision aids were very positive, quantitatively differences between the 'usual' practice and the use of the CDA were modest at best. This may suggest that women were getting the information they need from other sources, or were getting the information they needed from their physician without having to use a CDA. This is congruent with a finding from Peirce's [28] study; that most women were able to make a satisfactory decision regarding their breast cancer treatment without the use of a decision aid.

4.5. Longo model

The authors found that certain aspects of Longo's model were supported by the findings of this integrative review. In the information needs literature, the variables age and education ('demographic factors' in the Longo model), time since diagnosis (delivery of care), and degree of participation in decision-making (attitudes, intentions, behaviors) were found to influence the kind of information breast cancer patients desired. In the Longo model [36], these variables and others are posited to influence information seeking and use. The influence of factors (in the Longo model), such as culture, language, healthcare structure, etc., on information seeking and use are not supported in the literature. Either no significant statistical relationships have been found, or the influence of these factors on information seeking and use are too difficult or expensive to measure. For example, the influence of healthcare structure on information seeking would require a multi-national study involving countless participants and would likely be cost-prohibitive.

Although information needs are not the same as information seeking and use, it could be argued that information needs are a prerequisite for information seeking. In order for active information seeking to occur, a need must be perceived. It may be that the factors that influence the type, quality and/or quantity of information a patient requires also influence how (actively or passively) a patient acts to satisfy an information need. For example, a woman's high priority information need would be actively sought out, while a lower priority need may be passively received.

Longo mentions health outcomes, empowerment/locus of control, satisfaction, and ADLs as patient outcomes that are affected by information seeking behaviors and information use. These variables are similar to the outcomes that were measured in the CDA studies. While a CDA is only one of many different sources of information that could be used, the fact that they were found to significantly increase satisfaction (with the information, the decision, and the decision process) and improve health outcomes supports the relationship between information seeking and use and patient/consumer outcomes represented in the model. Connections between information seeking/use and locus of control/empowerment and activities of daily living were not supported by the reviewed literature.

One weakness of the Longo model is that it does not address differences in choice of information source as it varies by personal (e.g. age) or contextual (e.g. geographic proximity) factors. The assumption is that one of the three types of sources or 'channels' (used interchangeably here) will be used, but there is no indication in the model that these channels may be influenced by personal or contextual factors. In Johnson's comprehensive model of information seeking [35], source characteristics and perceived source utility are seen to influence source choice. In this review, age, education, degree of involvement in decision-making, and income were all found to be associated with source choice. Incorporating the characteristics of the individual, the context and the source (including utility) into the model would strengthen it, and would help to explain the role that source choice has in affecting outcomes, such as satisfaction with the decision made.

We suggest that a more refined version of the model would provide greater insight and understanding into the way in which consumers of health information determine what information is important, how that information is accessed, and how being the recipient of health information impacts outcomes such as satisfaction and well-being. The suggested relationships within the model that were not supported in the literature need to tested and developed. We suggest that further research is needed to explore these interactions.

4.6. Implication for future research

While we are beginning to understand what information is important to breast cancer patients, what sources they use, and the role of CDAs in providing information, many questions regarding information seeking and information use are left unanswered. For example, why are some sources preferred over others, what are the qualities of these information sources that make them attractive to patients, and are CDAs the best way of providing the information patients need to make an informed healthcare decision? Additional research designed to answer these and subsequent questions will provide the insight required to refine a model of health information use by patients.

5. Conclusion

Women with early-stage breast cancer who are facing surgical treatment for their disease express a desire for information about chances for a cure, the staging of their disease, and the available treatment. Several factors influence this expressed desire including age, stage of disease, and whether they are active or passive participants in decision-making. The sources preferred and accessed by these women to satisfy these information needs are overwhelmingly interactive ‘human’ sources, primarily in the studies we have reviewed, physicians. Age, education, and type of treatment chosen influenced the choice of information source. While qualitative findings supported the use of CDAs, the qualitative findings were more ambiguous. Patients using decisional support interventions were found to have less decisional conflict, higher satisfaction with the decision made and the decision process, and higher knowledge levels in some, but not all studies. In relation to the considerable cost of producing decision aids, the benefits of using them are fairly meager.

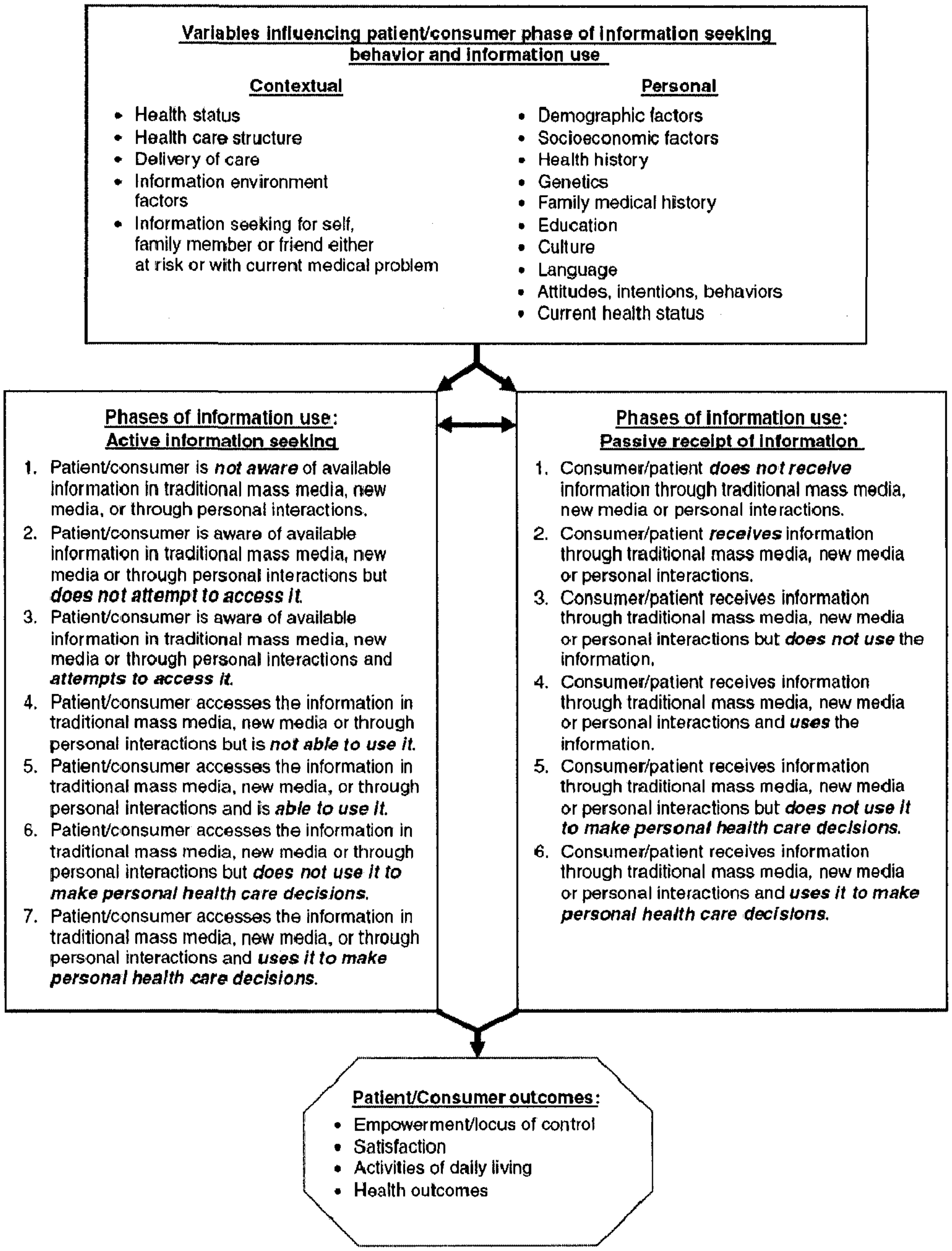
5.1. Practice implications

For those making breast cancer treatment decisions, we know that interactive ‘human’ sources of evidence are preferred and used far more than any other source, that treatment information is of high priority, and that many, but not all, patients want as much high quality information as possible. Increasing participation in healthcare decision-making by patients has necessitated the development of interventions that provide current, systematically derived research, thus ensuring that healthcare decisions can be made based on the 'best evidence'. Decision aids are not universally available, and when they are used, either by the patient themselves, or in conjunction with a healthcare professional, they produce limited benefits.

Of course, trends in information needs and source choice based on demographic characteristics do not imply that all members of a specific population hold similar preferences. Many authors stress the need to assess information needs on an individual basis. As well, assumptions about source use should not be made. Not all younger patients are Internet savvy, and not all older patients think that their physician's opinion regarding treatment is 'good enough'. Practitioners need to be aware of the 'trends', but not be limited by them.

Further research in this area should focus on determining the reasons certain sources are used, and in what contexts. If interactive 'human' sources are preferred by patients, then by what mechanism(s) are they evaluated? In addition, what role does 'traditional research' play in patient decision-making? A better understanding of the concepts surrounding source use (i.e. a conceptual model) would provide a solid foundation from which to create more effective ways of disseminating information to patients that is essential for optimal decision-making.

Figure 2-1: Expanded conceptual model of health information seeking behaviors and the use of information for health care decisions[4]



Variables influencing patient/consumer phase of information seeking behavior and information use

Contextual

- Health status
- Health care structure
- Delivery of care
- Information environment factors
- Information seeking for self, family member or friend either at risk or with current medical problem

Personal

- Demographic factors
- Socioeconomic factors
- Health history
- Genetics
- Family medical history
- Education
- Culture
- Language
- Attitudes, intentions, behaviors
- Current health status

Phases of information use: Active information seeking

1. Patient/consumer is ***not aware*** of available information in traditional mass media, new media, or through personal interactions.
2. Patient/consumer is aware of available information in traditional mass media, new media or through personal interactions but ***does not attempt to access it***.
3. Patient/consumer is aware of available information in traditional mass media, new media or through personal interactions and ***attempts to access it***.
4. Patient/consumer accesses the information in traditional mass media, new media or through personal interactions but is ***not able to use it***.
5. Patient/consumer accesses the information in traditional mass media, new media, or through personal interactions and is ***able to use it***.
6. Patient/consumer accesses the information in traditional mass media, new media or through personal interactions but ***does not use it to make personal health care decisions***.
7. Patient/consumer accesses the information in traditional mass media, new media, or through personal interactions and ***uses it to make personal health care decisions***.

Phases of information use: Passive receipt of information

1. Consumer/patient ***does not receive*** information through traditional mass media, new media or personal interactions.
2. Consumer/patient ***receives*** information through traditional mass media, new media or personal interactions.
3. Consumer/patient receives information through traditional mass media, new media or personal interactions but ***does not use*** the information.
4. Consumer/patient receives information through traditional mass media, new media or personal interactions and ***uses*** the information.
5. Consumer/patient receives information through traditional mass media, new media or personal interactions but ***does not use it to make personal health care decisions***.
6. Consumer/patient receives information through traditional mass media, new media or personal interactions and ***uses it to make personal health care decisions***.

Patient/Consumer outcomes:

- Empowerment/locus of control
- Satisfaction
- Activities of daily living
- Health outcomes

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Table 2-1: Articles examining the information needs of early-stage breast cancer patients

Author	Year		Country	Sample	Measurement Tools	Ranked/Listed Sources
Bilodeau & Degner[40]	1996	CAN	n=74 RR=Not reported	Information Needs (9-item list); Thurstone's paired comparison	Disease stage, chance of cure, treatment options, physical and emotional aspects, side effects	*Self-care* more important to older women and those with high school education or less
Degner et al.[17]	1997	CAN	n=278 RR = 84.6%	Information Needs (9-item list); Thurstone's paired comparison	Chance of cure, spread of disease, treatment options, family risk, adverse effects	*Sexual attractiveness* more important to younger women; *self-care* more important to older women; *family risk* more important to women with a family member with breast cancer; *chances of a cure* more important to those who want an active role in DM; *chances of a cure* more important, closer to time of diagnosis; *self-care* more important further from diagnosis
Galloway et al.[41]	1997	CAN	n=70 RR = 55.1%	51-item Toronto Informational Needs Questionnaire-Breast Cancer [TINQ-BC]	Disease, treatment, tests, physical, psychological	The higher the age, the lower the total score (fewer information needs). There were no differences based on marital status, income or education
Graydon et al.[42]	1997	CAN	n=70 RR not reported	51-item Toronto Informational Needs Questionnaire-Breast Cancer [TINQ-BC]	Treatment, disease, tests, physical, psychological	No differences between treatment subgroups and no differences based on marital status, education or income younger women had a greater need for information (higher total score)

Table 2-1 (con't)

Author	Year		Country	Sample	Measurement Tools	Ranked/Listed Sources
Hack et al.[43]	1994	CAN	n=35 RR=100%	Ranking statements describing information needs under each of 7 categories	No overall ranking; 7 stated hypotheses relating to decisional control (active/collaborative/passive) and information needs	'Active' patients want to receive detailed information about their illness and its treatment, some 'passive' patients want minimal information, but there is a subgroup of 'passive' patients who want detailed information, even though they do not wish to take part in DM
Henman et al.[44]	2002	AUST	n=20[a] RR not reported	Semi-structured interview by telephone	Not ranked	Reasons for information seeking: *to gain a sense of control, reduce anxiety, change behavior, to predict the future*. Most women wanted *as much information as possible*
Luker et al.[45]	1995	UK	n=150 RR not reported	Information Needs (9-item list); Thurstone's paired comparison	Disease cure, disease stage, treatment, family risk, side effects	For women <40 years of age and 40-60, information regarding *sexuality* was more important than for women >60 years of age; older women rated information regarding their *social life* as more important than did younger women
Wallberg et al.[46]	2000	SWED	n=201 RR= 77%	Information Needs (9-item list); Thurstone's paired comparison	Disease cure, disease stage, treatment risks	Rankings did not change with decisional control desired or time since diagnosis; women with intermediate levels of education rated information about *treatment options* as second and *stage of disease* as third priority

Table 2-2: Articles examining the sources of information used and/or preferred by early-stage breast cancer patients

Author	Year	Country	Sample	Measurement Tools	Ranked/Listed Sources	Factors influencing source use?
Rees & Bath[34]	2001	UK	N = 156 RR: 77%	List of sources used obtained from focus group interviews	Listed, not ranked by preference or use: healthcare professionals, family & friends, charitable organizations, support groups	Reasons to seek out information: to facilitate coping, to regain a sense of control, to increase confidence, to help in DM. Reasons to avoid information: to prevent worry, to avoid fears, to minimize feelings of negativity and depression
Silliman et al.[52]	1998	US	N = 388 RR: 78%	Likert-like scale to rate a list of sources (# in list not reported)	Percentage ('very' or 'somewhat helpful'): breast cancer physician (99%), written materials from physician (95%), other written (92%), friends & family (84%), primary care physician (72%)	Oldest women (>75 years of age) less likely to receive written information from sources other than their physician or from family/ friends. Younger women were more likely to find written information from physician or family /friends 'very' or 'somewhat' helpful
Smitt & Heltzel[53]	1997	US	N = 115 RR: 65%	Likert-like scale to rate a list of 19 sources	Mean score (sources used): Surgeon (4.5), primary care physician (2.8), spouse (2.4), radiation oncologist (1.7), medical oncologist (1.5)	Impersonal sources less influential. Spouse, children, friends and parents more influential for the mastectomy group. Radiation oncologist more influential for the BCT group
Talosig-Garcia & Davis[54]	2005	US	N = 287 RR: 74%	% of respondents receiving information from specific sources *at time of* and *after* diagnosis	Percentage (accessed first): health professional (29.9%), book, brochures or pamphlets (18.6%), Internet (13.4%), hospital or clinic (10.3%), cancer organization (8.2%) Percentage (sources 'very helpful'): books, brochures, pamphlets (98%), health professional (97%), spouse/partner (62%), newspaper/magazines (46%), Internet (39%)	Internet is not extensively used by minority breast cancer patients. 75% of women found the information they received at time of diagnosis to be adequate.
Ward et al.[55]	1989	US	N = 22 RR: 92%	Respondents chose top 3 sources from a list of 8 sources	Percentage (sources used): Physician (82%), family (41%), friends/clinic handout (tied at 36%), nurse (32%), media/clinic videotape (tied at 18%)	'People' sources significantly more important (t=3.43; p=0.003). Nurse was second most frequently used source for BCT group after physician; family and friends were second most frequently used source after physician for the mastectomy group

Table 2-2 (con't)

Author	Year	Country	Sample	Measurement Tools	Ranked/Listed Sources	Factors influencing source use?
Bilodeau & Degner[40]	1996	CAN	N = 74 RR: Not reported	Ranking sources from a provided list of 10	Ranking of sources used: physicians, friends & family, nurses. Ranking of preferred sources: physicians, nurses, friends or relatives, brochures, medical journals or textbooks	Correlation: level of education and use of medical journal (r=0.348; p=0.002). Overall, 'people' sources used more than 'written' sources.
Cawley et al.[47]	1990	US	N = 68 RR: 42.5%	List of 5 specific items and 'who' supplied the information	Ranking of sources used: Physicians were primary providers (no % given), nurses (23%). Also mentioned: American Cancer Society, library, pamphlets, friends	85% of the younger women (in their 50's) were satisfied with the information received from their physician, but only 61% in their 60's and 70's felt well-informed
Hughes[48]	1993	US	N = 71 RR: 60%	18-item background inventory (included a list of sources)	Top three sources used prior to consultation : lay media, relatives & friends, educational brochures. Also mentioned: healthcare professionals, neighbors, textbooks	Mastectomy group received information from more sources than did BCT group (p<0.01) before their consultation (author presumed sources were informal–friends, family, media)
Lacey[49]	2002	US	N = 12 RR: N/A	N/A	Listed, not ranked by preference or use: physicians, family, friends	Relevant themes elicited: 'trusting the opinion and advice of physicians about treatment decisions' and 'appreciating the importance of family & friends support in decision making'
Mastaglia & Kristjanson[50]	2001	AUST	N = 175 RR: 49%	16-item factors list (included influential sources)	Percentage (sources used): Surgeon (90.5%), general practitioner (73.5%), family (71.1%), friends (62.7%), cancer foundation (56.6%).	Mastectomy group named family as a more frequent source than the BCT group; BCT group named their GP as a more frequent source than did the mastectomy group
Petrisek et al.[51]	1997	US	N = 179 RR: 84%	15-item factors list (included influential sources)	Listed, not ranked by preference or use: physician (initial consult or 2nd/3rd opinion), family & friends	Seeking a second opinion declined with age; older age was associated with wanting someone else to make the treatment decision for them; younger women wanted as much information as possible; older women least likely to have discussed treatment decision with a layperson

Table 2-3: Clinical trials of consumer decision aids (CDAs) for surgical treatment of early-stage breast cancer

Article (year & country)	Description of Aid	Study Design	Sample Details	Control Intervention	Outcome Measures	Findings
Sawka et al. (1998, Canada)	Audiotape and workbook with values clarification, reviewed after consultation with surgeon re: diagnosis	sequential pilots (2)	Pilot 1: n=18 Pilot 2: n=10 Consecutive; patients from 2 surgeons	N/A	Level of anxiety, knowledge of treatment options, decisional conflict, decisional regret	Anxiety was unaffected by the CDA; knowledge level improved; some decisional conflict (subscale of the DCS) remains after using the CDA
Goel et al. (2001, Canada)	Audiotape and workbook with values clarification, reviewed after consultation with surgeon re: diagnosis	Cluster randomization clinical trial; data collected at T_1 (baseline), T_2 (prior to surgery), & T_3 (follow-up)	n=136; response rate of 32.8% of surgeons contacted; 85.4% of patients enrolled	Tri-fold pamphlet with same information as CDA, but no graphics, numbers, photos or values clarification	Level of anxiety, knowledge of treatment options, decisional conflict, decisional regret	No overall effect of CDA, but a trend towards overall decisional conflict reduction in women leaning towards MAS or those who were unsure at enrollment; many positive comments from participants (qualitative)
Molenaar et al. (2001, Netherlands)	Interactive Breast Cancer CDROM	Quazi-experimental; pre-test/post-test; longitudinal with 3 data collection points; three sites	n=167; response rate 93%. Consecutive; data collection pre-operative and at 3 and 9 months post surgery	Brochures, oral information from their surgeon; each site served as 'control' at least once	Decisional style, treatment preferences, decisional conflict, quality of life, breast cancer specific functioning and symptoms; satisfaction with: information (general and treatment specific), DM process, decision, and care	Positive effect of CDROM on satisfaction with information and treatment decision at T_2 and positive effect of CDROM on satisfaction with information, DM process, and communication with physician at T_3; CDROM group reported better general health at T_2 and T_3, and better physical functioning at T_3
Whelan et al. (1999, Canada)	Physician administered decision board; 25x20 inches, sliding doors reveal information in a sequential fashion; 2 information cards read before and after presentation	pilot study	n=175; response rate 71.7%; Consecutive patient from 7 surgeons	N/A	Satisfaction with: DM process, information provided, decision made, decision board. Comprehension of information presented, time required to complete, physician satisfaction with DM process	The decision board was : easy to understand , helped with decision , and helped patients think of questions to ask. Patients who used the decision board : recommended it be used with other patients, were satisfied with the information they received, and reported satisfaction with the DM process. Physicians found the intervention helpful for most consultations

Table 2-3 (con't)

Article (year & country)	Description of Aid	Study Design	Sample Details	Control Intervention	Outcome Measures	Findings
Whelan et al. (2004, Canada)	Physician administered decision board; 25x20 inches, sliding doors reveal information in a sequential fashion; 2 information cards read before and after presentation	Paired cluster randomized clinical trial (surgeons randomized); surgeons were 'pair-matched' based on age and gender	n=20 surgeons with 201 patients (94 intervention; 107 'usual' practice)	Usual practice: surgeon discusses treatment in the usual fashion without the decision board	Patient knowledge, decisional conflict, satisfaction with DM, and the treatment choice, anxiety and depression	CDA group vs. control group following consultation: higher knowledge scores (p<0.001); lower decisional conflict (p=0.02); and higher satisfaction with DM (p=0.05) at time of consultation--no differences at 6 and 12 months. No differences in anxiety or depression scores between intervention and control group at any time.
Sepucha et al. (2000, USA)	Consultation recording: 5 step intervention (contracting, agenda setting, mapping, commitments, and debriefing) administered during consultation by a researcher	Sequential controlled trial; measurement at 3 points: pre-intervention (#1), post consultation planning (#2) and post intervention (#3)	n=12 control arm, n=12 intervention arm 2 physicians with aprox. equal numbers in both arms	Researcher present during consultation but did not take part (physician conducted surgical consultation as per usual practice)	10-item Decision Quality Scale (patient and physician versions) 7-item UCSF Satisfaction with Consultation Scale (patient and physician versions)	Higher decision quality achieved with intervention (vs. control) on patient decision scale #3 (p=.008); amount of agreement between patients and physicians was fair for control group (kappa=0.28) and moderate for the intervention group (kappa=0.49) and significant (p<.0001); time to administer the intervention was not significant more than control.

Table 2-4: Summary of 'information needs' and 'information sources' findings

INFORMATION NEEDS:	
Variable	*Influence (# of articles with significant findings)*
Age	
Older age	• Preference for information about self care (2), social life (1) • Fewer information needs (1)
Younger age	• Greater need for information (1) • Preference for information about physical attractiveness (1), sexuality (2)
Education	
Lower education	• Preference for information about self-care (1)
Preferred degree of decisional control	• Preference for information about chances for a cure (1)
Family history of breast cancer	• Preference for information about family risk (1)
Time since diagnosis	
Further from diagnosis	• Preference for information about self-care (1)
Closer to diagnosis	• Preference for information about chances for a cure (1)
Actual role in decision making	
'Active' patients	• Preference for detailed information (1)
'Passive' patients	• Preference for minimal information, *but*, a subgroup want detailed information (1)
SOURCES OF INFORMATION :	
Variable	*Influence (# of studies with significant finding)*
Age	
Younger age	• seeking a second opinion (1) • wanting as much information as possible (1) • satisfaction with information received from physician (1) • written information from physician or family & friends 'very' or 'somewhat' helpful (1)
Older age	• wanting someone else to make the decision (1) • less likely to have discussed treatment decision with a layperson (1) • less likely to receive written information from sources other than physician or family & friends (1) • less likely to want more information about therapy choices (1) • less likely to have consulted 3 or more physicians about treatment (1)
Education	
Higher education	• use of medical journal (1)
Involvement in DM	
Higher involvement	• use of GP as an information source (1)
Type of surgery	
Mastectomy	• more sources used prior to consultation (1) • family more frequent source (1) • spouse, children, friends more influential (1) • family & friends second most frequent source after physician (1)
Lumpectomy	• GP more frequent source (1) • nurse second most frequent source after physician (1) • radiation oncologist more influential (1)

Table 2-5: CDA Outcomes

article reference #	know-ledge level	satisfaction with decision	satisfaction with DM process	satisfaction with information	anxiety/ depression	degree of decisional conflict	general satisfaction with CDA	physician satisfaction with CDA	degree of decisional regret	Tx chosen	health effects	increase in time	satisfaction with communication with physician
59	▲	x	x	x	NR	some	▲	x	x	x	x	x	x
60	NR	x	x	x	NR	NR	x	x	NR	x	x	x	x
64	x	▨ ▲	▨ ▲	▨ ▲	x	x	x	x	x	NR	▨ ▲	x	▨ ▲
61	x	x	▲	▲	x	x	▲	▲	x	▨ mast	x	x	x
62	▨ ▲	x	x	x	NR	▨ ▼	x	x	x	▨ lump	x	x	x
63	x	▨ ▲	x	x	x	x	x	x	x	x	x	NR	▨ ▲

▨ Intervention group compared to a control group; significant at $p \leq .05$

▲ Increased

▼ Decreased

NR No Relationship

X Not Measured or Not Reported

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Chapter 3: A qualitative examination of how early-stage breast cancer patients evaluate sources of information relevant to treatment decision making.

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A qualitative examination of how early-stage breast cancer patients evaluate sources of information relevant to treatment decision making.

1. Introduction

Active involvement of patients in decision making involves the application of both the products of scientific study, and patient values and preferences [1]. In situations where healthcare practitioners and patients share the treatment decision making process, it is important for both clinicians *and* patients to have access to good quality evidence on which to base decisions. Patient involvement in medical decision making has increased [2] for several reasons: increased patient autonomy, rising costs, broader access to information (e.g., the internet), and expanding clinical options [3]. Decisional support interventions, 'information products' that help patients with decisions that are complex or involve complicated tradeoffs, have been developed [4]. Several systematic reviews examining the effectiveness of one type of decisional intervention, the consumer decision aid (CDA), have showed mixed results. While there was no compelling evidence suggesting CDAs influenced treatment preferences or decisions, they were found to increase knowledge, the agreement between the patients values and the decision, the satisfaction with the decision and the decision making process, and to decrease decisional conflict and uncertainty [5-7].

The application of scientific knowledge in healthcare decision making is an area of great interest. Until recently, most of the knowledge translation literature focused on the translation of research to practitioners or policy makers [8]. However, interest in the effective provision of research evidence to patients and the general public has been increasing, resulting in the development of knowledge tools such the

CDA [9]. These tools are necessary for patients to be well-informed in the face of difficult medical decisions.

Many patients facing treatment options want to be involved in the decision making process in some way [10-13], but need to be aware of the risks and benefits of the treatments they are considering. Often, this information comes from the healthcare provider in either written or verbal form, but patients also seek out information on their own or with the assistance of family and friends [14]. Most patients do not have access to decision aids, and it is likely that the majority of treatment related decisions are made without them. It is important that patients be given the opportunity to access the evidence they need to be sufficiently informed about treatment, and if they choose, to be actively involved in choosing treatment options.

The great number of therapeutic options available to oncology patients, options that often involve complex tradeoffs, can complicate decision making. An example of such a tradeoff is surgical treatment for early-stage breast cancer which typically involves a choice between mastectomy and breast conserving therapy (BCT) (also termed ‘lumpectomy’). Both of these treatments have the same prognostic outcome, but each has distinct physical and psychological implications for the patient. Making a well informed treatment choice results in less decisional regret, and consequently, a better quality of life [15,16]. In order to ensure that patients get the information they need to make decisions with which they are satisfied, it is important to first understand how they evaluate and weigh this information.

1.1. Background

Interpersonal sources of information have consistently been reported as the most preferred and accessed sources of information for patients making decisions about their health [17-19]. Age [20-22], level of education [23], and type of treatment eventually chosen [24-27] have all been reported to be associated with source choice. Overall, patients rely heavily on healthcare personnel for treatment information, and are often dissatisfied with the amount and quality of information they receive [28-30]. Possibly in response to this dissatisfaction, patients generally seek out and use information from several different sources [31].

Early stage breast cancer patients mostly desire information about the chances for a cure, information about the stage of disease, and information about treatment options, and in general, want as much information as possible [17,32]. Individual factors such as age [11,23,33,34], education [23,35] degree of decisional control [11] and family history of breast cancer [11] have been shown to influence the kind of information requested. Younger women generally wanted more information and sought out information from more sources [34,36].

Models of information seeking behaviour [31,37,38] focus primarily on the antecedents to information seeking (e.g. a 'stimulus' such as a diagnosis of breast cancer), individual (e.g. age, education, desire for involvement) and contextual factors influencing information seeking (e.g. stage of disease, geographic location, interaction with physician), and the outcomes of information seeking (e.g. self-efficacy, reduced anxiety). To date, much of the emphasis has been on determining how individual and contextual factors contribute to the choice of information source, with little focus on the providers of information and how *their* characteristics contribute to treatment decisions.

The purpose of our study was to explore how newly diagnosed (Stage I and Stage II) breast cancer patients locate, assess, and use information in order to make a treatment choice between mastectomy and lumpectomy. More specifically, we wanted to examine the ways in which different information sources are evaluated relevant to their contribution to treatment decision making.

2. Methods

2.1. Design and setting

This study had two parts. First, we analyzed an existing qualitative data set consisting of transcribed interview data collected in 1999-2000 from six early-stage breast cancer patients. Second, we conducted focus groups in 2007/2008 with women who had had either a lumpectomy or mastectomy for breast cancer.

The original study that generated the individual interviews was a focused ethnography. Its purpose was to evaluate a decision support intervention and to identify how early-stage breast cancer patients assess information relevant to their choice of treatment. Participants in the initial study were all from one surgeon's practice in a major central-Canadian city. To verify the results of our secondary analysis and to augment theory development, we collected additional data from women who had undergone treatment for early-stage breast cancer in a major western-Canadian city. The focus group participants had been treated by different surgeons over a three year time period. Health Ethics Review Board approval was obtained for both the secondary analysis and collection and analysis of the focus group data.

Pseudonyms were used for all of the participants in this study. The choice (in the original study of the six women who has been recently diagnosed with breast cancer) of a focused ethnographic design meant that we had data in which the original investigators had hoped to uncover the meanings, values and beliefs that shape a particular behaviour, – information seeking, within a specific groups that shared a common experience such as a diagnosis of breast cancer [39].

2.2. Recruiting and sample

Individual Interviews: In the initial study, a convenience sample women within one week of diagnosis for Stage I or II breast cancer and facing a decision between mastectomy and breast conserving surgery (lumpectomy) was recruited. A member of the original research team met with the surgeon to explain the study and leave information sheets for prospective participants. Working with clinic staff, a research assistant was available at the clinic to explain the study, answer questions and obtain consent. The women received a consumer decision aid (CDA) designed for use by women facing treatment for early-stage breast cancer and a brief explanation about its use. The CDA used in this study, *Making Decisions About the Removal of my Breast Cancer: What do I Prefer?* [40], consisted of a 30 minute audio-tape recorded in a female voice, accompanied by a 33-page work booklet. The booklet contained an explicit presentation of probabilities, photographs and graphics, and a values clarification exercise that assisted the women in weighing the risks and benefits of the two surgical options (mastectomy and lumpectomy). The content was written at a grade 8 level. Women who were not able to articulate well or did not have good spoken English were excluded from the study. Six women were eventually recruited.

Focus Group Interviews: We purposively sampled women who had been diagnosed with Stage I or II breast cancer in 2007 and 2008. Potential participants were either identified by a cooperating psychologist at a regional cancer centre, or responded to a blanket email sent out to members of a breast cancer survivors support group. Interested individuals were offered information and asked to contact the investigators. Inclusion criteria included: a) diagnosis of Stage I or Stage II breast cancer, b) mastectomy or lumpectomy as treatment options, and c) surgery completed no more than 4 years previously. Written consent was obtained from all participants prior to data collection (**Appendix A & B**).

2.3. Data collection

Individual Interviews: Each of the six women was interviewed within a week of diagnosis and again approximately six months later at either the treatment centre or in the interviewee's home by CE (4 interviews) or a study nurse (2 interviews). The interviewers were experienced practitioners (minimum preparation was at the master's level) and had previous interview experience. The interviews were audio taped and subsequently transcribed verbatim and were approximately 90 minutes in length. The transcripts were later checked for accuracy and completeness. The purpose of the interviews *in the first study* was: to evaluate qualitatively the perceived usefulness of the CDA in helping the women to decide which surgical treatment to pursue, and to explore the sources of information (other than the CDA) the women used to facilitate their decision making and their weighting of these information sources.

Focus Group Interviews: Two focus group interviews were conducted over a 6 month period (2007-2008) with 3 and 5 women respectively, and with CE and KO conducting the first interview and KO conducting the second. The interviews were held at a mutually convenient time and location, and were between 60 and 90 minutes in length. Participants were given an overview of the findings of the secondary analysis and asked to comment on whether or not the results of the analysis reflected their own experience (**Appendix C**). They were also asked to comment on their own decision making process around making a surgical treatment choice for breast cancer, the sources of information used to make that decision, and the influence those sources had on the decision making process. The focus group interviews were audio recorded and transcribed verbatim. A small amount of demographic information was obtained from each of the participants (**Appendix D**).

2.4. Data analysis

We used thematic analysis as described by Miles and Huberman [41] to analyze the data from both data sets for themes. Analysis was conducted in three steps: data reduction (simplifying, abstracting, focusing, transforming the raw data), followed by data display (organization of the data in order to draw conclusions) and finally, conclusion drawing /verification (confirming that the conclusions are valid). Transcribed data were managed using N6™ software. The analysis of the six individual interviews was completed before data were collected from the focus group interviews. The purpose of the focus group interviews was to validate and augment the results of the secondary analysis.

3. Results

3.1. Participants

Individual interviews: The six women who participated in the original research study were all patients of one surgeon at a tertiary care hospital in a major city in central Canada. Selected demographic information is listed in **Table 3-1**. All but one of the women had some post secondary education. Although English was a second language for 2 of the women, they both conversed comfortably in English. All six had been diagnosed with Stage I or Stage II breast cancer prior to the first interview; three of the women had a history of breast cancer in their extended family.

Focus group interviews: The eight women who participated in the focus groups were all residents of a major city in Western Canada. Demographic information is presented in **Table 3-1**. As a group, the focus group participants were younger and had attained higher educational levels than the women in the primary study. At diagnosis, the focus group participants had been referred to several different surgeons, with surgeries being performed in three different facilities. None of the women used a decision aid to assist in decision making. While English was a second language for one of the eight women, she was able to converse in English without difficulty. Three of the eight women had a history of breast cancer in their extended families.

3.2. Sources of treatment information:

One of the purposes of the original interviews was to ascertain the information sources used by these women and to assess how they weighted these sources - that is, were some information sources privileged over others? We developed a taxonomy of sources (**Table 3-2**) to display the main categories of sources used. Information sources from both data sets are displayed in the taxonomy, and while sources used in decision making were similar between the two groups, information from 'nurses' and 'consumer decision aids' did not contribute to the decision making of the focus group participants.

All of the women in this study made the choice between mastectomy and lumpectomy using *multiple* sources of information. For most of the women, one or two sources of information had more influence on their decision making than the other sources they accessed. While each of the women had differing patterns of source use, there were more similarities than differences in how the women viewed each of the sources listed in the taxonomy.

Interpersonal sources: Sources that involved talking with someone about treatment options were preferred over sources that were 'static'. The most consistently mentioned source was the surgeon. In terms of its influence, information from the surgeon was ranked the highest with most of the women. Information from other healthcare professionals contributed only marginally to decision making. Family and friends provided both information and emotional support, and their input helped to facilitate the decision making process. The illness narratives of cancer survivors provided insight into the cancer experience, and helped to demonstrate to the women the impact of the different treatment options. Additionally, the women also acknowledged that previous personal experiences with serious illness and/or the healthcare system influenced their treatment decision making. Data excerpts relating to each of the source categories is included in **Table 3-3**.

Non-personal sources: Sources that were 'static', i.e., sources that did not involve social interaction, were also considered important in contributing to the decision making process. Books, booklets, pamphlets and other printed material from recognized sources were considered important 'consolidators' of information that were valued for their portability. The CDA was mainly used to confirm what the surgeon had said during the consultation, allowing the women to review their decision making process and reduce uncertainty. The women who used the internet generally retrieved information from sites they considered well-known and reputable. The lack of computer skills and/or internet access was an issue for several of the women. The media was rarely mentioned as a valid source because the general nature of the information provided.

3.3. Types of knowledge

As we analyzed the data, it became clear that informants were discussing two kinds of knowledge: technical knowledge (biological, epidemiological, surgical, etc.) and personal knowledge (the experience of treatment). Whether in printed, electronic or verbal form, patients sought technical knowledge from healthcare professionals and personal knowledge mainly from women who had previously undergone treatment for breast cancer. The degree of influence each of these knowledge types had on decision making varied with the individual.

While it was important for *all* of the women to have practical medical information about diagnosis and treatment, it was also important for many of them to know how other women reacted to the different surgeries and how they dealt with potential problems. This was a particularly salient point for the women who participated in the focus groups. Kim, a healthcare professional, describes the need for both kinds of information:

> *The technical information for me, that wasn't an issue because I knew that part, right? But the information about the experience you're going through, I truly don't feel that anyone prepares you for that. I was, I thought, going into it OK. This is fine, but when you come home that next day after the surgery and you take off that dressing and you look in that mirror, nobody, absolutely nobody prepares you for that.*

It was easier to get information about the technical aspects of forthcoming surgery than it was to get information about its emotional or experiential aspects. Not all of the women had breast cancer survivors within their social network, and those who did considered themselves very fortunate to have access to this information.

3.4. Characteristics of information sources

Over the course of analysis, six characteristics of information sources emerged from the data: credibility, relevance, utility, accessibility, responsiveness, and comprehensiveness. Information sources that were strong in several or all of these characteristics were more likely to influence the decision making process. Descriptions of each source in terms of its characteristics are listed in **Table 3-4**.

Credibility. Two aspects of credibility that were described by the women: technical information was credible if it was research-based and objective, and experiential information was credible if it was first-hand information shared by someone who had close personal ties or shared similar personal or situational characteristics with the woman. Reputation played an important role in determining the credibility of interpersonal sources. Several of the women describe what they had learned about the surgeon and how it influenced their perceptions:

> *When I phoned and I said I don't know this Dr. T. And then she said, well, he's the best in his field and you get the top-notch man and it made me feel very good.* (Betty)

This also held true for organizations, media outlets, and internet sites. Credibility could also be gained through association. For example, Judy comments that if information, "...came from the hospital here I wouldn't have any problem with it." Credibility of a source was enhanced if the same information could be validated by several other sources. Sometimes, sources that were in agreement were difficult to ignore. Bev, who did not initially want to have chemotherapy after her surgery, changed her mind when she found several sources on the internet providing similar information: "I just know that there was just so much evidence that said I had to."

Relevance. Information relevance had to do with the applicability of the information to the individual. The women recognized that some information has to be general because it is meant for a wider audience. Rose commented that the CDA had to be "...general because you can't get specific with something that affects so many people." The most specific information was provided by the surgeon. Specific details about treatment had the potential to influence the decision making. For example, Rose said that knowing *where* the radiation treatment took place could have a bearing on which surgery someone chose, as the logistics of going through daily therapy at a distant site may have an impact on a patient's quality of life.

Relevance also played a role in information the women gathered from non-professionals. The experiences of other women had special relevance to the six women, especially if they felt an affinity with the story teller. Stories from women who were perceived as different from the listener, were less influential:

> *I wouldn't mind talking to some[one] of the same temperament as I am...some people are definitely hysterical and then you have to discount what they were saying.* (Rose)

Utility. The utility of information from a specific source has to do with the ease or difficulty with which the information was understood or used. Utility was enhanced when the flow of information was controlled by the individual. Several of the women commented that the shock of being diagnosed with breast cancer rendered them unable to fully absorb the information presented to them during the consultation. Having a source available when the women were 'receptive' to information was important:

> *With the ability to play the thing over again, I think that's quite an important feature because even when I went through it the first time, certain things occurred to me after I had done it the second time that ...hadn't really sunk in the first time.* (Rose)

Graphic representations, such as the surgical photos of other mastectomy and lumpectomy patients made a greater impression and were easier to recall than information in written form.

Accessibility. The accessibility of information dealt with how easy information was to obtain, especially in terms of timeliness and convenience. Accessibility was judged in terms of physical accessibility (e.g., geographic proximity to an information resource such as a library) or intellectual accessibility (e.g., having the skills to access web-based information). Sources that were more accessible were often less credible, for example, mass media (magazines and television). While the internet was accessible to those who were computer savvy (or had proxies to access it on their behalf), often the information obtained from it was regarded with suspicion: "I would still use my own sifting through, you know, and see because I know there's a lot of junk on the

Internet. You really have to watch." (May). One of the women lived far from a major centre and talked about the absence of good quality information close to her home:

> *We live in a small town so where do you go to find this information? And you want to make sure that its current information; you don't want something that's a couple of years old...* (Judy)

Responsiveness. A source was considered responsive if there was an opportunity for clarification, correction or explanation of information. Generally, sources that were the most responsive were human sources, such as healthcare professionals, family/friends, and cancer survivors etc. Verbal interaction with these sources allowed the women to focus on and pursue their specific information needs. Responsiveness was, to some extent, situation-dependent. May describes her meeting with the surgeon:

> *I mean he may be a great surgeon, but...I had to run after him after and ask him how long I was going to be in there (laughing)...my own doctor was very surprised; because I didn't get the information from him that I should have got...and I couldn't talk to him.*

Her description of meetings with her family physician was quite different: "...when I've got a problem and he'll sit down, he'll take as long as *I need* to talk with me".

Comprehensiveness. A comprehensive source covered all aspects of a topic of interest in a thorough and complete manner. How comprehensive a source was judged to be, was determined by the individual information needs of each woman. The women from the primary study felt that the most complete information came from the surgeon and the CDA. Betty commented that the CDA, "...touched really every aspect of the operation and radiation", and Bev described the surgeon's information as being, "very thorough". Several participants from the focus groups had a different strategy for ensuring they were getting the most complete information: accessing multiple sources. Overlapping sources not only ensured a greater range of information was accessed, but also helped to validate information that was repeated across sources.

While the way in which the characteristics described above were applied to each source was unique for each individual in the study, there were patterns of use that appeared during analysis of the data. Credibility was the *most important source characteristic*, and was associated with the sources that were *most influential* in decision making. Generally, information from the surgeon and cancer survivors were considered the most credible sources, the former for its technical, and the latter for its experiential components. Accessibility for both of these sources was sometimes an issue, however. Some of the women considered the surgical consultation to be limiting in that answers to the questions or concerns specific to their situation that came up after the visit were not always addressed. Additionally, in the short time between diagnosis and the initiation of treatment, access to women who had previously undergone treatment , and could share their experiences, was not always possible. None-the-less, the credibility of an information source contributed greatly to the level of *trust* an individual developed in that source.

3.5. Trust

Trust was a theme that appeared repeatedly in the data, especially with regard to the use of interpersonal sources of information, and particularly in the context of speaking with a healthcare professional. In order to develop trust in a healthcare professional, the patient had to recognize both professional competence and a sense of compassion in the individual. Betty's 'instant connection' with her surgeon, along with her appreciation of his skill during a physical examination contributed to her high degree of trust in him as a source of information. Ann's trust in her sister-in-law as a source was also based on these two aspects:

> *My most influential source was one of my sisters-in-law who lives in Florida. She is a long time nurse who's actually done a lot of studies and research herself in holistic medication and care of the elderly and over the years I've just really come to trust her opinions and so when I was diagnosed with breast cancer, she was actually the first person I phoned....she was most influential in helping me decide what course of action to take... [It was] her knowledge and her caring.*

Lack of trust in a healthcare professional also rested on how the patient perceived the professional's level of competence and degree of compassion. While the surgeons' level of technical competence was rarely questioned, the degree of compassion the surgeon demonstrated to his/her patient became a key factor in determining the level of trust. Irene sought out a second surgeon after an unsatisfactory visit with the first:

> *She [GP] sent me off to just the most beastly surgeon... he was an absolute, cavalier cowboy in his approach and wasn't particularly helpful. I was just supposed to lay down on the table and whatever it was that he decided was fine. Oh yes, "Sign here, sign here"... and [he] was really pushing the papers and I just took them away at lunchtime and just said that there is no way this cowboy's coming near me.*

Trust was an issue with the internet and print sources as well, but trust was placed in the person or organization who produced the document, or in the person who disseminated the document. Organizations that were well-known, assessed as unbiased, considered experts in their respective areas, and were perceived to be motivated by altruism (i.e. non-profit) were assumed to produce and distribute trustworthy information.

In summary, the sources given the most weight were those that had the most credibility in the eyes of the women—the surgeon and cancer survivors. In order to develop trust in a healthcare professional, the patient had to recognize *both* professional competence and a sense of compassion in the individual. Human sources were valued over documentary and electronic sources because they were responsive, and because they offered emotional support as well as informational support. Experiential as well as technical information was required by most of the women in order to make an informed decision concerning their treatment.

4. Discussion

Our finding that the surgeon was the most preferred and influential source of information for women seeking information to inform their treatment decisions for early-stage breast cancer is congruent with the literature [10,14,17]. In making their decisions, these women used information from a *variety* of sources—a finding that is consistent not only for studies examining information seeking for breast cancer patients [17,42,43], but for cancer patients in general [18,31,44]. There is speculation that seeking out multiple sources satisfies the need to ensure that all of the options are covered, and it is not necessarily an indication of information inadequacy in one source [45]. Checking the consistency of information across sources can be an indication of the information's validity [46,47]. The women in our study discussed using the CDA and other print-based sources as a way to validate or confirm what the surgeon had told them during the consultation. Confidence that one has the best information available may contribute to greater participation in decision making.

4.1. Information source characteristics

The women in this study evaluated a variety of information sources based on six source characteristics: credibility, responsiveness, relevance, utility, comprehensiveness, and accessibility. Despite the tacit manner in which the women ranked each source, they were able to verbalize the qualities a source had that made it desirable or undesirable. The more positive qualities a source had, the more likely it was to be used in the decision making process. This is similar to the 'attributes of innovations' in Rogers' [48] diffusion of innovations model, where the qualities of an innovation contribute to the likelihood of the innovation being adopted and the rate at which adoption occurs. In Rogers model, relative advantage, compatibility, complexity, trialability, and observability are the attributes of an innovation as perceived by a potential adopter. One could argue that there is some overlap between these two lists of characteristics (e.g., relevance and compatibility, utility and complexity, accessibility and trialability). Rogers states that understanding how potential adopters perceive new ideas helps us to determine the nature of the diffusion process. In the same way, knowledge of how patients perceive information sources, helps us to have a better understanding of information behaviour.

4.2. Technical vs. experiential information

Despite the fact that healthcare professionals are generally the most *preferred* sources of health information for patients [19,49], studies of information acquisition by healthcare consumers routinely report friends and relatives as an important source of health information [10,19,43]. Patients who are not able to obtain information from professionals, may seek it out from other sources within their social network, sources that may be less reliable and not necessarily evidence-based [50]. We argue that the kind of information being gathered from non-professional sources is fundamentally different. It is information based on experience rather than scientific evidence. McCaughan & McKenna [42] describe this seeking out of others' experiences as a way for the individual to make sense of their own disease and predict how their own disease might progress. Understanding how *other* women dealt with the outcomes of the two surgical options was important for our study participants in determining how they themselves might cope with the effects of treatment. This experiential information was also a key ingredient in the decision making process. In order to make a well informed decision, patients must have knowledge of their own values and preferences as well as the requisite medical knowledge [51]. It may be difficult for some people to imagine what their values and preferences are in situations they have never encountered, which may explain why experiential information from others is so valuable [52] Johnson and Meischke [14] argue that individuals have both cognitive needs (factual information), and affective needs (information on dealing with emotional impact of cancer) and that the value of a source is based on its ability to meet each of these needs.

Information gathering also includes an emotional component that cannot be overlooked. Those within the close social network of the individual provide not only informational support but emotional support as well [18]. The women in our study talked about the devastating consequences of receiving a diagnosis of breast cancer, and how that affected their ability to absorb information and to make decisions regarding their treatment. A common strategy employed by the women was to enlist the help of their family and friends in information gathering. Using the information gathering expertise of others gave the women access to information they may not have been able to get on their own, or may not have been capable of getting during a period of emotional crisis. Seeing that other women had successfully completed the same stages of treatment they themselves were facing also provided reassurance and hope that they could accomplish the same.

4.3. Trust

An overriding theme that emerged from the data was that of trust. In the medical literature, trust is most often studied within the context of physician-patient interaction. Components of trust: fidelity (considering the patient's best interests), competence (technical, cognitive, interpersonal), honesty, confidentiality, and open communication [53,54] were all apparent in the data when the women spoke about a positive experience with their surgeon. Another aspect that emerged from the data was that while trust often develops over the course of a relationship, it can also develop rather quickly in certain situations [53]. Trust is developed when, like the women in this study, one of the individuals in a dyad is vulnerable in the relationship (due to inequalities in power, resources, knowledge, etc.), and has no choice but to optimistically accept the situation in the belief that the person trusted will be mindful of his or her interests [53]. In order to determine if a physician is worthy of trust, the patient must develop some sort of criteria by which the determination is made. Actions that increase a patient's trust in a physician include those that show superior interpersonal and technical skills as well as the degree of empathy the physician has for the patient [55-57]. In particular, skill in interpersonal communication is important in developing trust because it is one of the few ways that patients can establish a physician's level of competence [53,54].

The women in our study talked about their trust in several sources, but most often in their surgeon, family physician, or a close personal friend or family member. Women in both groups who found their surgeon's interpersonal skills lacking, actively sought out other medical opinions, either by requesting another surgeon, or by seeking out other sources to 'back up' what the surgeon had told them. In particular, the women mentioned pressure to get through the consultation quickly and evasiveness on the part of the surgeon. This lack of trust may reflect the women's belief that the surgeon was motivated by something other than their best interests.

Patients reported a high level of trust in friends and family as sources of information. According to the definition of trust presented earlier, this is not surprising since there is a strong desire by loved ones to safeguard the interests of patient. As was the case with several study participants, if a patient had a family member or friend in the healthcare field, their information was seen as being more trustworthy presumably because they have both a personal interest in the wellbeing of the patient and some medical expertise.

Trust in sources that were non-personal was related to who produced or disseminated the information. Organizations or individuals who were: motivated by the patient's well-being, considered unbiased, operated on a not-for-profit basis, and were recognized as experts in their field (e.g. Canadian Cancer Society) were the most trusted. Information from some mass media sources were cited as being of dubious credibility because the women felt that their motivation in presenting information was to sell papers. Sites on the internet that were trying to sell something or were perceived as biased in some way were also looked at as being untrustworthy, a finding that has support in the literature [58,59].

4.4. Study implications

The findings from this study suggest that trust is an crucial component of the information seeking process. Since demonstrating concern for the patient as well as being an effective communicator are essential components in building trust, it is vital that these competencies be demonstrated in the consultative process prior to surgery. Dissatisfaction with the quality, amount or delivery of information during the surgical consultation will lead patients to either seek out other sources, or to possibly make decisions in an atmosphere of uncertainty. While the decision itself may not change, information provided in a more satisfactory way may lessen the patient's need for other sources of information. Patients need to know that their questions and concerns will be addressed in a way that *reduces* uncertainty. There was recognition that surgeons may not have time to adequately address patient concerns during the consultative visit, or that patients may not be ready to discuss treatment option during the relatively narrow window of opportunity that the office visit presents. We suggest that a nurse, working with the surgeon in the role of a patient educator may be one way of lessening time demands on the surgeon, and providing a valuable and credible information source that is more accessible and available when the patient is more receptive to information.

Information seeking research to date has focused on either the antecedents to information seeking or on factors influencing the types or sources of information sought, (such as age, education, etc.,). While these factors are important *predictors* of information behaviour, they cannot be manipulated to yield more effectual information seeking. Understanding what makes a source attractive (e.g., its credibility, accessibility, etc.) allows researchers and practitioners to design more effective strategies to disseminate information that decision makers need to make informed decisions. We suggest that future research focus on determining the ways in which such characteristics interact with situational and individual characteristics to influence information seeking.

4.5. Limitations

Secondary analysis of an existing qualitative data requires that a close relationship exist between the original research question and that of the subsequent study. In Paper #2, the focus of the original study included an emphasis on the use of a CDA, and questioning of the informants included several questions specifically about that one source. The focus of the subsequent study was broader in scope (included the use of *all sources* of information). The result may be that there was an under-representation of 'other' sources in the initial study. While the themes in this study were consistent throughout both the interview and focus group phase of the study, they cannot be generalized to other populations of early-stage breast cancer patients.

5. Conclusions

Women facing a treatment choice between mastectomy and lumpectomy prefer to seek out information from interpersonal sources, and in particular, their surgeons. The most salient information source characteristic was credibility, although accessibility, responsiveness, comprehensiveness, relevance and utility of the source were also important in determining how a source was perceived. The women in this study also described two kinds of information that contributed to their decision making: technical and experiential. Technical information related to the actual treatment procedure and its medical consequences, and it came primarily from healthcare practitioners or literature written by healthcare practitioners. Experiential information related to the experience of going through treatment and its emotional and psychological consequences, and came primarily from people within the woman's social network who had lived the experience. Trust in an information source was an important determinant of source choice, and developed when the patient recognized both concern for their best interest and expertise in the source.

Table 3-1: Demographic and treatment-related characteristics

	Name	Age	Marital status[a]	Education[b]	Initial surgical preference[c]	Eventual surgery performed[c]	Chemo-therapy received
Primary study							
	Betty	68	M	PG	Lr	Lr	no
	Rose	72	S	SH	M	L, Mr	yes
	Erica	59	D	U	M	Lr	no
	May	65	CL	SU	Lr	Lr	yes
	Bev	51	M	U	Lr	Lr	yes
	Judy	59	M	U	Lr	Lr	yes
Focus groups							
	Ann	59	M	U	M	M	no
	Kim	56	M	U	M	M	no
	Linda	54	M	U	Lr	Lr	no
	Karen	50	M	U	Lr	Lr	yes
	Irene	50	M	U	Lr	Lr	yes
	Yvonne	69	W	U	Lr	L	yes
	Barbara	50	M	U	Lr	Lr	no
	Jane	60	M	SU	Lr	Lr	no

[a] *M=married, S=single, D=divorced, CL=common-law*

[b] *SH=some high school, SU=some university, U=undergraduate degree, PG=post graduate*

[c] *Lr=lumpectomy with radiation, M=mastectomy, Mr=mastectomy with radiation*

Table 3-2: Taxonomy of sources of knowledge used by early-stage breast cancer patients to inform their surgical decision

Inter-personal				***Intra-personal***	***Non-personal***			
Professionals		Non-professionals			Print	Electronic		
Surgeon	*Nurse and other Healthcare Professionals	Support Groups/Cancer Survivors	Family & Friends	Self/Personal Experience	Books/Patient Education Materials	*CDA	Internet	Media

'Nurse' and 'CDA' were used by women in the primary study only

Table 3-3: Data excerpts relating to each information source

Information Source	Data Excerpt	Participant	Data Set
Surgeon	"Now I decided okay he's got to be good because my doctor said he was, and I had good confidence in my doctor...regardless of his people skills, he's got to be good or he wouldn't be there."	May	Int
	"Talking to [the surgeon] made me feel so comforted. I was very nervous when I came here and he made me feel easy...and I felt so confident in him and I said this is the doctor ...sent from Heaven."	Betty	Int
	"The final authority for me would be the medical profession because they're the only ones that are going to make a totally...matter-of-fact decision."	Rose	Int
	"I don't really care much for his people *skill*. I mean he may be a great surgeon, but...I had to run after him and ask him how long I was going to be in there (laughing)...so if I want answers, I ask my doctor."	May	Int
	She was just like a breath of fresh air. She was just wonderful. And she explained everything like that to me...the lumpectomy versus the mastectomy and cure rate, and what to expect, and everything...it was just like, okay, I'm in your hands...she just made me feel wonderful.	Barbara	FG
	My surgeon was very personable too. He took the time, he just sat and said, 'What are your questions?' And he just kept going until we were satisfied that every question had been answered...he never once looked at his watch.	Linda	FG
Other Healthcare Professionals	"She [family doctor] knows me very well...she knows my temperament...[the surgeon] knows nothing about me. He's probably forgotten my name at this point, he sees so many people."	Rose	Int
	"If I want answers, I ask my [family] doctor because...he figures he's got the best of both worlds because he doesn't have to worry about all the paperwork and money and everything and he can take as long as he wants with his patients."	May	Int
	"Well, I think people tend to trust nurses more than they trust doctors in general because nurses are their primary contact. The doctor comes in, does his thing, and then goes out, and the nurse is there to carry on and smooth it over...she's your *real* contact."	May	Int
	Actually my doctor [GP] told me not to go on the internet, 'There's too much out there—it'll just frighten you', because she knows me, my personality and she said don't go there.	Karen	FG
Decision Aid	I would know what to look for and I will know that my breast will look different than the other one, which probably would have frightened me if I hadn't seen the [decision aid] pictures.	Bev	Int
	The *ability to play the thing over and over again,...that's quite an important* feature because ...certain things occurred to me after I had done it the second time...that hadn't really sunk in the first time.	Rose	Int
	I was excited that someone had built that [online DA] because I think that was what my process was internally and to see it on paper was a terrific thing...[it would be] helpful to family and everybody.	Irene	FG
	I think it's the lack of personal contact that puts that [DA] on the back burner. I think that when you're in this emotional state, you want it [information] from a person, not a machine.	Karen	FG
Family & Friends	It makes him [husband] uncomfortable even going into the hospital to visit somebody (chuckles), that's the way he is...but he is very supportive. He tells me he loves me...and that I can count on him. He doesn't need to know all the details.	Betty	Int
	My family will influence me to the extent that their being upset about the prospect of me not being around,... that is going to have weight with me. Their reaction is totally emotional, and that isn't a decision you can make from an emotional basis.	Rose	Int

Table 3-3 (con't)

Information Source	Data Excerpt	Participant	Data Set
Cancer Survivors & Support Groups	I had so many people say 'Oh well, you know this person had cancer and has radiotherapy and they're just fine', which is just fine. I'm happy for them (chuckles). But when you hear that somebody breezed through it, it doesn't necessarily make me feel any more confident that I'm going to...If you hear about someone who had a bad experience, *that* raises your apprehension level.	Rose	Int
	One of them really went into detail with me and we sat for a long time talking *real detail*, and that was very helpful. She really told me what to expect.	Bev	Int
	The technical information for me, that wasn't an issue...because I knew that part. But the information about the experience you're going through, I truly don't feel that anyone prepares you for that. When you come home that next day after the surgery and you take off that dressing and you look in the mirror, nobody, *absolutely nobody* prepares you for that.	Kim	FG
Books/Patient Education Materials	So I am using all of the resources at the hospital and then the books I was given...the hospital gave me another one—this Pat Kelly book...[and] Susan Love's book.	Bev	Int
	This [DA] was easier for me to read. The other one [booklet] has a lot more information in and some of it I wasn't ready for.	Judy	Int
	And the next step was to go to the library and get lots of books...I have seven books at home right now.	Erica	Int
	It [the booklet] answers a lot of questions. [The surgeon] explained to me she was going to do the lymph node, the sentinel node and it explains it in there...it just kind of refreshes what she had said to me in the room.	Barbara	FG
Internet	I am not familiar enough with it. I have friends who do...I would be skeptical of anything I would get on the Internet on my own because I wouldn't know whether I was actually getting fact or not.	Judy	Int
	I mean these were medical journals, medical organizations that were putting this information out [on the internet]...National Health Institute in the States, I mean these were organizations that you know...I probably printed two hundred pages of information. I didn't take one source, I took *a lot* of sources.	Bev	Int
	I was on the internet like 'right now'. I wanted to know exactly how it [the surgery] was going to be done...I have to know, and I'm pretty good at weeding out the nonsense from the good stuff...I would go to the Mayo Clinic site, I wouldn't just go to some chat room.	Ann	FG
	As a matter of fact, I was afraid to go on the internet because I was afraid to see things that I didn't want to see and I trusted what people had told me...I was afraid to find something that was negative.	Kim	FG
Media	I don't have much faith in the journalistic community any more...we all know what the press is like. They grab a notion and all of a sudden it's supposed to be a fact, and all they're doing is trying to sell papers or magazines.	Rose	Int
	[I might believe the information on] Oprah a little bit...I'm thinking maybe [public broadcasting channel] or with a doctor or someone of credibility speaking. But then again, you don't really know who they are either. I listen with an open mind.	Judy	Int
	I think what I learned in terms of media was to pay attention to what kind of journal things were published in and study size...you spend so much time deflecting 'junk' that you just want to make sure you catch all the right ones...I call it my 'crap detector'.	Irene	FG
Personal Experience	Everyone relies on its [sic] own experiences and I think to make a decision it's up to the individual. Whatever knowledge you have.	Erica	Int
	It depends on your personality too...who you are...gives you different concern. Not everybody approaches something like this or anything else the same way.	Rose	Int

Table 3-4: Information source descriptions

	Information Source	Description	Positive Aspects	Negative Aspects
Interpersonal Sources	**Surgeon**	- Most mentioned, most influential - Information need at consultation depended on degree of preparedness - Surgeons who were considered the best sources were competent, communicated effectively, and showed compassion to their patients - Very short relationship	- Provided clinical expertise - Information specificity - 'Privileged' knowledge	- Difficult to access after the consultation - Some patients didn't want to 'waste the doctors time'
	Other Healthcare Professionals	- GP: 'interpreted' information from surgeon - A relationship developed over time - Nurses & other allied health: little input into decision-making, some supportive care	- 'Holistic' knowledge of the patient - More accessible than specialist	- Lacking 'special' knowledge; a generalist
	Family & Friends	- Used to validate decision - Most often consulted for 'experiential' knowledge - If family/friends were healthcare professionals, they were consulted for their 'technical' knowledge - While it was important to include some in decision making, others had to be 'shielded'	- High level of trust because of emotional investment - Provided emotional support as well as information	- Sometimes provided well-intentioned but unhelpful advice - Will base decisions on emotion rather than logic
	Cancer Survivors/ Support Groups	- Provided experiential information Included both technical and emotional aspects of treatment	- Very credible because of their personal experience - Other's positive experiences gave sense of hope	- Other's experiences not always relevant - Negative experiences of others are frightening
Intra-personal Sources	**Self/Personal Experience**	- Past experience with healthcare providers or illness - Own educational background	- Degree of self awareness important in determining which treatment outcomes valued	-Some individuals had little experience with serious illness to draw from
Non-persoanl Sources	**CDA**	- Most often used to consolidate, confirm other sources, usually the surgeon - Not offered to focus group participants	- Easy to understand, comprehensive, - Comforting voice, convenient, - Graphic information important	- Lack of availability - Too general in nature
	Documentary Sources	- Used to augment or confirm information from other sources - Credibility of information producer an issue - Friends/family often helped access	- Convenient	- Conflicting information caused anxiety or confusion
	Internet	- Legitimacy/credibility of sites an issue - Friends/family often helped access	- Convenient - Comprehensive	- Access, skills required - Quality of information based on search strategy's level of sophistication
	Media	- Credibility of media source an issue	- Convenient access	- Motives questioned - Information too general - Not always relevant

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Chapter 4: Summary of Results, Contribution, and Limitations

1. Results

In the previous chapters I presented the two papers that comprise the substantive portion of my paper-based thesis. The aim of the combined works was to summarize the literature regarding the influencing factors and outcomes related to information seeking behaviour of women prior to early-stage breast cancer surgery, and to determine how different information sources are evaluated, and how their characteristics influence the decision making process. In the following section, I will summarize the findings from each study and then discuss the research and practice implications as well as the limitations of the combined studies.

Study 1: Information acquisition for women facing surgical treatment for breast cancer: influencing factors and selected outcomes.

This paper reported the findings from an integrative review of the literature pertaining to information needs, sources of information preferred and utilized, and the outcomes related to the provision of information (in the form of a consumer decision aid or CDA) intended to inform decision making for early-stage breast cancer treatment. The two initial searches yielded 557 and 1922 articles respectively. The searches were further narrowed using limiting terms and the abstracts of the remaining articles were evaluated for relevance to the present study using pre-determined inclusion criteria. Of these, 11 articles fit the criteria. Another 14 articles were retrieved using ancestry searches and hand searches of several relevant journals.

The final 25 articles included in the review formed three categories based on each article's focus of inquiry: information needs, information sources, and CDA-related outcomes. The information needs of early-stage breast cancer patients was the focus of eight of the articles. The greatest needs were for information about chances for a cure, stage of disease and treatment options. Overall desire for information was high, and three personal factors (age, education, and desired role in decision making) and one contextual factor (time since diagnosis) were found to influence the type of information wanted. Articles reporting on the sources of information used by early-stage breast cancer patients numbered eleven. In general, the most preferred and utilized source of information for breast cancer treatment was a physician, with other healthcare professionals, family and friends, printed material, and the internet (approximately in that order) ranking lower. Again, three personal (age, education, and involvement in decision making) and one contextual factor (type of surgery eventually chosen) were associated with differing patterns of source use.

Six studies evaluated the outcomes related to the use of a CDA designed to assist women with their choice of surgery for early-stage breast cancer. While the results among the studies were mixed, generally, for women using the CDA, level of knowledge, satisfaction with the CDA, satisfaction with the decision, and satisfaction with the decision making and communicative processes were increased. Decisional conflict was decreased, and levels of anxiety and depression were not affected. Although qualitative comments regarding the CDAs were overwhelmingly positive, quantitative differences between the 'usual practice' and the use of the CDA were modest.

The disparate nature of the research methods used precluded any systematic quality assessment from being performed. Findings from the information needs and information source studies were mainly at the descriptive level. Findings from the CDA studies, while more rigorous, found only modest differences between the intervention (CDA) and control (usual practice) groups. Application of the results to Longo's [1] expanded conceptual model of health information seeking provided a structure for understanding the relevance of the findings in terms of the larger concept of information seeking behaviour. In assessing the results of the integrative review, it became apparent that very little research had been conducted beyond a small number of nonmodifiable variables (personal and contextual). The Longo model failed to address the differences in choice of information source as it varied by personal or contextual factors. In this study, I found that age, education, degree of involvement in decision making, and income were all associated with differing patterns of source use. I argued that incorporating the ways in which personal, contextual *and* source characteristics influence source choice would strengthen the model.

Study 1: Contribution

This is the first integrative review that I am aware of that combines the literature regarding information needs, information sources and the outcomes related to CDAs in the context of decision making for early stage breast cancer. Greater understanding of the information needs and information seeking patterns of early-stage breast cancer patients at this specific location along the disease trajectory is essential in order for healthcare providers to design effective strategies for the dissemination of treatment information.

Study 2: A qualitative examination of how early-stage breast cancer patients evaluate sources of information relevant to treatment decision making.

This paper reported the findings of a secondary analysis of an existing qualitative data set consisting of interviews (two each) with six early stage breast cancer patients and the subsequent analysis of data from two focus group interviews with three and five women respectively. The purpose of the earlier study was to evaluate qualitatively the perceived usefulness of a CDA in helping the women to decide between mastectomy and lumpectomy, and to explore the sources of information (other than the CDA) used to facilitate their decision making and their weighting of these information sources. The purpose of the collection and analysis of the focus group data was to validate the finding of the secondary analysis and to augment theory development.

While disease-related characteristics were similar between the two groups of women, the groups differed in that the women from the original study were all patients from one surgeon's practice. Women in the subsequent study were not. The focus group participants were also younger and had higher levels of education attainment than the original group. Despite these differences, findings for the two groups was very similar. I developed a taxonomy of sources with sources primarily being separated into two types: interpersonal and non-personal. Interpersonal sources included the surgeon, nurses and other healthcare professionals, family and friends, cancer survivors, cancer support groups, and personal experience. Non-personal sources included books and other patient materials, CDAs, the internet, and media sources.

Overall, the most influential source of information regarding treatment options was the surgeon. In general, 'interactive' interpersonal sources were preferred over more 'static' non-personal sources. The internet, print materials and the CDA were often used by the women to consolidate their choice, or to review their decision making process. Family and friends provided both informational and emotional support and often helped to facilitate decision making. I was able to differentiate between two types of knowledge that was needed for decision making: technical knowledge, mainly provided by the surgeon and other healthcare professionals, and experiential knowledge, information about the experience of treatment and its impact on the individual. Breast cancer survivors were the most important providers of experiential knowledge.

Six information source characteristics emerged from the data: credibility, relevance, utility, comprehensiveness, accessibility, and responsiveness. The most influential characteristic was credibility, which contributed to the development of 'trust' in a source. The greater the degree of trust the women had in a source, the greater the influence that source had on decision making. In order to develop trust in a 'human' source (particularly the surgeon), the patient had to perceive that the person was technically competent, empathetic towards them, and was an effective communicator. Trust in lay sources of information was also important. Breast cancer survivors, by virtue of their own very personal experiences, were considered very credible sources of experiential information. The closer the emotional bond between the 'patient' and the 'survivor', the more trustworthy the information became. Trust in non-personal sources such as the media and the internet were based on the legitimacy or the credibility of the individual or organizations creating or distributing the information.

Study 2: Contribution

This study has added to the body of literature in the area of patient information behaviour by the development of a taxonomy of information sources used by early-stage breast cancer patients to inform treatment decision making. Taxonomies are useful in highlighting similarities and differences among components of a given domain, which can help in theory development. In the case of this study, the taxonomy helped to distinguish important differences between interpersonal (responsive, interactive, etc.) and non-personal sources of information (static, nonresponsive, etc.). Additionally, the identification of six information source characteristics that help to explain how sources are evaluated by information seekers was completed. Understanding the basis by which patients evaluate the sources and determine preferences helps to explain and predict information behaviour, and ultimately contributes to the successful development and dissemination of information products.

This study also provides evidence for the existence of two kinds of information sought out by breast cancer patients prior to making a treatment decision: technical information, and experiential information. In this study, the value of having both kinds of information prior to decision making was emphasized. Few research studies have acknowledged the desire by patients to be informed about the affective 'experience' of treatment. This finding should encourage researchers and practitioners to consider providing to patients, *all forms* of information, not just the products of scientific inquiry.

Finally, a beginning investigation into the role that trust plays in the acquisition of information relevant to treatment decision making was presented. Patient vulnerability coupled with an inequitable distribution of specialized knowledge contributes to the development of a relationship between provider and patient where trust is a necessity. This study offers insight into possible ways to increase information uptake by building trust in the patient-provider relationship.

2. Summary of Contributions

The contributions that this thesis makes to research literature are as follows:

1. First integrative review to combine literature regarding information needs, information sources and the outcomes related to CDAs in the context of decision making for early stage breast cancer.
2. Development of a taxonomy of information sources used by early-stage breast cancer patients to inform treatment decision making.
3. Identification of six information source characteristics that help to explain how sources are evaluated by information seekers.
4. Identification of two distinct kinds of information sought by breast cancer patients prior to making a surgical choice: technical and experiential.
5. Beginning investigation into the role that trust plays in the acquisition information relevant to treatment decision making.

3. Implications

3.1. Research implications

The acquisition of information patients need to make informed choices about their healthcare can be looked at from two vantage points. Information seeking behaviour models describe the antecedents, the influencing factors and the outcomes of this activity from the perspective of the person who seeks out and uses the information. Viewing this behaviour from the other point-of-view, that of the information provider, may contribute new insights into how information might be better 'packaged' and disseminated in a way that provides the most benefit to the end user.

In Study #1, the integrative review I discussed the findings in terms of Longo's [1] expanded conceptual model of information seeking behaviour. Longo's model describes the personal and contextual factors that are thought to influence information behaviour, the different levels of information acquisition and use, and the important distinction between active seeking and passive receipt of information. I argue that the model would be strengthened if it incorporated explanations of *how* personal, contextual and source characteristics (alone or in combination) influence the choice of information source. Since there has been virtually no study of how information seekers assess information sources, I attempted to fill this gap in the research by conducting the second study (Paper #2). The next logical step is to conduct a study to further investigate the influence each of the source characteristics has on source choice. Johnson [2] has done some preliminary work in this area with his description of information channels, carriers and sources. He identifies characteristics that are roughly equivalent to several of those identified in our study, but fails to explain in his information seeking model, how they influence source choice, or subsequent outcomes such as satisfaction with the decision making process or level of knowledge.

Further investigation into how the different types of knowledge, 'technical' and 'experiential' contribute to decision making. Based on the results of the second study, in addition to some of the comments made by the women in that study, the experiential information needs of women facing surgery for breast cancer may be underestimated. Hearing about the experiences of other cancer patients allow patients to put their own disease and treatments into perspective, as well as gain insight into ways of coping with cancer treatment and its effects [3]. Future research focused on determining the relative contributions of each information type to the decision making process would assist investigators to design interventions to provide decisional supports containing information consistent with patients needs.

Finally, further investigation into the role that trust plays in the relationship between the healthcare provider and patient, specifically in the context of shared decision making for treatment of a life-threatening illness. Do different personal or situational factors influence the level of trust that is experienced during a physician-patient interaction, and, do differing levels of trust influence outcomes such as satisfaction with the decision, or decisional conflict? Determining the nature of these relationships will contribute to a more comprehensive and accurate model of information seeking and use.

3.2. Practice implications

Breast cancer is the most frequently diagnosed female cancer in Canada [4]. Despite two decades of study into the informational needs of this population, there is still dissatisfaction among breast cancer patients with the amount and quality of information that is provided by healthcare professionals. The rise in internet searching for health-related information, especially by women [5], may remedy this to some extent, but, as evidenced in this thesis, there is still a desire to receive information from interactive 'human' sources. The stress of diagnosis coupled with the expectation of active participation in treatment decision making may leave some patients struggling to cope with the need for information. Healthcare providers have the opportunity to assist women in

The effective provision of health information requires a plan that includes identifying the knowledge needs of the end-user, assembling and synthesizing the highest level of evidence into a 'knowledge product' that is appropriate and acceptable to the target population. It also involves designing an effective dissemination strategy that takes into account the needs of the intended user, any barriers to information use that exist, and the context in which the information will be used. The Knowledge-To-Action framework [6] introduced in Chapter 1 provides a dissemination plan that could be applied to the provision of information to early-stage breast cancer patients in the context of making a treatment choice. Combining the 'action cycle' portion of the framework with Longo's [1] expanded conceptual model of information seeking behaviours helps to illustrate how the results of this thesis could be used in practice (**Figure 4-1**).

The 'path' of the information user and the information provider intersect at the knowledge uptake and use stage. This is illustrated in **Figure 4-1** which shows personal and contextual variables influencing how knowledge is taken up and used (as per the Longo model). The provision of information for uptake entails several steps that starts with the identification of the 'problem'(#1), and ends with the selection, tailoring and implementation of the intervention (# 5) (as per the Graham et al. framework). Successful provision will require knowledge of the variables that influence knowledge uptake by the user—in this case, a knowledge of the personal and contextual variables, as well as an understanding of how different sources are evaluated by the user. This understanding will allow the provider of information to select, tailor and implement the most effective and appropriate interventions to increase knowledge. For example, knowing that women prefer treatment information to come from an interactive 'human' sources such as a healthcare professional will direct providers to pay more attention to the discussion of treatment options during the consultative visit. Overall, better understanding of the needs and preferences of the users of information will permit healthcare professionals to create and disseminate knowledge products that allow for more informed decision making and ultimately, better patient outcomes.

4. Limitations

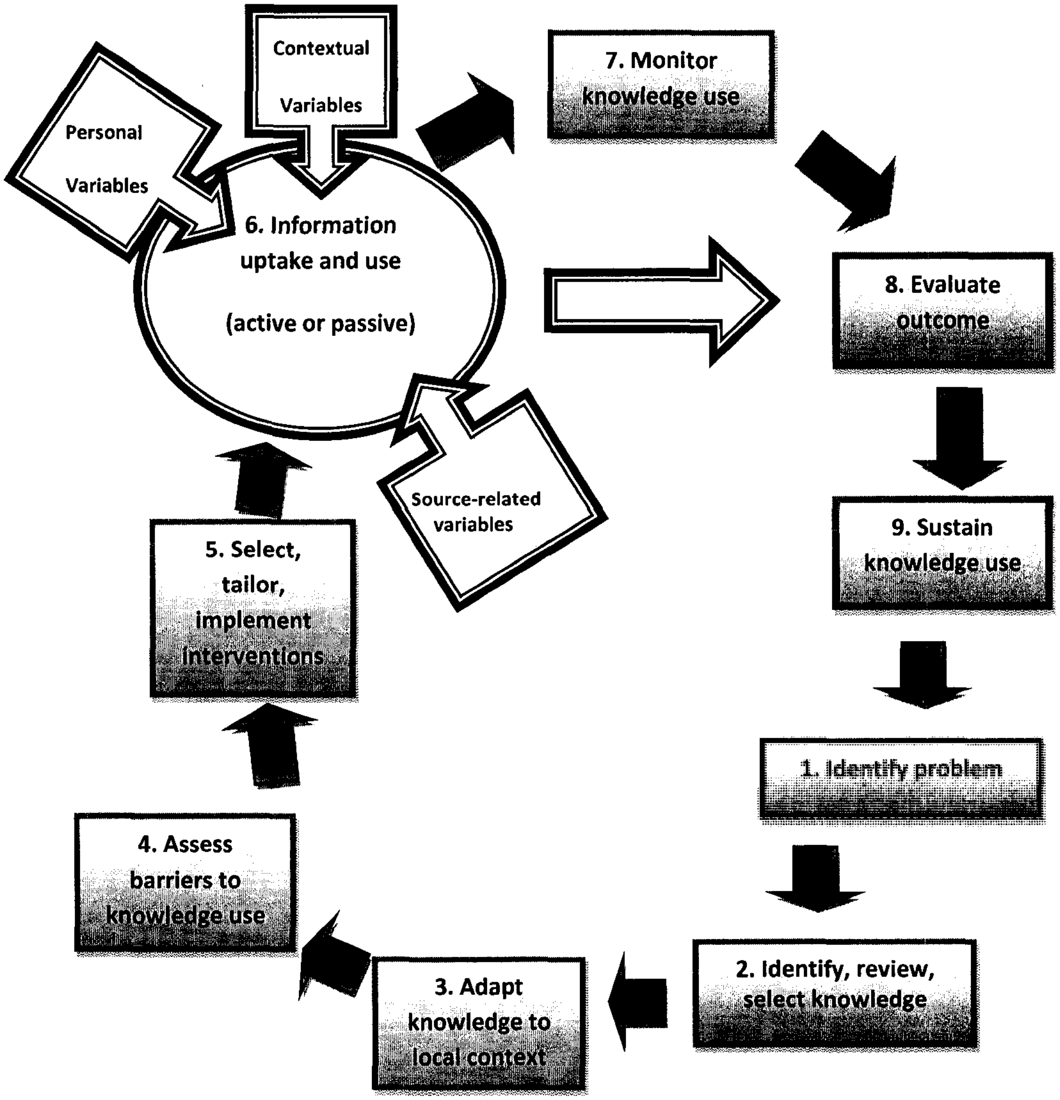
1. Some form of quality assessment of the included articles in the integrative review would have strengthened the review, however given the dissimilarity of the methods used, a narrative review of the methods used was acceptable.

2. The homogeneity of the sample in Paper #2 may limit the applicability of the results to populations with characteristics different from those of the study sample.
3. Secondary analysis of an existing qualitative data requires that a close relationship exist between the original research question and that of the subsequent study. In Paper #2, the focus of the original study included an emphasis on the use of a CDA, and questioning of the informants included several questions specifically about that one source. The focus of the subsequent study was broader in scope (included the use of *all sources* of information). The result may be that there was an under-representation of 'other' sources in the initial study.
4. The period of time between diagnosis and data collection for some of the focus group participants was as much as 3 years, which may introduce the problem of recall bias.

5. Conclusion

This thesis identifies the factors that influence information seeking for early-stage breast cancer patients as well as some outcomes of providing evidenced-based information in the form of a CDA. Effective and appropriate provision of information by healthcare professionals requires a comprehensive understanding of the factors that influence knowledge uptake of health information by patients involved in shared decision making for treatment of their illness. Patients who are well informed and take part in decision making at a level that they are comfortable with, experience better health-related outcomes.

Figure 4-1: Combining Graham's (2006) Knowledge-To-Action framework (action cycle) and Longo's (2005) expanded conceptual model of information seeking behaviours



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Appendices

Appendix A: University of Alberta information and consent form.

Appendix B: Alberta Cancer Board information and consent form.

Appendix C: Focus group interview schedule

Appendix D: Focus group demographic questionnaire

Appendix A

Information Sheet & Consent Form

Title of Research Project: Examining the forms of evidence used by early-stage breast cancer patients within the context of making a treatment choice between mastectomy and lumpectomy

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Principal Investigator:
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Sub-Investigator:
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University of Alberta
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E-mail: koleary@ualberta.ca

> This information sheet is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information.

Background: The focus of this research project is on the decision-making process that newly diagnosed breast cancer patients go through when they are faced with choosing between mastectomy and lumpectomy (or Breast Conserving Therapy--BCT). Both treatments give an equal chance of long-term survival. This means that the treatment choice is based on what the patient **prefers**. I am interested in finding out what **information** women use to make this choice, **where (or who)** this information comes from, and which information is the **most/least valuable** when making the decision.

Purpose: You are being asked to participate in a research study to help find better ways of communicating information that is important to women making treatment choices for breast cancer. This research contributes to the completion of my master's degree in Nursing.

Procedures: I will be conducting **focus group** interviews (a group of breast cancer patients like yourself) at the University of Alberta. At each of the focus group interviews there will be approximately 4-8 participants who have shared a similar experience-surgery for early stage breast cancer. At the start of the interview, I will share with you the results of research I have done on interviews that were recorded several years ago with women who were involved in making a choice between mastectomy and lumpectomy. I will be asking you to comment on whether your experience was similar to theirs, or different. The interviews will be approximately 60-90 minutes in length, depending on how the discussion goes. You are invited to participate at a level that is comfortable for you. You are not obligated to participate, and you are free to leave the interview at any time. Refreshments and a $10 reimbursement for parking will be provided. The focus group interview will be tape recorded. I will analyze the contents of the recorded interview, and incorporate them into my final report.

Attached to this letter is a consent form which will need to be completed, signed, and witnessed before you can be accepted to participate. If you have any questions, please feel free to contact me at any time leading up to, during, or after the interview. My contact information is located at the top of the previous sheet. Please feel free to contact my supervisor, Dr. Carole Estabrooks, as well.

The interview recording, the transcription, and any other documents related to the research study will be kept in a secure location during the research process, and for a minimum of five years after completion of the project. The data (transcribed interviews) may be used for research studies in the future. All participants will be given fictitious names, and the identities of the individual participants will only be known by me, my supervisor, and the participants of the focus group. My supervisor and I will be signing confidentiality agreements that state that we will keep the information shared during the interview confidential; but please be aware that we cannot guarantee that the other focus group participants will keep the proceedings confidential. The court reporter also is bound by a professional code of conduct and a confidentiality agreement. I will ask everyone in the group for permission to record the interview again at the very start of the recording.

Possible Benefits: The possible benefits to you by participating are that you will be contributing to knowledge in the area of treatment decision making and you will have the opportunity to share experiences and support fellow breast cancer patients.

Possible Risks: Reflecting on your own or other's experiences of making a treatment decision may cause you to experience distress. It is not expected that this discussion will cause you or the other participants harm in any way, but if you feel the need for counseling as a result, psychological counseling will be provided for you.

Confidentiality: Personal records relating to this study will be kept confidential. Any research data collected about you during this study will not identify you by you actual name, only by an alias. Your name will not be disclosed outside the research clinic. Any report published as a result of this study will not identify you by name.

I plan to conduct the focus group on XXXXXXX **at 7:00 pm**
It will be held in:

Rm 5-112 on the 5th floor
Clinical Sciences Building,
University of Alberta
Edmonton, Alberta

If you have any questions concerning matters related to this research, please contact :

Katherine O'Leary RN, BScN, MN(student) Ph. (780) 492-2126 or (780) 995-5508

OR
Dr. Carole Estabrooks, Ph. (780) 492-3451

If you have questions concerning your rights as a possible participant in this research, please contact:

Dr. Christine Newburn-Cook , Associate Dean of Research, Faculty of Nursing, University of Alberta at (780) **492-6764**.

The above research procedures have been explained to me. Any questions have been answered to my satisfaction. I have been given a copy of this form to keep.

______________________________ ______________________

Signature of participant Date

The University of Alberta Health research Ethics Board has approved this study

Consent Form

Project Title: **Examining the forms of evidence used by early-stage breast cancer patients within the context of making a treatment choice between mastectomy and lumpectomy**

Principle Investigator: **Carole A. Estabrooks, PhD,** Professor, Faculty of Nursing 5-112 Clinical Sciences
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Co-Investigators: **Katherine A. O'Leary,** Master's Student, Faculty of Nursing, 6-135 Clinical Sciences
Bldg., University of Alberta Phone: (780) 492-2126 (bus) / (780) 995-5508 (cell)
E-mail: koleary@ualberta.ca

	YES	**NO**
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached information sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study at any time, without having to give a reason and without affecting your future medical care?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your records?	☐	☐
Do you want the investigator(s) to inform your family doctor that you are participating in this research study? If so, give his/her name ______________________________	☐	☐

Who explained this study to you? ____

I agree to take part in this study: **YES** ☐ **NO** ☐

Signature of Research Subject: ____

(Printed Name): ____

Date: ______________________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of the Investigator: ______________________________________ Date: _____________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH SUBJECT

Alberta
CANCER BOARD

Appendix B

Alberta Cancer Board Consent Form

Breast cancer patients' use of evidence in the context of making a treatment choice between mastectomy and lumpectomy

CONSENT FORM

This form is part of the process of informed consent. It is designed to explain this research study and what will happen to you if you choose to be in this study.

If you would like to know more about something mentioned in this consent form, or have any questions at anytime regarding this research study, please be sure to ask your doctor or nurse. Read this consent form carefully to make sure you understand all the information it provides. You will get a copy of this consent form to keep. You do not have to take part in this study and your care does not depend on whether or not you take part.

Your participation in this study is entirely voluntary. Please take your time to make your decision. It is recommended that you discuss with your friends and/or family about whether to participate in this study.

"WHY IS THIS STUDY BEING DONE?"

Sometimes, treatment for cancer will involve having to choose between two options that offer the same chance of survival, but have very different consequences. 'Decision Aids' are tools designed to help patients through the decision process by providing the most current research-based information possible. Also included in Decision Aids are exercises that help patients decide what treatment is the most acceptable to them. Not all patients have access to these tools, are aware that they exist, or choose to use them. As researchers, we would like to find out what sources of information (including Decision Aids) patients use to help them decide on a treatment choice.

"WHAT DO WE HOPE TO LEARN?"

We hope to learn how breast cancer patients locate, evaluate and use information from different sources to support their treatment choices.
The purpose of this study is to help find better ways of communicating information that is important to women making treatment choices for breast cancer.

"WHAT IS INVOLVED IN THIS STUDY?"

A psychologist within the Psychosocial and Spiritual Resources Department at the Cross Cancer Institute will screen new referrals to the Department and will identify suitable candidates for our study. The Department's secretarial staff will provide these candidates with an information sheet containing the researcher's contact information, and an explanation of the study. Attached to the information letter will be a form where potential participants will be invited to submit their name, phone number and the time they prefer to be contacted. This form will be left with the secretarial staff. A researcher will contact potential participants by phone, and will provide any additional information needed. Only those women who wish to be contacted will be contacted. A location, date and time for the focus group interview will be given to interested participants.
We will be conducting focus group interviews (a group of breast cancer patients like yourself) at the University Extension Centre (8303 112 Street, Edmonton). At each of the focus group

interviews there will be approximately 4-8 participants who have shared a similar experience-surgery for early stage breast cancer. At the start of the interview, we will share with the participants, the results of research that has been done on interviews, conducted within the last 6 years, with women who made the choice between mastectomy and lumpectomy. We will be asking you to comment on whether your experience was similar to theirs, or different. The interviews will be approximately 1-2 hours in length, depending on how the discussion goes. You are invited to participate at a level that is comfortable for you. You are not obligated to participate, and you are free to leave the interview at any time. Refreshments and coupons for parking will be provided to you. The focus group interview will be audio recorded and a 'real-time' reporter will be recording the interview in written form. We will analyze the contents of the recorded interviews, and incorporate them into our final report.

In the event that the researchers require more a more in-depth description of the decision process, you **may be invited** to take part in a one-on-one interview, as well as the focus group interview. The interview will be audio recorded and should last about 1-1½ hours. The topics discussed during this interview would be the same as during the focus group interview, but perhaps in more depth. The individual interview will take place in the same location as the focus group interview. Refreshments and parking coupons will be provided. Confidentiality and anonymity will be maintained. Risks and benefits of participating in the individual interviews are similar to participating in the focus group interviews. You are **not obligated** to participate in either the focus group or the individual interview or you may choose to participate in one and not the other. You will need to sign an additional consent form before participating in the individual interview.

The interview recording, the transcription, and any other documents related to the research study will be kept in a secure location during the time that the research is being conducted, and for a minimum of five years after completion of the project. The data that is collected (transcribed interviews) may be used for research studies in the future. If so, it will first be looked at by the appropriate research ethics board. You along with the other participants will be given fictitious names, and the identities of the individual participants will only be known by the research team and the participants of the focus group themselves. Members of the research team will be signing confidentiality agreements that state that we will keep the information shared during the interview confidential; but please be aware that we cannot guarantee that the other focus group participants will keep the proceedings confidential. The 'real-time' reporter also is bound by a professional code of conduct and a confidentiality agreement. We will ask everyone in the group for permission to record the interview again at the very start of the recording.

"HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?"

About 8-16 people will take part in this study.

"WHAT WILL MY PARTICIPATION INVOLVE?"

Candidates eligible to participate in our study will be identified by a psychologist within the Psychosocial and Spiritual Resources Department at the Cross Cancer Institute. Secretarial staff will supply suitable candidates with an information letter that explains the study. Potential participants will be invited to leave contact information with the secretarial staff of the Department. A researcher will contact the potential participants will information about the location, date and time of the focus group interview. At the start of the focus group interview, we will conduct a short presentation of the findings from an analysis of interviews carried out previously with other women who made a treatment choice between mastectomy and lumpectomy. Your participation involves reflecting on **these** results, as well as talking about **your own experiences** of making a treatment choice.

"HOW LONG WILL I BE INVOLVED IN THE STUDY?"

Your time commitment for the study will be for as long as the focus group interviews take—usually about 1½ to 2 hours

"ARE THERE ANY BENEFITS TO PARTICIPATING IN THIS STUDY?"

Participation in this study may or may not be of personal benefit to you. However, based on the results of this study, it is hoped that, in the long-term, patient care can be improved. The possible benefit to you **personally** is that you will be contributing to knowledge in that area.

"CAN I WITHDRAW FROM THIS STUDY?"

You are free to withdraw from the study at any time.

"ARE THERE COSTS TO ME FOR TAKING PART IN THIS STUDY?"

Your parking costs for participating in this study will be covered by the research team.

"WHAT ARE MY RIGHTS AS A PARTICIPANT?"

If you suffer an injury or become ill as a result of participating in this research, you will receive all medical treatments (or services) recommended by your doctors. No compensation will be provided beyond this point. However, it is important to note that nothing said in this consent form alters your legal rights to recover damages (e.g. legal action).

WHAT ARE THE POSSIBLE RISKS IN TAKING PART IN THIS STUDY?

Reflecting on your own or other's experiences of making a treatment decision may cause you to experience distress. It is not expected that this discussion will cause you or the other participants harm in any way, but if you feel the need for counseling as a result, psychological counseling will be provided for you through the Psychosocial and Spiritual Resources Department at the Cross Cancer Institute.

"WILL MY PERSONAL INFORMATION BE KEPT CONFIDENTIAL?"

Identifiable health information will be collected during this study. This information may be used by the researchers who are carrying out this study. Any research proposal to use information that identifies you for a purpose other than this study must be approved in advance by the ACB Research Ethics Board.

Direct access to your identifiable health information collected for this study will be restricted to the researchers who are directly involved in this study except in the following circumstances:

Your identifiable health information may need to be inspected or copied for quality assurance (to make sure the information being used in the study is accurate) and for data analysis (to do statistical analysis that will not identify you). The following organization may do this inspections:

- Alberta Cancer Board Research Ethics Board

Any disclosure of your identifiable health information will be in accordance with the Alberta Health Information Act. Your identifiable health information collected as part of this study which includes records of your responses to questions will be kept confidential in a secure facility.
Although absolute confidentiality can never be guaranteed, the Alberta Cancer Board will make every effort to keep your identifiable health information confidential, and to follow the ethical and legal rules about collecting, using and disclosing this information in accordance with the Alberta Health Information Act and other regulatory requirements.

"WHO DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?"

For information about this research, you may contact the Principal Investigator, **Dr. Carole Estabrooks at 492-3451**, Co-Investigators, **Katherine O'Leary at 492-6836,** or **Dr. Ceinwen Cumming at 432-8766.**

If you feel, at any time, that you have not been informed to your satisfaction about the risks, benefits, or alternatives of this study, or that you have been encouraged to continue in this study after you wanted to withdraw, you can call the **Patient Representative at (780) 432-8585.**

UNDERSTANDING OF PARTICIPANTS

I can refuse to take part or withdraw from this study at any time without jeopardizing my health care. If I continue to take part in the study, I will be kept informed of any important new developments and information learned after the time I gave my original consent.

I also give consent for the Principal Investigator and the Alberta Cancer Board (the Custodian) to disclose identifiable health information, as per the Alberta Health Information Act.

I have read and understood all of the information in this consent form. I have asked questions, and received answers concerning areas I did not understand. I have had the opportunity to take this consent form home for review and discussion. My consent has not been forced or influenced in any way. I consent to participate in this research study. Upon signing this form I will receive a signed copy of the consent.

(PRINT NAMES CLEARLY)

Name of Patient	Signature of Patient	Date &Time
Name of Witness	Signature of Witness	Date & Time
Name of Person Obtaining Consent	Signature of Person Obtaining Consent	Date & Time
Name of Investigator	Signature of Investigator	Date & Time

Appendix C

Interview Schedule for Focus Group Interviews

A. Review findings from secondary analysis:

Did the participants agree/disagree with the following statements (if not , why?)

a. The surgeon was the most important source of information I used.
b. It was important that my surgeon had good technical skills, good communication skills, and showed that he/she cared about me as a person.
c. I only considered information from sources I trusted
d. Other cancer survivors were important sources of information because they could tell me what the treatment experience was like.
e. I looked for 2 kinds of information: information about the technical 'medical' aspects of the surgery, and information about the experience of going through treatment
f. My family doctor was helpful in explaining all of the information and helping me to make a decision
g. Family and close friends helped me by going through my decision making process with me and 'validating' and validating my choice.
h. I used a decision aid
i. I was very selective in terms of which media sources I got information from.
j. I found that sources had some or all of the following characteristics: (list the 6)
k. Credibility was the most important characteristic for a source to have.

B. Additional questions or prompts:

1. Does any part of what I have just described sound familiar to you? Were your experiences with having to choose between lumpectomy and mastectomy *similar* or *different* from what I have just described?
   i) if not, describe what your situation was like and how it was different
   ii) if it was similar, can you describe it in your own words?

2. Can you tell me what sources of information you used to help you make the decision between mastectomy and lumpectomy?
   i) Was it important to use more than one source?
   ii) Were there sources that you relied on more than others?

3. Now, thinking about the source(s) that you relied on most, what made it/them different (or better) than the other sources?

4. When you look for information to help you make a decision (like one you made concerning your breast cancer) –what do you look for?

5. Is it important to know *where* the information comes from, or *who* is giving you the information?
    i) Who do you think would be a *good provider* of information?
    ii) Where does *'good'* information come from?
    iii) How would you know if information was *'bad'*?

6. What kind of information was *most helpful* when you were making your treatment decision? (for example, personal stories from cancer survivors, information from your doctor, information I read in a book, information about different treatments I found on the Internet etc)

7. What kind of information was *least helpful* or not important to you?

8. Is there information that you wish you had had when making your decision? Describe this information. Where might you have gotten it? How do you think it would have influenced your decision-making? Your decision?

9. Is there anything else you would like to tell me, or that you think I should know about the experience of making the decision between mastectomy and lumpectomy?

Appendix D

Focus Group Demographic Questionnaire

Name:____

What surgery did you have?

a) Mastectomy____________
b) Lumpectomy (breast conserving therapy or BCT)____________
c) Other____

When did you have your surgery (year/month)?______________________________

What other treatment did you have?

a) Radiation____
b) Chemotherapy______________________________________
c) Other (list)____

What is your birthdate (yyyy/mm/dd)?__________________________________

What is your marital status?
Married/common-law______Separated/divorced_______widowed_____single_____

Before you were diagnosed, had someone close to you been diagnosed with breast cancer?
Yes______________ No_________________