

Breast Cancer Patients' Expressed Information Needs: Results of a
Literature Review

by

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Abstract

This literature review was conducted to explore the relevant research regarding the expressed information needs of women newly diagnosed with breast cancer. A literature review was chosen to support the learning needs of the author as a novice researcher and to ensure future practice guidelines are evidence based.

A number of the authors work in this review utilized Lazarus and Folkman's (1984) theoretical framework of coping, illness behaviour, and outcomes which guided the work for their research. Women experienced heightened anxiety and stress when faced with a life threatening illness.

The Information Needs Questionnaire (Degner et al., 1998) and the Toronto Information Needs Questionnaire Breast Cancer (Galloway et al., 1997) were used to assess the information needs of women. All women articulated high information needs irrespective of the treatment they received. The most important needs of women with a new diagnosis of breast cancer are: disease stage, treatment, and investigational tests. The difference among the women was in relation to the priority order they wanted their information needs met.

This review contributes to a better understanding of information needs of women as they journey through their cancer treatment. Women with breast cancer tell us they require information to help them manage their illness. Oncology Nurses can play a significant role in understanding a women's individual need for information when they are faced with a new diagnosis of breast cancer. The ability to understand the patients' perspective is the key issue for nurses when probing information needs.

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Introduction

Cancer is one of the most feared diseases in the western world due to its unpredictable nature and its sudden unexpected appearance without warning (Sawyer, 2000). In 2007, the estimated incidence of new cases of cancer in Canada was 159,900 (Canadian Cancer Society Statistics, 2007). Breast cancer is the most common cancer in women worldwide as well as in Canada and it is estimated to affect 22,000 Canadian women each year. In Ontario that represents 7,200 women. One in nine women will be diagnosed in her lifetime.

Patients with cancer represent a vulnerable population who are at a crossroad in their lives when faced with a life threatening illness. They face this poignant experience with their existing values, beliefs, culture, and coping skills, and apply these to an unfamiliar environment where they are reliant on health care professionals to assist and direct them as they begin their journey. In addition to personal and spiritual aspects of the cancer experience such as suffering and meaning making, this journey requires the patient's attention to the physical manifestations of the disease throughout the course of the diagnostic testing, medical and nursing consultations, cancer treatments, and symptom management phases of their journey. Survivorship and palliation issues often surface for attention. For many people with cancer, there is a great deal of exposure to unfamiliar terminology, treatments, and the side effects of treatment that drastically alter their quality of life.

Newly diagnosed patients embark on a journey of uncertainty toward an unfamiliar destination. They encounter stress, anxiety and are eager to acquire hope and support (Corner, 1997; Drew, 2002; Sawyer, 2000). Women with breast cancer are no exception they seek to obtain support, information, advice, and direction to guide them along their cancer journey.

Purpose of the Project

This project critically examines research about the expressed information needs of women newly diagnosed with breast cancer. A cancer diagnosis and the subsequent treatment regimen often creates a threat to the daily activities for women. A perceived lack of information is a significant factor in determining women's ability to cope and move forward with their illness (Graydon, Galloway, Palmer-Wickham, Harrison, Rich-van derBij, West, Burlein-Hall & Evans-Boyden, 1997; Lindop & Cannon, 2001; Skalla, Bakitas, Furstenberg, Ahles & Henderson, 2004). Women have distinct information needs along their breast cancer journey and support in meeting these needs is pivotal to help them gain control over their lives (Fitch, Nicoll & Keller-Olaman, 2007; Rees & Bath, 2000; Galloway et al., 1997). Stacey, DeGrasse and Johnson (2001), suggest that "support is the provision of information, help, and emotional comfort to enhance coping and feelings of empowerment, make better health-related decisions, minimize distress, and promote health, and self care (p.78).

My purpose in doing this review. Last summer I did a research paper using Grounded Theory methodology to examine the influence of nurses in the delivery of information and emotional support to patients with cancer. This started my inquiry around the information needs of patients with cancer. The results from that work left me with a number of thoughts: patients seem to receive too much information when newly diagnosed, each nurse delivers that information differently, and there is no consistent standard that is followed when delivering information to the patient.

In the fall of last year I began a new role as a Clinical Nurse Specialist in our cancer centre focusing on women with breast cancer. I wanted to learn more about how the nurses were supporting women with regard to information so I did some shadowing and again it became clear that there was no consistent standard and women were often being overloaded with information. The resulting observations motivated me to learn more about the information needs of women newly diagnosed with breast cancer. I wanted to gain a better understanding of women's information needs and clarify what information they wanted related to their breast cancer diagnosis. I also wanted to seek clarity around the nurse's assessment of the patient's information needs and try to work together as a nursing team to bring about consensus and planning (practice guideline) in the delivery of information (recommendations from this literature review). I wanted to learn from the patient's perspective their

expressed concerns, frustrations, and fears related to their information needs.

Why the project is necessary. Women are often overwhelmed with the diagnosis of cancer and it may elicit a surge of emotion and feelings. The harried activity of events after a breast cancer diagnosis combined with the need to make complex decisions about treatment and life changes hinders the women's ability to deal with the plethora of information.

This project was needed to help gain an understanding of the current published studies that focus on the information needs of women newly diagnosed with breast cancer. It provides a critical review of current research and will aid nurses in planning care by providing a more thorough understanding of the challenges women face as the phenomenon of expressed information needs unfolds. Based on a review of the literature this project provides recommendations to help enhance the practice of nurses as they draw on existing theoretical and experiential knowledge.

Quality information can help women in terms of their physiological as well as psychological outcomes, enabling them to gain control over their lives and participate fully in their treatment (Drew, 2002; Fitch, 2005; Sawyer, 2000).

The knowledge gained from this literature review will be useful as the foundation upon which evidence based guidelines can be developed in my

worksite. These guidelines will focus on the patient's perspective of information transfer across the trajectory of their cancer experience.

Definitions and Context of Terms

The identification of some of the definitions of common terminology used throughout this literature review is required to bring clarity to the content. In the research studies for this project the following terms have been used and are defined. These include: information, needs, and information needs, stage of disease, newly diagnosed, community oncology centre, phases of breast cancer treatment, and coping.

Information and Information Needs

Information is defined in Webster's Dictionary as the "communication or reception of knowledge or intelligence, concerned or related to a particular fact or circumstance, it can come from study, facts or data" (retrieved January 29, 2008). A need is described as the patients expressed desire for information, or a lack of something requested (O'Leary, Estabrooks, Olson & Cumming, 2007; Webster's Dictionary, 2008). "When put together, information needs are understood as a natural occurrence spurred on by a major life event, assisting the individual to cope" (Timmins, 2006, p.377). Expressed information needs in the case of women with a breast cancer diagnosis vary depending on the women's perceptions of the information that they will need when faced with a diagnosis of breast cancer. Women's need for information can change over the trajectory of their illness and are linked to women's coping

strategies when they are faced with a health related illness (Cowan & Hoskins, 2007; Lazarus & Folkman, 1984; Lee, Frances, Walker & Lee, 2004; O'Leary et al., 2007).

The patient's perspective is a key issue when assessing information needs. Their perception of the information during the interview or interaction is relevant to the manner in which they understand and process the information they are given. In a study about information preferences of women receiving chemotherapy, Cowan and Hoskins (2007) suggest that there is evidence to show that an individual's personality dictates how they will perceive information. Personality in this context is in reference to monitors and blunterners, and their behavioural signature or attention process style (Rees & Bath, 2000). Individuals who are monitors actively seek information to help them through their treatment. The information they seek can be written as well as face to face support from a health care professional. Individuals who are blunterners like to distance themselves from the entire event, not needing any information or support (Folkman & Lazarus, 1986; Rees & Bath, 2000).

Women find information to be of benefit only when it corresponds to a need. (Cowan & Hoskins). A number of coping responses occur when a woman receives information related to an expressed need. The awareness and understanding they received from the information is assimilated in two ways: either women receive help from the information and it facilitates their coping allowing them to work through the

experience or they avoid the assimilation of information and present with greater anxiety less able to deal with the severe life stress (Cowan & Hoskins, 2007).

Stage of Disease

Another key concept related to information needs is the stage of their disease at diagnosis. The individuals' expression of a need for information during all aspects of care is paramount. In the literature I reviewed it states that information needs prior to the initiation of breast cancer treatment relate to concerns surrounding diagnosis and stage of disease (Galloway et al., 1997; Graydon et al., 1997; Harrison et al., 1999; Lee, Francis, Walker, & Lee, 2004). Women need to understand the stage of their disease and process the corresponding information to establish an accurate description of their cancer, subsequent treatment options, and related side effects (Graydon et al., 1997; Landmark, et al., 2002). Cancer may be perceived by the individual as a threat to their life and knowing the extent of the threat, (stage of disease) is often a priority for women with breast cancer (O'Leary et al., 2007). Women need information about staging in order to plan and respond to the changes and challenges that lie ahead of them (Lee et al., 2004).

Newly Diagnosed

The focus of this project is women newly diagnosed with breast cancer. For the purpose of this project, I am using the definition of newly diagnosed that is used at my work place. Newly diagnosed in our setting

denotes women who have a positive pathology and are candidates for treatment, (one to five months) which can include systemic therapy (chemotherapy or hormonal therapy), neo adjuvant surgery, radiation, or a combination of these.

Community Oncology Centre

The setting where care is delivered is an important consideration in the care of women with breast cancer. Women in early stages of breast cancer are generally cared for in ambulatory care settings, the setting of my practice. Our ambulatory care setting is part of a 400 bed community hospital integrated with the cancer centre on site, a regional centre that serves many diverse cultural and ethnic groups. This creates challenges in understanding and supporting the expressed information needs of these women. The challenges arise from the tension between knowing that each woman has her own unique information needs and responds to her diagnosis in a unique fashion which is guided by her cultural background, religion, customary beliefs, social norms, values, conventions, and social practices. (Graydon et al., 1997; Luker, Beaver, Leinster, Owens, Dregner & Sloan, 1995). The nurses' understanding and awareness of the impact of cultural influence on illness behaviour is essential when providing information to meet expressed needs (Lee et al., 2004).

Phases of Breast Cancer Treatment

Generally women present at our centre after their surgical treatment intervention has occurred. Consequently I have reviewed literature that reflects the adjuvant treatment phase for women with breast cancer.

Coping

Coping is defined as the individuals constant changing cognitive and behavioural efforts to manage the demands (external and internal) that are considered as tough or exceeding a person's resources (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986, p. 993).

Attention to all the aspects of care discussed is pivotal in coming to an understanding of the expressed informational needs of women newly diagnosed with breast cancer. The combined information needs of the individual, stage of the disease, culture, and ethnicity along with the phases of breast cancer treatment and coping within the context of the woman's experience will support a greater understanding of those needs by nurses. The knowledge gained by nurses will support the development of future work, and provide an impetus for such work to be completed (Gopal, Beaver, Barnett & Ismail, 2005; Lee et al., 2004).

Methodology

Literature Review

Definition. "A literature review is a critical summary of research on a topic of interest, often prepared to put a research problem in context" (Polit & Beck, 2004, p.722). This literature review will draw upon the

integrative review process outlined by Whittemore and Knafl (2005). The research is reviewed, critiqued, and synthesized on a specific topic in an integrative way so that new frameworks and perspectives are generated” (Torraco, 2005, p.356).

Description of method. The integrative review process that is described by Whittemore and Knafl (2005) is a framework by which a review of primary literature takes place using a five step process. The literature review is the foundation that ensures that changes in nursing practice are based on credible evidence (Whittemore & Knafl).

This reviewer utilized five steps. The first step identified and describes the problem. The second step involved an extensive search of both empirical and theoretical literature for identifying articles that describe the phenomenon of this project. Whittemore and Knafl (2005) suggest that the review is inclusive of step three which entailed an evaluation of the data and step four which involved a detailed analysis of the data. The final stage includes a presentation of the findings.

This framework required obtaining pertinent information about study characteristics, methodology, and findings. The format I used can be found in Appendix B and includes: (a) citation type and authors, (b) identified research problem, (c) methodology, (d) sample (design and data collection), (e) timing of data collection, (f) measures, (g) data analysis (outcome measures), and (h) results (limitations and strengths).

Whittemore and Knafl (2005) suggest using a 2-point scale (high or low) of coding results when critiquing reviews. This scale marking is directed to the literature that has strong rigour (high) or weak rigour (low). High coding also indicates that the research has a strong correlation between the problem/question and results. A weak or low score does not provide strong convincing evidence of the questions. They suggest that “scores are indicated as a variable in data analysis stage” (p. 549). They suggest that low scores often play a lesser portion to the analytical process development and course of action and should therefore not be totally dismissed (Appendix A).

Why this method of review is appropriate to the project goal. A literature review was chosen to support the learning needs of the author as a novice researcher. The use of the integrative review framework offers potential for identifying changes in the way we think (Torraco, 2005; Whittemore & Knafl, 2005). Drawing on Whittemore and Knafl’s methodological approach, a critique of the literature was conducted to capture the essence of what is new and changing for women related to expressed information needs. The findings of this review will contribute to a better understanding of information needs, accounting for experiences, and emotions of a woman’s journey through cancer treatment. These findings will hopefully bring about greater understanding of a mature topic that will enable nurses to learn more about the phenomena of informational needs expressed by women with breast

cancer. Whittmore and Knafl's approach to critically reviewing the literature is an appropriate framework for this project because it provides a strategy to assimilate findings and contribute to a comprehensive portrayal of women's informational needs.

Presentation of Literature

Scope of the Literature Review

The literature search was accomplished using various databases including CINAHL, ERIC, Ebsco host, and Academic Search Elite from 1985 through to 2007. The key search terms used included: information needs, breast cancer, newly diagnosed, ambulatory care settings, health promotion, and patient education. I reviewed the reference listing of each article to identify any other relevant work that should be examined. In addition, researchers whose articles were repeatedly cited in other works were retrieved.

Inclusion/Exclusion Criteria

The research studies included in this work are written in English, directly associated with the expressed information needs of women newly diagnosed with breast cancer, and include women with a positive pathology diagnosis ready for adjuvant treatment. Some retrieved articles were excluded from the literature review because: (a) the study participants were health care professionals, family members, or family caregivers rather than women with breast cancer, (b) studies that focused on interventions or dissemination of information, (c) the study participants

were patients with other types of cancer, (d) women with advanced or recurrent breast cancer; and (e) surgical treatment focused articles.

According to the evaluation of research, scoring of the research and the inclusion/exclusion criteria seven articles were found that were relevant to this topic of review. (Appendix B).

Findings

Introduction

The findings and analysis are discussed using the previously outlined Whittemore and Knafl framework (2005). A brief summary of the research studies and conceptual framework are presented below followed by further detail of the analysis process used in critiquing the research and the findings based on this critical review.

This population of women newly diagnosed with breast cancer often find themselves in a foreign learning environment where they have little or no time emotionally or psychologically to understand the diagnosis of a life-threatening illness before they are asked to decide upon their treatment option (Galloway et al., 1997).

A comparison of the evidence/findings and how it is presented in each article was conducted. Additionally the influences of the author's interpretation of the evidence and the extent to which the authors' interpretations are justified are presented.

Brief Summary of the Research

Several information need themes were identified by the women and relate to information regarding: the disease stage, the treatment options, the likelihood of cure, sexual attractiveness, investigative tests, management of side effects, and the potential and possibility of cancer spread. The women with a breast cancer diagnosis who have participated in these studies deal with these issues related to their disease and treatment.

Cowan and Hoskins (2007) in a cross sectional survey investigating the relationship between information seeking behaviour of women receiving chemotherapy for breast cancer and the satisfaction of the health information accessed found that women faced with a life threatening event cope by seeking out information (monitoring) or by distracting themselves (blunting) from it. These authors found that high information seeking behaviour influenced the type of information sources used by women to find out about chemotherapy however, it did not influence the level of satisfaction with the information sources used. Women were identified as either high or low monitors based on their particular method of coping when faced with a health threat. Information facilitates coping for women identified as 'high monitors' because it gives them increased certainty, helps them attach meaning to their experiences, and supports them in working through their experience. High monitors (women with high information seeking behaviours) have been noted to cope better and

have a reduction in their stress (Cowan & Hoskins). Low monitors (women with low information seeking behaviours) on the other hand are prone to be more anxious when presented with information. Cowan and Hoskins suggest that coping strategies employed when faced with a life threatening illness are inherently linked to the importance it holds for the woman diagnosed with breast cancer.

Galloway et al. (1997) used a descriptive study design to develop and test the Toronto Information Needs Questionnaire for Breast Cancer (TINQ-BC). This questionnaire was designed to identify the preferred information that women with a recent breast cancer diagnosis required to better deal with their illness. Galloway et al. determined that women are often not given the information they need by health care professionals. They found there is incongruence between the information that women want and the information that is given to them by health care professionals. Women were found to have high information needs and they felt that often the individualized nature of their needs was not given the attention they required. Women in this study felt that individualized information with respect to quantity (the amount of information they requested) and uniqueness (specific information to meet their identified need) would be beneficial to enhance their ability to cope and care for themselves.

In contrast to Cowan and Hoskins (2007), the study by Galloway et al. (1997) focused specifically on the expressed information needs of

women. Their findings identify a ranking of importance to information needs (position priority) which are prioritized according to the valued importance for the study participants. Women articulated that information about the aspects of their disease was first, information regarding their treatment was second, and information about their investigational tests (both procedure and results) was third. The findings of a woman's preference of information are congruent with the theoretical perspective of Lazarus and Folkman (1984) which states that people in threatening situations will seek information to understand what is happening to them.

Gopal, et al. (2005) used a survey design to examine the information needs of women newly diagnosed with breast cancer in Malaysia. The impetus for this study was to compare and evaluate the needs of Malaysian women with English women (Luker et al., 1995) to determine social and cultural differences and ascertain if the information needs were different for the two groups. They used the Information Needs Questionnaire (INQ) to conduct their study. The tools (INQ & TINQ-BC) appear similar in origin and content. The reliability and validity of these tools are discussed later in this paper. In contrast to findings from the other studies reviewed in this project, the Malaysian women identified information regarding the likelihood of cure as their first need, followed then with information related to sexual attractiveness as second, and finally possible/future disease spread. Another difference in the Gopal et al. study is the time frame that was used for the start of the study. Women

were not allowed to participate until a few months post diagnosis as the ethics committee felt that they were too vulnerable to contribute any sooner.

Graydon, et al. (1997) utilized the TINQ-BC questionnaire to evaluate the information needs of women during early treatment for breast cancer. In this study the methodology was not described and the women who participated were receiving a combination of treatments for their breast cancer including: surgery, chemotherapy and radiation therapy. Again women in this study gave a priority position to their information needs and these were congruent with the findings of Galloway et al. (1996). Of particular note, Graydon et al. found that the treatment modality did not change the women's need for information to help them deal with their illness.

Information needs of Chinese women with breast cancer receiving chemotherapy were the focus of the research conducted by Lee et al. (2004). This study included a descriptive survey using the TINQ-BC measure. Lee et al. also found that Chinese women gave a priority to their information needs however their needs differed slightly from the findings in the other studies included in this review. Lee et al. found the information needs for Chinese women surveyed with breast cancer were prioritized to: disease, treatment, cancer spread, and the management of side effects. The women were also asked to fill out the questionnaire at two different intervals (chemotherapy treatment week one and after week

three). The rationale for these data collection points was that the two different times gave the authors an opportunity to discern if information needs and priority position of these needs changed along the trajectory of treatment. The authors found the information needs to be consistent at the beginning and halfway through the chemotherapy treatment.

Through the use of a longitudinal follow up study, Luker et al. (2007) endeavoured to explore the particular types of information that were important to women newly diagnosed with breast cancer. The women in the treatment group of this study were waiting for surgical intervention and they were compared to a control group of women who had benign breast disease. The priority information needs of the newly diagnosed women (treatment group) in the Luker et al. study were identified as: information regarding the likelihood of cure, spread of disease, and treatment. The women in the control group identified their priority needs to be: disease cure, disease stage, and treatment. The results of these two groups varied in the priority position that was reported. These priority positions are in contrast to the Gopal et al. (2005) study (as reported earlier in this review).

Finally Harrison, Galloway, Graydon, Palmer-Wickham, and Rich-van der Bij, (1999) conducted a prospective longitudinal study to examine the information needs and preferences for information of women with breast cancer during the first course of radiation therapy. The time of data collection of this study varied greatly from all the other studies in this

review. Women were randomized to one of four groups. During the course of radiation treatment women in group one filled out the TINQ-BC four times; beginning, middle, end, and one month following treatment. The women in the other three groups filled out the TINQ-BC only once (group 2 in middle of their treatment, group 3 at the end of their treatment and group 4 one month post treatment). This detailed evaluation process was used to identify any changes in information needs of women during the course of their radiation treatment. Although this study covered a longer time frame of assessment of the women's information needs, the conclusions are congruent with the other studies in this review. The women identified they had high information needs when receiving radiation therapy, and gave a priority preference to their needs.

In summary, the authors of all seven studies provide support and evidence that women require information to help them cope with breast cancer during their treatment phase. The evidence identifies common as well as unique aspects that alter the information needs of women. The authors also examined different stages of the cancer treatment trajectory which provides strong evidence that a women's information needs do not change based on their treatment option or the time frame in which their treatment is delivered.

Of particular significance in these studies, is the support for the theoretical framework of coping, illness behaviour, and outcomes.

Lazarus and Folkman (1984) provide the theoretical framework for the research studies reviewed in this project.

Conceptual Framework

The theoretical framework of Lazarus and Folkman (1984) provided guidance for five of the studies in this review (Cowan & Hoskins, 2007; Galloway, et al., 1997; Graydon, et al., 1997; Harrison et al., 1999 & Lee et al., 2004). The use of Lazarus and Folkman's theoretical framework of stress and coping in research helps to augment the understanding of the process of integration related to health and illness (Whittemore & Knafl, 2005). A perceived stress alters the relationship between an individual and their environment. The individual's appraisal of that stress event is deemed relevant to her well being and consequently resources are implemented to deal with the stress.

Illness can be a source of stress because of the demands on an individual. If their demand is perceived as threatening, unpleasant, or overwhelming it becomes a stressor that requires mobilization of resources to adapt and cope with it (Baldacchino & Draper, 2001). Lazarus and Folkman (1984) explain that an individual first appraises the stressor by identifying its meaning to determine the degree of threat or challenge. Following this interpretation, the individual determines whether their coping resources and options available are sufficient to manage the situation. The individual evaluates whether an encounter with the environment is relevant to her well being, and if so in what way. The

person evaluates whether she has anything at stake in the encounter, as well as the potential harm or benefit related to their goals, values, or commitments. The individual evaluates a variety of coping options which can include: altering the situation, seeking information, or holding back from acting impulsively. Uncertainty in illness is an experience that may affect individual adaptation after a breast cancer diagnosis.

(Wonghongkul, Dechaprom, Phumivichuvate & Losawatkul, 2006). This uncertainty may alter the individual's ability to provide meaning or value to a situation. Coping is a continuous process using both physical and psychological strategies to deal with excessive external or internal demands that exceed the individual's resources (Graydon et al., 1997).

Lazarus and Folkman's Stress and Coping theory recognizes the perception of uncertainty that illness presents to an individual when they are faced with a life threatening illness. Their use of different coping strategies affects adaptation outcome. Adaptation outcome is defined "as the adjustment of somatic health, morale or life satisfaction, and the ability to function at the work place and social living" (Wonghongkul, et al., 2006, p.251). This framework provided the foundation for the development of the TING-BC. Patients with cancer perceive uncertainty in illness due to their surrounding situation, delays in treatment, information around disease, and uncertainty about their future (Galloway, et al., 1997; Wonghongkul et al., 2006).

The use of a theoretical framework can provide a better understanding of what it is like to live with cancer and how information helps the woman with breast cancer move toward well being. Based on the stress and coping theory we can begin to evaluate the data to assess the relationship of women's expressed information needs and the benefit of information in supporting strategies of coping with a life threatening illness (Galloway et al., 1997; Lazarus & Folkman, 1986).

Data Evaluation

Appraising the quality of the research studies in this literature review method and critique process can be complex and varies depending upon the research designs. A framework for the evaluation phase includes analysing details about the sample characteristics and data collection methods. The examination of data using consistent criteria developed before the evaluation process was important to guide me in the evaluation and subsequently the analysis phase of this review.

Whittemore and Knafl (2005) suggest a coding process when critiquing reviews. The coding process used for this project is described in Appendix A. I developed the criteria for the critique process based on Polit and Beck's (2004) four decision points which are: design-problem, setting and participants, data collection, and data analysis. In addition ethical and nursing considerations were added to guide my critique (Polit & Beck). Each article was reviewed and evaluated according to this criteria and a score was assigned.

The research included in this review consists of empirical reports. Although the research designs are different, the findings are consistent. The common themes identified in the findings of these seven studies suggest that the expressed information needs of women newly diagnosed with breast cancer are extremely important. The most frequently requested information is in relation to: (a) likelihood of cure, (b) spread of disease, (c) treatment options, (d) investigative tests, (e) sexual attractiveness, (f) side effects, and (g) management of the side effects. The ranking of importance (position priority) for their needs varies and are discussed in more detail later in this paper.

By using established and consistent criteria for this critique the data evaluation component of this review brought to light the similarities and differences of the research studies. Data evaluation was used to provide a foundation to further critique the studies through ongoing analysis to determine the value, and significance of the findings through careful appraisal and study (Whittemore & Knafl, 2005).

Data Reduction – Samples

Whittemore and Knafl (2005) suggest that data reduction is a strategy to extract, simplify, summarize, concentrate, and categorize the data into a manageable framework. Sample sizes in the seven studies reviewed range from 34 to 150 subjects, with a total 556 participants within study groups and 290 subjects in control groups. The numbers also represent women in various modalities of treatment; 129 participants were

in chemotherapy, 35 participants were in radiation, and 150 participants had surgery only.

The women's ages ranged from 21-91 with a mean age of 52.4 years. Their mean age is based on six of the studies. The income status of women in two studies (Graydon et al., 1997; Harrison et al., 1999) was reported as lower or middle income. In two studies (Gopal et al., 2005; Cowan & Hoskins, 2007) a report of income status is described as social class variable (Figure 1). Luker et al., 1995 describe social class as affluent (1-2), middle (3-4), and deprived. (5-6), but does not give any further definition as to the meaning of these numbers. Galloway et al. (1997) and Harrison et al.(1999) did not report information regarding socioeconomic status. Socio-cultural orientation of the women included: White European, British, and English speaking. One study (Lee et al., 2004) worked with a population of Chinese women and another study (Gopal et al., 2005) with Malaysian, Chinese, and Indian women with breast cancer. Education levels of the women were reported in all seven studies.

Social class	Gopal et al.	Luker et al.
I	Professional 29%	
II	Administrative and management 17%	Managerial and technical 25%
III	Clerical and related 19%	Skilled 49.3%
IV	Sales & service workers 26%	Partly skilled 9.7%
V	Agriculture & fisherman 1%	Unskilled 9.7%
VI	Factory workers/labourers 8%	NA

Figure 1. Social class variables

In summary, about half of the studies in this review included women of Caucasian population with a grade 12 education in a lower to middle income bracket. In the economic class system references, most women were of class 1-4 which represents affluent and middle class (Cowan & Hoskins, 2007; Gopal et al., 2005; Lee et al., 2004; & Luker et al., 1995) (Appendix B). The population of women identified in these research studies are demographically similar to those found in my community. Given the similar population demographics it may be feasible to discern that these findings can be relevant to the women in the Waterloo/ Wellington region (my area of practice). Therefore the findings that have been identified may have significant bearing to the proposed question as well as to the population of women served in my community who have a diagnosis of breast cancer.

The studies included different methods of sampling, including: consecutive, convenience, and purposive. This was to ensure representation of women with recent breast cancer diagnosis in the various treatment phases of their disease. The time between diagnosis and data collection varied substantially among the studies. Some women participated in the studies as long as three months after the beginning of their treatment, making data vulnerable to recall bias. Nevertheless, the reported information needs of the women remained consistent across the treatment trajectory of the disease process regardless of the time of their assessment.

The research included in this paper describes the population of women to be in one of the following phases: newly diagnosed, early treatment, or recently diagnosed with breast cancer. As there was no clearly defined terminology for these descriptors in these studies, the assumption is that they are referring to the same or similar time frame of treatment.

Galloway et al. (1997) suggests that women with breast cancer should be supported to select the amount of information they desire and the time they wish to have particular information. Information needs are high in any treatment modality (Graydon et al., 1997; Lee et al., 2004; Luker et al., 1995; Gopal et al., 2005). Since information can be a key in helping women cope with their illness, information should be available as early as possible in their illness trajectory. This may mean even before a positive pathology is confirmed. Women of all ethnic origin require timely, relevant information (Lee et al., 2004; Gopal et al., 2005).

When this project was proposed there was some discussion around the definition of what constitutes newly diagnosed. Given my clinical experience in a community cancer centre I felt the definition of newly diagnosed should reflect a positive pathology. The authors findings thus far would suggest that the need for information is broader and includes all aspects of treatment for a breast cancer diagnosis and not just once a positive pathology is received.

In my review of the ethics approval process, six of the study authors mentioned ethics approval. However, few of the authors provided a description of the project, the consent process, or the ability of women to withdraw from the study.

Research Instruments

When critiquing research it is important to understand the data measurement used in order to make comparisons. If the data measurement is not included the information presented is weak and makes conclusions guarded and questionable (Whittemore & Knafl, 2005). Data measurement is achieved in quantitative research through the use of instruments individually or combined such as: questionnaires, tests, or observations to address a research problem or question (Polit & Beck, 2004). Measurement is a language of communication concerning accuracy and makes it possible to obtain reasonably precise information. In addition, measurements and tools help researchers quantify data objectively minimizing subjectivity and guess work (Polit & Beck).

Of the empirical studies cited, all seven authors used quantitative methods to assess patients' information needs. Two authors used the INQ developed by Degner et al. (1998) to elicit women's perception of information needs related to the experience of breast cancer while receiving adjuvant treatment (Gopal et al., 2005; Luker et al., 1995). The INQ-BC developed by Harrison-Woermke and Graydon (1997) was adapted and revised by Galloway et al. (1997) and became known as the

TINQ-BC and was used in further studies. Four of the studies (Galloway et al., 1997; Graydon et al., 1997; Lee et al., 2004; Harrison, et al., 1999) in this review used the TINQ-BC instrument thereby increasing the construct validity of the instrument. “Construct validity is inextricably linked with theoretical factors, and always involves logical analysis and tests predicted by theoretic consideration” (Polit & Beck, 2004, p.425). Does the scale adequately capture the construct of interest (Galloway et al., 1997)? The strength of the data and findings is stronger if reliability and validity are evident. (The reliability and validity issues are discussed later under data comparison of measures).

In summary, tools and instruments help to assess specific information related to needs of specific populations. The INQ and TINQ-BC are both tools that assess the informational needs of the breast cancer population. The data collected using these instruments provides the specifics on the expressed information needs of women. This data was used for analysis and to verify the women’s responses.

Data Analysis

“Data analysis is the systematic organization and synthesis of research data and the testing of research hypothesis using those data” (Polit & Beck, 2004, p.716). Data analysis of quantitative methodologies can include reporting frequencies/rankings and the use of various statistical tools to determine if differences in rankings according to a specific variable (age, education, marital status, ethnicity etc.) are

statistically significant (Whittemore & Knafl, 2005) (Appendix B).

Galloway et al. (1997) reported on the development and testing of the questionnaire tool (TINQ-BC) used with women newly diagnosed with breast cancer. Women in the study had high information needs regardless of the treatment regimen. There was variability thereby showing that the tool was sensitive to the individual needs of women during their illness experience (Galloway et al., 1997; Polit & Beck, 2004). In three other studies (Graydon et al., 1997; Lee et al., 2004; Harrison et al., 1999) the TINQ-BC was also used and the results were congruent with Galloway et al. (1997). However, the priority order women placed on their needs were different among the studies results (Appendix C).

In contrast there was no description of the tool used in the Luker et al. (1995) study. However, there is a description of the questions asked of the women and these questions appear to be similar to the INQ tool. Luker et al. conducted a study in which women with a benign breast disease (control group) were compared with women who were awaiting surgery for a breast cancer (treatment group). Women in both groups identified that when facing alterations in their health they have information needs related to their benign breast disease or their breast cancer diagnosis. This data gives us a broader perspective of identification of the information needs of women whether their biopsy for breast cancer is benign or malignant.

The Malaysian study by Gopal et al. (2005) was conducted after the Luker et al. study. Its goal was to look specifically at the needs of Malaysian women (which included Malaysian, Indian and Chinese women) and to compare their information needs to those of the women in the Luker et al. (1995) study. The study findings were quite similar apart from the high emphasis the Malaysian women placed on sexual attractiveness.

The INQ was developed by Degner et al. (1998) to identify the perceived information needs of women with breast cancer. An extensive literature review of over 200 articles was conducted to identify the most important information needs of patients with cancer. Ten patients along with ten oncology nurses reviewed the information categories to assess the content validity prior to the use of the tool (Degner et al., 1998). Changes were made based on their responses. The nine categories included: (a) stage of disease, (b) likelihood of cure, (c) effects of treatment on social activity, (d) effect of disease on family and close friends, (e) self-care needs, (f) effect of treatment on usual sexual activity, (g) types of treatment available (advantages and disadvantages), (h) risk of a family member developing the disease, and (i) side effects of treatment (Degner et al., 1998, p. 140).

The 9 items were seen with every other item making 36 pairs. “These pairs were arranged according to the Ross matrix of optimal ordering” that determined the precise order the 36 pairs were arranged for

women to make their choice (Degner et al., 1997, p.1487). “This procedure gave the greatest extent of spacing for the maximum number of items to avoid selection bias” (Degner et al., 1998, p. 140). Women made a choice from these pairs identifying the information needs they wanted addressed first (preference) (Degner et al., 1998).

In Thurstone’s scaling each item produces a single number that reflects the degree of preference that a group of people have for an item, it is ranked in terms of the attribute. In Luker et al. this attribute was the woman’s perceived importance. In this questionnaire (INQ) women put a ranking order or preference of the information need. This ranking has been previously discussed in this review.

The original INQ-BC was developed in 1989 specifically for research with breast cancer patients. The 5-point Likert type questionnaires were developed to elicit women’s perception of informational needs related to their experience of having breast cancer. The INQ-BC was designed with 73 items plus nine subscales. These items were based on literature in nursing, medical and psychology journals as well as the eleven member research group that frequently asked patients about their experiences. The research team was comprised of experts in the oncology field. This speaks to content validity.

The TINQ-BC was developed from this tool by Galloway et al. (1997). Before they began their research a pilot study was conducted with 33 participants to determine the validity of the tool. Once validated, the

tool was used in a study with 114 women at the completion of their treatment. This was carried out to determine if there were any differences in their expressed information need at a different point in the trajectory of their illness. The TINQ-BC included five subscales in the area of: disease, investigative tests, treatments, physical, and psychosocial domains. Each subscale measured a relatively unique and specific component of the topic or constructs of interest (Galloway et al., 1997). The TINQ-BC measures information needs about the breast cancer experience. Each item begins with the stem 'to help me with my illness, it is important for me to know'. The questionnaire has a five point Likert type scale with a value of 1 being 'not important' to 5 being 'extremely important'. Women indicated whether or not they felt the information needs were important to them.

After the study was completed Galloway asked 70 women who had scored 1-5 on each of the 51 items to participate further to determine normative scores (assess the applicability of the tool items to women with breast cancer). "If interim correlation was below 0.20 it was deleted as it may not represent the phenomena of interest" (Galloway et al., 1997, p.1180). "If 2 items had inter item correlations of 0.80 or higher one item was deleted and the researchers would ask does the tool measure the same information need and if we keep that item would it elevate the score unduly" (Galloway et al., 1997, p. 1180). As a result of this further examination 22 items were dropped from the tool, leaving 51 items

(questions) in the five different subscales of the TINQ-BC tool (Galloway et al., 1997).

The authors of these studies identified that women had high information needs throughout the course of their treatments and answered the question posed for this project. Women have clearly expressed their information needs and given specific clarity and ranking to what their needs are (Galloway et al., 1997; Gopal et al., 2005; Graydon et al., 1997; Harrison et al., 1999; Lee et al., 2004; Luker et al., 1995).

Data Comparison of Measures

The next step in the integrative review framework is a repetitive process of data comparison of measures to provide clarity to theoretical and empirical support emerging (Whittemore & Knafl, 2005). This comparison and interpretation of data measures solicits important and accurate patterns as well as verification of the findings.

A tool is reliable if it consistently measures what it is supposed to measure and similar results are achieved in different settings at different times (Polit & Beck, 2004). This value shows a positive relationship among the phenomena (Polit & Beck). The most widely used and common form of internal consistency is Cronbach's alpha with a normal range between .00 and 1.00. Higher values reflect higher internal consistency. Cronbach's Alpha estimates the extent to which the subparts of the instrument are equivalent in measuring critical attributes. The TINQ-BC had a Cronbach's alpha of 0.96 for the tool developed by

Galloway et al. and a range of 0.81 - 0.93 for the subscales. The correlations of subparts of instrument are equivalent in measuring critical attributes. In Graydon et al. the Cronbach's alpha for the subscales was 0.85-0.90 and for the Harrison et al. the subscales measured 0.78-0.83. In the Chinese study by Lee et al. the subscales were identified as 0.71-0.92. (Galloway et al., 1997; Graydon et al., 1999; Harrison et al., 1999; & Lee et al., 2004).

In the TINQ-BC questionnaire information needs were rated high scoring over 200 in a possible range of 51-255. The scores in the questionnaire can total 255, as each subscale has a number of questions which all have a value placed on them when checked off by the woman completing the tool. Content validity is based on findings in the literature as well as the opinion of expert nurses. Having a panel of substantive experts that evaluate and document content validity is very important. (Polit & Beck, 2004, p. 423).

Kendall's coefficient is another way to measure the level of consistency and the degree of correspondence between two rankings and test the significance of said correspondence. The normal range is -1.00 to +1.00 and when all items measured are totally consistent and there is no error it measures 1.0. Two studies that utilized the INQ questionnaire had results of 0.76 for priority informational needs (Gopal et al) and 0.979 for (Luker et al) showing consistency between both the newly diagnosed

treatment group and the benign group (Gopal et al., 2005; & Luker et al., 1995).

Construct validity is inextricably linked with theoretical factors. The concepts put forward in each of the studies focused on the information needs of women with breast cancer. The determinants of information needs were achieved through the INQ and the TINQ-BC questionnaires. Through the questionnaire, women validated that they did have information needs which required attention (Appendix B).

Coping for the women studied was/is congruent with Lazarus and Folkman's (1984) stress and coping theory in that they wanted information to help them deal with the new stressor in their lives—specifically a breast cancer diagnosis. The information provides assistance to them in establishing meaning, understanding their disease process, and the trajectory of their cancer illness (Galloway et al., 1997; Graydon et al., 1997; Harrison et al., 1999; Lee et al., 2004). (Appendix B).

In this literature review a scoring system was used to rank the studies on a scale of 0-16 (Appendix A). The studies with the three highest scores were Galloway et al. 1997; Gopal et al. 2005; Harrison et al. 1999. All three of these authors used a questionnaire with reported reliability and validity to determine the information needs of women with a breast cancer diagnosis.

Ranking of Information Needs (priority position)

This review focused on the expressed needs of women newly diagnosed with breast cancer. Although identifying the priority position of information needs was not a part of the expressed needs question for this project, women in these studies have prioritized their needs in order of importance (Appendix C).

In three of the seven studies women identified their information needs in a priority position to be: disease stage, treatment options, and investigational tests. This priority position is one that is given to the information needs by the women and the order that the information is given is reported to assist them in understanding and coping with their breast cancer and treatment that follows.

A common finding across the studies was that women placed a high importance on information that is tailored to meet their specific need. This information assists them in managing their illness. “This high importance of information may be a reflection of a high degree of perceived threat, actual gaps in knowledge, or a lack of comprehension of the information provided” (Graydon et al., 1997, p.63). This is significant to consider when looking at practice implications. Women need a plan of care that is holistic in nature yet tailored to their identified needs. This requires a collaborative care plan which involves information and support across the breast cancer treatment trajectory as identified by the woman’s need(s).

The top ranking trio of information needs were identified as: (a) disease, (b) treatment, and (c) investigational tests.

Disease. Information about the disease process, disease spread, and prognosis was identified by women in six of the seven studies (Appendix B). Although the priority position order of information needs among the women in the studies varies, it is evident that information regarding the disease process provides women with the information needed to make informed decisions regarding their treatments (Appendix C). The impact of cancer on an individual is a constant reminder of what has changed and can create an anxiety that looms over one's future. Women desire to know about the various aspects of the disease and what to expect along the trajectory of their illness (Galloway et al., 1997). Women in the various studies state they want accurate, relevant information and when it relates to the disease process this entails factual data about prognosis, disease stage, potential cure with treatment, treatment options, and expected outcome. This information was paramount for all women regardless of the treatment modality to help them deal with their illness (Galloway et al., 1997; Graydon et al., 1997; Gopal et al., 2005; Lee et al., 2004). The information was thought to help enhance their quality of life and equip them to make better choices and decisions. Graydon et al. also hypothesize that disease information may assist women to maintain hope.

The Chinese study by Lee et al. (2004) was consistent with the Canadian studies reviewed (Galloway et al., 1997; Graydon et al., 1997; Harrison et al., 1999). The focus of information for women was on disease, chances for effective treatment, and knowledge of disease activity. Fear of recurrence although discussed with disease information is a source of anxiety for women with breast cancer. Their anxiety is focused on the recurrence of disease and how women will know if the disease has returned.

Treatment. Information regarding treatment was positioned as a second priority in four studies (Galloway et al., 1997; Graydon et al., 1997; Harrison et al., 1999 & Lee et al., 2004) and third in priority in one study (Luker et al., 1995) (Appendix C). Since treatment information is necessary to help women cope with and understand what is ahead, the participants gave it a high priority. In all of the studies but one (Gopal) women scored high on treatment information (Appendix B). This is important regardless of their type of treatment regimen (Galloway et al., 1997; Graydon et al., 1997; Harrison et al., 1999; Lee et al., 2004; Luker et al., 1995). The authors of these studies compared information needs at various points along the illness trajectory of treatment and found that apart from the initial phase of treatment, an ongoing need for information did not diminish during the treatment phase of their breast cancer illness (Gopul et al., 2005; Harrison et al.; Lee et al., 2004).

According to Galloway et al. (1997), the ongoing need for information could be related to: (a) gaps in delivery of care, (b) lack of communication, (c) decreased amount of time spent at treatment facility, (d) decreased contact with health care professionals, (e) lack of attention to individual preferences for information, and (f) the degree of side effects. Therefore, information should continue to be provided to women throughout the treatment phase. Treatment information changes with respect to content, but does not change in relation to the amount or intensity of information that is required. (Gopal et al., 2005; Harrison et al.,; Lee et al., 2004). Changes to a woman's body are variables during treatment and with these new experiences comes the need for information in order to cope with the alterations and maintenance of the individual's well being. The coping ability of women continues to be re-evaluated as new situations arise and the need for more information is required (Folkman et al., 1986). The lives of breast cancer patients are in constant flux and information seems to be one positive way they can cope with and handle changes that occur. Small amounts of information at regular intervals seem to work well (Lee et al., 2004).

Investigative tests. The tests were positioned as third in priority of information needs. These tests were reported as a constant source of challenge and frustration for women with breast cancer. Women noted in all the studies that the tests create many questions and women desire information regarding the rationale for the test, the process, and expected

sensations associated with each test, or procedure used to diagnose and monitor their disease and treatment (Galloway et al., 1997 & Gopal et al., 2005). They frequently ask questions about their blood work as it often signifies how their body is adapting to treatment

In addition to the priorities of disease, treatment, and investigative tests, the cultural components of women in two of the studies are of particular importance in this review. One study was conducted with a Chinese population and one was conducted with a Malaysian population. Although the need for information is very important, culture plays a vital role in beliefs pertaining to health and illness (Gopal et al., 2005). Culture holds strong ties to myths and fears, religious beliefs, and marginalization of women. Gopal et al. found that Malaysian women first seek alternative therapy of traditional healers, herbal medicine treatment, and prayer before seeking medical help. Their greatest fear was losing a breast and becoming sexually unattractive to their husbands. These women found themselves in a challenging situation. According to Gopal et al. Malaysian men can have more than one wife and women with breast cancer fear rejection and loss of their partners. This gives strong credence to the higher scores on their questionnaires regarding sexual attractiveness.

These information needs are congruent with Lazarus and Folkman's (1984) theory that individuals with a life threatening situation need and will seek information in order to understand what is ahead and

how it affects their well-being. Individuals when faced with stressful situations like illness attempt to find meaning out of what is happening in their own unique way. Each individual appraises the threat differently which in turn leads them to choose different coping strategies and they react with a different emotional pattern (Folkman et al., 1986; Galloway et al., 1997; Graydon et al., 1997; Harrison et al., 1999; Lee et al., 2004; Gopul et al., 2005; Mills & Sullivan, 1999; Wonghongkul et al., 2006).

Discussion

This literature review focused on several areas of the literature in which information was identified as an important need for women newly diagnosed with breast cancer. The studies analyzed in this review covered a defined time frame of their treatment phase (newly diagnosed, one to five months) and did not engage in the collection of data in other phases along the illness trajectory (eg. follow up, survivorship or advanced disease).

Recommendations

I examined the studies in this literature review and was stimulated to identify some recommendations to enhance future information sharing with women newly diagnosed with breast cancer. These recommendations are for health professionals or nurses to:

- Continually assess the priority information needs of patients
- Accurately evaluate what is relevant to the individual's situation/need

- Understand and be aware of the impact of cultural pressure on illness behaviour
- Individualize the approach to information needs of women
- Make information clear, accurate and relevant
- Be cognisant that information is important to women with breast cancer and helps them manage their illness

These recommendations support the need for a concise assessment of breast cancer patients information needs. This information the patient and the family holds, a formal knowledge of health, personal knowing, and social situation impact the diagnosis of breast cancer on their health and well being. The nurse brings critical thinking, experiential, and theoretical knowledge and together they build outcome appraisal goals with mutually derived plans of action that can help women feel supported. This goal setting can enhance their ability to make an accurate evaluation of their illness and treatment phase, obtaining the unique information that they need to cope with their breast cancer diagnosis.

Conclusion

The studies examined provide me with the findings that answer the project question about the timeliness and content of information needs of women newly diagnosed with breast cancer. The findings from these studies provide nurses and health care professionals with consistent results and highlight the importance of knowing how information helps women cope in these stressful situations. Although the priority importance of the

particular items may vary, information needs for women are common and span Western and Eastern societies (Gopal et al., 2005).

Implications for Nursing Practice

Lazarus and Folkman (1984) suggest that information helps individuals appraise and cope in new and stressful situations. Information helps to identify what is happening and gives order and clarity to the new experience and in turn helps individuals manage or gain some control over a threatening situation.

Women in this review have not only identified their needs for information but have ranked their needs in order of preference or importance

As nurses we receive clarity and new understanding from this review to help us improve our care and practice to better meet the information needs of women newly diagnosed with breast cancer. Nurses can and do play a pivotal role in this adaptation process by seeking to identify the priority information needs of women. Women are better able to adapt to changes in their life when they are provided with the right information and support.

The assessment and dissemination of information through an evidence based guideline could be a useful tool to give nurses guidance, support, and an enhanced understanding of the structure needed to ensure that the information needs and concerns of women are met. Dialogue with women should continue along multiple points of the treatment trajectory

and be tailored to the women's individual needs at any given point (Fitch, Nicoll & Keller-Olaman, 2007).

Limitations

All studies reviewed in this project used quantitative research designs. There were no qualitative studies found during initial searches although recent studies are using qualitative designs. This is a limitation to the kinds of knowledge generated and the scope of understanding for nursing practice. Nevertheless, findings consistently suggest that that women need concrete answers and information to deal with the many physical components of care they are faced with (i.e. diagnosis, consultations both medical and nursing, disease stage, treatment, and symptom management) (Cowan & Hoskins, 2007; Galloway et al., 1997; Gopal et al., 2005; Graydon et al., 1997; Harrison et al., 1999; Lee et al., 2004; Luker et al., 1995).

In review of Maslow's hierarchy of needs we are reminded that deficiency needs must be met first and the hierarchy moves from physical needs up to psychosocial needs. Once an individual's growth needs are met only then can women look for support and information to meet their psychological or spiritual needs.

The authors of the research reviewed all identified that women's information needs change over time but do not diminish. The exact nature of information that is needed changes along the trajectory of the illness (Fitch et al., 2007).

Landmark, Bohler, Loberg, and Wall, (2008) suggest “that women as a consequence of diagnosis and treatment have a need for knowledge and a need for psychosocial support” (p.195). The changes women experience are described as bodily changes, losses, and emotional reactions all requiring coping, a constant changing cognitive and behaviour effort to manage demands imposed by their breast cancer.

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Appendix A

Evaluating Research through integrative review – critical review Quantitative literature
 An integrative review provides a succinct, current, thorough synthesis of the research evidence about a clinical problem. To augment the definitions provided by Whitemore & Knafel (2005) high and low scale I will draw on Polit & Beck's (2004) criteria for evaluating research. Polit and Beck use 4 major decisions points which are: design-problem; setting and participants; data collection; and data analysis. In addition, I have added Ethical and nursing considerations to guide my critique of the literature.

Scoring process= one point for each question answered in review.

Decision	Explanation of critique	Score
Design - problem	<ol style="list-style-type: none"> 1. Has the research problem been clearly identified? 2. Does it have significance to the expressed information needs of women newly diagnosed with breast cancer? (my question) 3. Was study design described? 	3
Setting and participants	<ol style="list-style-type: none"> 1. How was sample determined? 2. How were they recruited into the sample? 3. Are the size and key characteristics of sample described? 	3
Data Collection	<ol style="list-style-type: none"> 1. How was data collected? 2. Who collected the data? 3. Where and under what circumstances were data collected? (this will include looking at how the data collections were carried out, by whom, and their role and relationship with the study participants). 4. Who paid for the study? 	4
Data analysis	<ol style="list-style-type: none"> 1. Is there congruence between the research variables as discussed in the introduction and as described in the methods section? 2. Does the report offer evidence of the reliability of measures? (from the research itself or based on other studies)? 3. Were statistical results detailed? (test value, p-value)? 	3
Ethical considerations	<ol style="list-style-type: none"> 1. Did the study discuss ethics approval? 	1
Relevance to nursing	<ol style="list-style-type: none"> 1. Does the researcher offer implications of the research for nursing practice, nursing theory or nursing research? 2. Are specific recommendations made concerning how the study could be improved or for further research investigations? 	2
Total score		16

Polit & Beck (2004) Total scoring will be High= 12-16 Medium= 6-11 Low= 1-5

Adapted from Polit, D.F. & Beck, C.T. (2004). *Nursing Research: Principles and Methods* (7th ed.).

Appendix B

Table of Evidence

Citation and authors	Research Problem identified	Methodology Sample, Design & data collection	Timing of data collection	Measure	Data analysis	Results	Score
<p>Cowan, C & Hoskins, R. (2007). Information preferences of women receiving chemotherapy for breast cancer. <i>European Journal of Cancer Care</i>, 16, 543-550.</p>	<p>Identify the possible relationship between information-seeking behaviour of patients receiving chemotherapy for breast cancer with source, type, amount and satisfaction of health information accessed.</p>	<p>Cross sectional survey, descriptive analysis, n= 88 women identified and recruited through consecutive attendance. 2 patients were not approached to fill out questionnaire as they had just received bad news. Of the 86 patients invited to participate 36 returned the questionnaire (response rate of 36%). Not all the women were newly diagnosed. Theoretical framework Miller Monitor process Model. The Miller Behavioural Style Scale (MBSS) was</p>	<p>Women had to have at least one cycle of chemotherapy. No details given when they returned surveys.</p>	<p>Anonymous self report questionnaire completed and returned by the participant during a visit. (Not sure which visit it was returned after) Patients could have severe side effects and not return questionnaire.</p> <p>Patient's questionnaire could have been done by family member. Patients could have felt some pressure to respond? **</p>	<p>Ethics approval was sought and granted by the local Research Ethics committee. No information about consent, confidentiality or ability of women to withdraw at any time. Section 1-included sources of information with a series of questions asked relating to where women sought out information. Section 2=modified MBSS tool (Miller Behavioural Style Scale) measures attitudes toward information Section 3= demographic details. Descriptive statistics were used to discover frequencies of behavioural characteristics (significance between variables) Data was analysed further using inferential statistics to discover significant relationships to variables.</p>	<p><u>Limitations</u> Unknowns of this study include: The time the questionnaire was completed; time frame from diagnosis; and the symptom effects on the women. This date of the questionnaire completion could alter the data results as the needs of information may change over the course of treatment. As well symptom effects may decrease ability to respond effectively and /or correctly. **Participation bias=bias influence findings as patient often do not want to</p>	<p>5</p>

		<p>used in this study and served as the premise of the work, looking at the monitors/blunters. The scale differentiates through a series of questions those who actively seek threat relevant information and those who distract</p> <p>This scale then identifies women who are monitors-those who are information seekers and those who are blunters-those who avoid information.</p> <p>There was also brief mention of Lazarus (1973) theory of stress and coping a Theoretical framework based on theory/premise that people want information about what is</p>		<p>This MBSS measured:</p> <ul style="list-style-type: none"> • 56% of women were high information seeking • 44% of women were low information seeking <p>This behaviour is linked to coping strategies when women are faced with a health threat they will behave and or react to that stress in a distinct manner.</p>	<p>criticize health care professionals and patient not able to comment more specifically on role of the providers in way of support. Single site sampling, cannot generalize findings to another site.</p> <p><u>Strengths</u> There is a stronger focus on the type of information and satisfaction with information provider than on the determination of what the expressed needs of women are. The preference for information is inherently linked to coping strategies and information is relevant when linked to coping strategies. There could be some relationship between the information seeking</p>
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Expressed Information needs
52

		<p>happening in order to clarify elements in a new experience. A way to manage emotions in a threatening situation.</p>			<p>behaviour and wanting information. <u>Results</u> Focus of coping strategy provides some interesting information regarding motivation to express needs. This study helps with an understanding of how women deal with information and the importance they may place on it. This study does not correlate directly with expressed information needs of this project. We do not know any details of the MBSS tool with regard to the questions asked, or how rigor was insured? There was lack of description of tools tested as well as descriptions to the data that was put through the</p>	
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Citation and authors 2.	Research Problem identified	Methodology Sample, Design & data collection	Timing of data collection	Measure	Data analysis	Results	Score
<p>Galloway, S., Graydon, J., Harrison, D., Evans-Boyd, B., Palmer-Wickham, S., Burlein-Hall, S., Rich-van der Bij, L., West, P. & Blair, A. (1997). Information needs of women with a recent diagnosis of breast cancer: development and initial testing of a tool. <i>Journal of Advanced Nursing</i>, 25, 1175-1183.</p>	<p>To develop a questionnaire to measure information needs of women during first course of treatment with recent diagnosis of breast cancer. What type of information is desired by women with breast cancer?</p>	<p>Non experimental descriptive study. This questionnaire was originally tested in a pilot to determine validity of the project. Lay individuals and health care professionals (n=33) who reviewed the questions that were developed for clarity in the wording of items and acceptability of the format. Lazarus & Folkman's theory of stress and coping provided direction for development of the Toronto</p>	<p>They were asked to participate at: week 2 of chemotherapy; week 1 of radiation or 24 hours post operatively. (n=39 chemo) (n=40 radiation) and (n=35 surgery). They also measured women's responses near completion of their treatment phase to look for evidence to determine if there were any differences in their information needs.</p>	<p>Likert (1-5) measures were used. 1 - not important to 5- extremely important Retained items of TINQ-BC were: i. Diagnostic tests ii. Investigative tests iii. Treatments iv. Physical v. Psychological vi. Family vii. Financial (Financial subscale was deleted because there were not any items that remained. As well low numbers in family scale so it was combined with psychological sub scale. The diagnosis subscale was renamed</p>	<p>Ethical approval was obtained from the Institutional review boards at the hospital and clinic. Written informed consent was obtained. None of the women had difficulty completing the questionnaire and were able to respond to the questions without assistance. Upon completion of the questionnaire women were asked open ended questions about any informational needs that were not covered by the TINQ-BC and 95% stated there were no additional areas to discuss. Six women suggested additional information needs to include necessity of mammography; treatment schedules; and roles of various nurses and how to deal with curious neighbours. The questionnaire had content validity based on findings in the literature and opinions of expert oncology nurses. Cronbach's alpha was used to estimate internal reliability of</p>	<p>there was no discussion around expressed need in this study.</p> <p>Limitations Small sample size, further testing of tool to discern construct validity <u>Strengths</u> There is construct validity of the TINQ-BC, the women's perspective and needs are congruent with the theoretical perspectives of Lazarus & Folkman and hold similar results with other studies in this review. The item analysis included the following criteria: The areas of highest information need expressed by the women were associated with;</p>	<p>14</p>

		<p>Informational needs questionnaire- Breast Cancer (TINQ-BC). Lazarus & Folkman theoretical framework provides theory that people want information about what is happening to them in order to clarify elements in new experience and manage their emotions in a threatening situation. Purposive sampling was carried out by nurses in hospital and clinic who identified potential subjects' women with a recent breast cancer diagnosis the treatment phases of their treatment This sampling was used to ensure a most</p>		<p>Disease The sub scales need to represent and measure sensitivity to a unique and specific component of the topic or construct of interest</p>	<p>TINQ-BC, alpha co- efficients above 0.80 represent high internal consistency, and the internal consistency reliability established for this tool was 0.96. Inter item correlations were done to assess necessity of keeping low score items in the tool. To make certain that the scores from the present study could be compared to future findings, 70 subjects who scored 1-5 on each 51 items were used for further analysis. If 2 items had inter item correlations 0-80= question do they measure the same informational need and if it was kept would unduly increase sub score. So as a result of this items analysis 22 items were dropped from the original scale, leaving 51 items remaining in the 5 subscales. Also analysis showed no difference in scores related to demographics; marital status, education or income (small sample size). Content validity was established by extensive literature review as well as the opinion of 11 oncology nurse experts. Total sample size was 200 N=70 was standardized to 5 point scale it was 4.19. Each</p>	<p>disease, treatments and investigative tests. Women have high informational needs in spite of the treatment they are receiving. Steps were well laid out explaining how data collected, and analyzed, strengthens rigor. <u>Results</u> The TINQ-BC identified the expressed information needs of women with breast cancer. These identified categories of need are the beginnings of answers to this project question. Women have identified through this questionnaire a hierarchy of their needs for information when diagnosed with breast</p>
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		<p>representative sampling for the questions asked. 127 women met the criteria and 114 agreed to participate. All subjects were accounted for in the study.</p>			<p>treatment group standardized mean scores were: 4.1 surgical 4.3 chemotherapy 4.2 radiation When developing a questionnaire each subscale should measure a unique component of the construct of interest. This uniqueness acts to increase measurement sensitivity and is seen when the subscales are relatively uncorrelated with each other but correlate well with the questionnaire. In TINQ-BC intercorrelations of subscale to total score was 0.78-0.88. The intercorrelations of the subscale scores was 0.38-0.73 (r=0.45 to 0.70).</p>	<p>cancer. Women have expressed their information needs and have also ranked them in order of importance.</p> <p>The tool was developed and tested on a separate group (n=70) to determine if the questions were appropriate and if the information received was in fact from the questionnaire and not a matter of chance. Inter-rater reliability was evident through the separate sample group that was utilized at the end of the study to test the tool further. As well the questionnaire was used with women who had different</p>
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Citation and authors 3.	Research Problem identified	Methodology Sample, Design & data collection	Timing of data collection	Measure	Data analysis	Results	Score
<p>Gopal, R., Beaver, K., Barnett, T. & Ismail, N. (2005) A comparison of the information needs of women newly diagnosed with breast cancer in Malaysia? Are the information needs of Malaysian women with breast cancer similar to those of women in the United Kingdom? (Included in this review, Luker et al., 1995). Do sociodemographic factors (ethnic, age, level of education, social class) influence the information needs of Malaysian women diagnosed with breast cancer?</p>	<p>What are the priority information needs for women newly diagnosed with breast cancer in Malaysia? Are the information needs of Malaysian women with breast cancer similar to those of women in the United Kingdom? (Included in this review, Luker et al., 1995). Do sociodemographic factors (ethnic, age, level of education, social class) influence the information needs of Malaysian women diagnosed with breast cancer?</p>	<p>Survey design conducted in two major government hospitals. Both had radiotherapy and oncology units and served cancer patients from other states and private hospitals. All participants were attending radiotherapy or oncology day hospitals for adjuvant treatment. The sample of 100 women was retrieved by posters explaining the study and those interested were</p>	<p>Between 3-4 months from diagnosis. The authors had intended to interview women 2 weeks from diagnosis but one of the committee members felt the women were too vulnerable at this time in their illness to be approached. This study was attempting to replicate the work conducted in the United Kingdom. The INQ was administered by 1 of 3 research associates.</p>	<p>INQ (information needs questionnaire) was used to measure priority information needs for women with breast cancer. This scale consists of 9 items presented in pairs; each of the nine is seen with every other item to give a total of 36 pairs [n(n-1)/2]. The scale was prepared in 4 different languages to cater to the 3 main ethnic groups; Malaysian, Chinese and Indian. Three women from each</p>	<p>Approval to conduct the study was obtained from directors of hospitals, nurse managers and clinicians and Research Ethics Committees. There were no conditions on this approval. Thurston's scaling approach forces a choice between 2 items at a time and the analysis of the INQ data involve production of a scale. A positive score indicates that more than half of the study sample preferred a particular item. Pairs are presented according to the Ross matrix of optimal ordering to ensure equal spacing between items to reduce selection bias. Participants were asked to state a preference for one item of the pair. After they had completed the questionnaire women were asked about</p>	<p>Limitations Small sample size Lower social classes were underrepresented The UK study is not directly comparable with this study as it represented post surgical women and this study represents women in adjuvant treatment <u>Strengths</u> In this study a validated tool/measure, INQ was used to establish prior information needs of women with breast</p>	<p>13</p>

		<p>to contact the ward staff. The ward staff provided written information about the study for patients to read and consider if they wished to participate.</p>		<p>group were asked to complete the questionnaire and then were interviewed by the researchers to assess whether the translations were readable and understandable. The INQ was developed in Canada and has a list of 9 important items women chose in relation to their needs. These include information about:</p> <ul style="list-style-type: none"> • Advanced disease • Likelihood of cure • How treatment may affect ability to carry on daily activities • Caring for self at home • How the treatment may affect personal feelings about body and sexual attractiveness • Different 	<p>other information needs that might not have been included in the measure. Kendall's coefficient of agreement was used to measure the degree of consistency between study participants when making judgments about the importance of the INQ items. The closer the value is to 1 the closer the women were to complete agreement about the relative importance of the INQ items. The Kendall coefficient was 0.75, indicating a high degree of agreement among women as to priority information needs. SPSS was used for analysis of the variables of the INQ descriptive statistical data. Descriptive statistics were used to present characteristics of the study samples and inferential statistics (<i>t</i> tests) were used to compare INQ findings. <i>t</i> tests and analysis of variance (ANOVA) tests were used to examine the impact of sociodemographic variables on INQ scores. Two measures of reliability were applied to INQ data to ascertain the degree of consistency in study</p>	<p>cancer.</p> <p><u>Results</u> The priority information needs as identified by the Malaysian sample were:</p> <ol style="list-style-type: none"> i. Likelihood of cure ii. Sexual attractiveness iii. Spread of disease <p>The comparison of the two countries indicates significant differences for 4 out of 9 items. These are related to culture as well as the differences in disease phase. There is a great deal of denial as well as use of alternative therapies before Malaysian group of women seek medical support. Often their disease is advanced at the time of diagnosis. As well there is a</p>
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				<p>types of treatment and the advantages of each</p> <ul style="list-style-type: none"> • Whether children or other family members are at risk of getting breast cancer • Unpleasant side effects of treatment 	<p>participants' judgements. In the Malaysian sample, 49% made no circular triads with remaining 51% making between 1 and 3. This indicates that the study sample was consistent in the choices.</p>	<p>fight between cultural attitudes, religion and a strong instilling of myths and fears, prior to a diagnosis which can affect the results in this particular study and change the priority order of needs. Although the studies were with women of different treatment modalities the results were comparable. The priority order of the needs is different and is discussed in the body of this paper. The results did answer the questions of inquiry for this project.</p>	
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Citation and authors 4.	Research Problem identified	Methodology Sample, Design & data collection	Timing of data collection	Measure	Data analysis	Results	Score
<p>Graydon, J., Galloway, S., Palmer-Wickham, S., Harrison, D., Rich-van der Bij, L., West, P., Burlein-Hall, S & Evans-Boyd B. (1997). Information needs of women during early treatment for breast cancer <i>Journal of Advanced Nursing</i>, 26, 59-64.</p>	<p>Purpose: to determine the informational needs of women during early treatment for breast cancer. Early treatment is defined in this study as: involving any one of three treatment modalities, surgery, chemotherapy and radiation where women had completed at least one treatment. (These definitions will be further discussed in the body of the findings in this paper). There is a surgical component to this study but this author felt it imperative to include this study in the integrative review because of the chemotherapy and radiation component n=48.</p>	<p>The study does not state the methodology but it appears to be a needs assessment questionnaire. 70 women participated in this study. Purposive sampling was used in this study and women were recruited from a large urban hospital and regional cancer centre. Lazarus & Folkman's theoretical framework provides theory of stress and coping. People want information about what is happening to them in order to clarify elements in new experience and manage their</p>	<p>Women were asked to participate in three various group: i. Chemotherapy (n=25) ii. Radiation (n=23) iii. Surgery (n=22)</p>	<p>In the TINQ-BC questionnaire each item begins with "To help me with my illness, it is important for me to know". The score is rated on a five-point Likert scale from 1 (not important) to 5 (extremely important). 5 item sub scales are: Disease Investigational tests Treatment Physical Psychosocial</p>	<p>After Institutional Review Board approval all women eligible were invited to participate. Written consent was obtained. It took women about 40 minutes to complete the TINQ-BC. The women in the Chemotherapy and Radiation therapy groups had completed at least one treatment. The women in the chemotherapy group completed the questionnaire before receiving any pre treatment medications. Regardless of the treatment modality all women wanted information to help them deal with their illness. Cronbach's alpha was 0.94 for the total questionnaire and alphas 0.85 -0.90 for the subscales. Scores above 0.80 shows that high internal consistency was replicated in this study after initial development of the tool. Increased reliability and validity strength. Percentage means were calculated to determine areas of greatest information need. Need scores above 4.75 were identified as extremely important by the women who</p>	<p><u>Limitations</u> Small sample size All women with breast cancer not represented in this study. The instrument is still new and requires further validation. Does simply asking women about their information need increase its importance? <u>Strengths</u> In this study similar results have been reached and compared to the Galloway study using the TINQ-BC tool.</p>	<p>9</p>

		<p>emotions in a threatening situation.</p>		<p>participated. These high scores were identified by women regardless of whether they were being treated by surgery, chemotherapy or radiation. (Discussed further in the body of the paper).</p>	<p>Results All women wanted information to help them deal with their illness. It does not matter where the women were along their treatment trajectory, information gives them hope and control over their situation and fills a gap in their knowledge. These findings are congruent with Lazarus and Folkman's stress and coping theory that suggest individuals facing a new situation will seek information in order to determine their coping options. Again the women not only identified their expressed need but also ranked their need in priority. The areas that women identified</p>	
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Citation and authors	Research Problem identified	Methodology Sample, Design & data collection	Timing of data collection	Measure	Data analysis	Results	Score
<p>Lee, Y., Francis, K., Walker, J. & Lee, S. (2004). What are the information needs of Chinese breast cancer patients receiving chemotherapy? <i>European Journal of Oncology Nursing</i>, 8, 224-233.</p>	<p>Evaluate the information needs of Chinese women with breast cancer who were receiving chemotherapy in Hong Kong.</p> <ul style="list-style-type: none"> Identify information that breast cancer patients desire at different cycles of chemotherapy treatment. Prioritize type of information needed at different cycles of chemotherapy Compare significant differences in information needs of the 	<p>Descriptive survey using a repeated measures design. Women newly diagnosed with breast cancer. Patients were recruited 54 patients were invited to participate in the survey and 51 returned their survey (94%).</p>	<p>Newly diagnosed breast cancer patients who are undergoing chemotherapy on the first day of chemotherapy and again half way through their treatment course. (to identify the priority and the change of information needs between early cycle and the mid cycle of treatment)</p>	<p>Used the TINQ-BC questionnaire. 52 items measuring 5 sub scales</p> <ol style="list-style-type: none"> Information about disease Investigative tests Treatments Physical Psychological aspects <p>5 point Likert scale to rate the information need from not important (1=lowest score) to extremely important (5=highest score). The TINQ-BC was translated to Chinese and a pilot study was conducted to test</p>	<p>Ethical approval was sought from the Ethics in Human Research Committee of Charles Sturt University and Survey and Behavioural Ethics committee of Chinese university of Hong Kong. Excellent description of the process involved down to the details of confidentiality, consent and the ability of women to withdraw whenever they decided to.</p> <p>An analysis of the data was done using Statistical Package for Social Science (SPSS). Repeated <i>t</i> tests were used to compare if there were significant differences between the administration of the measure of Time 1 (first day of chemotherapy and Time 2 (mid point of treatment). The x^2 test was performed to examine if there were any</p>	<p>regarding information need were:</p> <ol style="list-style-type: none"> Disease Investigative tests Treatments <p>Results</p> <p>Limitations One hospital small convenient sample doesn't give typical subjects in the population. Women volunteered to participate in this study. Therefore not a typical group, weakest form of sampling. Strengths This study was conducted using the TINQ-BC instrument. The findings were similar to the two previous studies done using the same tool.</p> <p>Results</p>	<p>11</p>

	<p>patients</p> <ul style="list-style-type: none"> Measure variables influencing the patient's information needs. <p>In this study two specific times for the questionnaire were used. Time 1 was at the first treatment. Time 2 was when the woman was half way through her treatment.</p>		<p>the feasibility of the study to test Chinese version of the instrument for its reliability to ensure that it measures what it is suppose to, specifically with this Chinese population. A convenience sample 10 breast cancer patients. Content validity index=2 breast cancer specialists to validate questions and validity indices 98%.</p>	<p>significant differences between the information needs and the variables like age, education, marital status, chemotherapy regimens and treatment modalities.</p> <p>Reliability was established by using Cronbach's alpha test the internal consistency among the five domains. The α values were 0.71, 0.92 and 0.82 for the subscales of disease, investigative tests and treatments. The α values were 0.90 for both physical and psychosocial subscales. This means that internal consistency was not by chance and there was reliability of the TINQ-BC tool. (Galloway et al., 1997).</p>	<p>There are consistent findings with the other studies in that the women require information. The top ten most important items of the questionnaire were tabulated at both times (time 1 and time 2) and there are differences. The most important information needs in these two points are:</p> <ol style="list-style-type: none"> Disease Treatment options <p>These two domains were the highest priority at both time points. As well physical and psychological sub scales remained the same priority at both time points. There was no evidence of difference among age groups in this study.</p>	
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Citation and authors 6.	Research Problem identified	Methodology Sample, Design & data collection	Timing of data collection	Measure	Data analysis	Results Excluded from findings information	Score
<p>Luker, K., Beaver, K., Leinster, S., Owens, R., Degner, L. & Sloan, J. (1995). The information needs of women newly diagnosed with breast cancer. <i>Journal of Advanced Nursing</i>, 22, 134-141.</p>	<p>The aim was to explore what particular types of information were important to women newly diagnosed with breast cancer.</p>	<p>Longitudinal follow up study. Group 1=150 women who had a breast cancer diagnosis and were having surgery. Control group= 200 women with benign disease, they had a symptom but on investigation it was found to be benign. A consecutive sample taken from the consultants list of a large teaching hospital.</p>	<p>Group 1 was interviewed in hospital pre operatively. Group 2 was interviewed in the out patient clinic. It does not indicate who they received approval from to carry out the study.</p>	<p>A questionnaire was used that asked 9 questions, 36 pairs. It did not specify which questionnaire was used.</p>	<p>Verbal consent by author does not state who or if they obtained ethics approval. SPSS-PC was used for producing profiles of information needs. Thurstone's scaling technique was used (when 2 stimuli together could be ranked). The study does not discuss the results. Pooled variance <i>t</i> test to examine significance differences in ranking between 2 profiles (no further details given) Kendall's coefficient of agreement= consistency zeta=0.979. All were consistent in judgment. Kendall to assess choices women made arbitrary or random.</p>	<p><u>Limitations</u> There was no discussion of the particular tool that was used in this study. Steps in the data collection phase of the study are vague. There are aspects of the data collection that may have influenced outcome. Women were interviewed prior to their surgical intervention for their breast cancer; they would be in a high anxiety situation which could have altered their answers. The study was vague in explanations and one is left questioning and asking further questions regarding the</p>	<p>6</p>

				<p>One way ANOVA search for variable of age revealed that newly diagnosed group of women 40 or younger and 40-60 years of age rated information regarding sexual attractiveness as more important than the over 60 age group. No other difference with regard to age was found through this analysis. This is the only study where sexual attractiveness was rated higher (except for the Malaysian study) and this could be because the women in this study were pre op, awaiting surgery and anxious and their surgery was paramount on their mind. Sexual attractiveness will be discussed further in the body of the paper.</p>	<p>results. <u>Strength</u> It provided future work for Gopal et al., study which is included in this review. <u>Results</u> Priority information needs 2.5 weeks from diagnosis were identified and congruent with the other studies in this literature review and include: i. Likelihood of cure ii. Spread of disease iii. Treatment options In this study they compared benign group of women with a breast abnormality to a malignant group of women awaiting surgery. What influences would this have on the outcome of the data, a question that is left unanswered?</p>	
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Citation and authors	Research Problem identified	Methodology Sample, Design & data collection	Timing of data collection	Measure	Data analysis	Results	Score
<p>Harrison, D., Galloway, S., Graydon, J., Palmer-Wickham, S., & Rich-van der Bij, L. (1999). Information needs and preferences for information of women with breast cancer over a first course of radiation therapy. <i>Patient education and counselling</i>, 38, 217-225.</p>	<p>This study assessed the information needs of women receiving a course of radiation therapy for breast cancer and the relationship between information needs and preference for information.</p>	<p>Prospective Longitudinal study. Women were accrued from cancer centre in Canada over a 15 months period. They were recruited into one of four groups. The first group (group 1) received an interview 4 times during the course of their treatment. The subsequent groups (2-4) received only one interview. All participants filled out the TINQ-BC questionnaire. Women who agreed to participate in the study were identified by the clinic nurse and randomly</p>	<p>Group 1 had 4 opportunities to fill out the TINQ-BC; 1, 2, 3 were done in the clinic at the beginning, middle and end of their radiation treatment and interview 4 was done by telephone one month post treatment (the instrument was mailed out ahead of time). The questionnaire was mailed out to the participant for that interview. Control groups 2, 3, and 4 were given the questionnaire at their first visit to the radiation department only. The control groups served to identify women's information needs at different times</p>	<p>TINQ-BC and the (HOS) Hospital Opinion Survey. HOS measured women's preference for information. A 16 item scale which measures preference for information and behavioural involvement in health care situations.</p>	<p>Ethics was written and verbal consent. No statistical significant difference in total scores of the TINQ-BC or HOS groups when compared using <i>t</i>-tests or Pearson's product moment correlation=prior exposure did not affect the women's scores on subsequent questionnaires. There were two items added to the TINQ-BC tool with specific attention to radiation therapy. "What the area being treated will feel like and "what the area being treated will look like. The same 5 subscales and the same remaining content of the TINQ-BC questionnaire were used. The same validity and beginning construct validity was reported here in this study as in the other TINQ-BC studies using this instrument. Consistent results were achieved among the studies using this instrument. Internal consistency reliability was assessed using Cronbach's alpha =0.97 total score and 0.78-0.83 for the</p>	<p><u>Limitations</u> Study carried out at one Canadian centre with women who were middle class, Caucasian and above average education. As well the majority of women had lumpectomy for their surgical intervention and may not have faced the same challenges related to sexual attractiveness. <u>Strengths</u> Adequate sample size of various groups. Consistent findings with other studies in this review. <u>Results</u> Women want specific information related to their</p>	<p>14</p>

		<p>assigned to one of the 4 groups. Data was obtained by one of the three nurse research assistants trained to standardize their approaches. No research assistant interviewed same women four times. Women were randomly assigned to group; 1 n=35 2 n=31 3 n=31 4 n=28 3 participants dropped out and there was not discussion in the study regarding the reason for their withdrawal from the study. Group 2. Lazarus & Folkman (1986) theoretical framework provides theory that people want information about what is</p>	<p>along the radiation treatment trajectory to identify if prior exposure to the instrument influenced scores on subsequent administration.</p>		<p>subscales signifying internal consistent reliability. As well descriptive stats for demographics Chi square tests of proportions for demographics was used to identify if significant differences in characteristics existed. <i>t</i>-tests were used to compare scores of group 1 (all 4 intervals) to group 2, 3, 4 respectively. Alpha set at 0.05 to guard against Type 2 error. The results show that women's needs did not change over time when compared with group 1 scores compared with group 2, 3, & 4. Therefore the results show that null hypothesis is rejected and the hypothesis is supported by empirical evidence and results are not due to chance. One way ANOVA was used to detect significant difference between TINQ-BC and HOS scores over time in group 1. A mean score of 207 was seen in each questionnaire reviewed and no variance in the mean scores was seen over the four times the questionnaire was filled out by the woman. There was no statistical difference between TINQ-BC scores and demographics or illness variables. Some items related</p>	<ul style="list-style-type: none"> • disease, treatment, and investigation al tests. <p>There is value in providing information tailored to needs of patient with cancer and has been shown to increase knowledge and decrease need for information. The level of satisfaction is also increased. Prior exposure did not significantly affect scores. No statistical significant difference among groups on basis of age, marital status or education.</p>	
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Appendix C

Priority preference of Information needs

	Did not address my question	Disease Treatment Investigative tests	Likelihood of cure Sexual attractiveness Disease [spread]	Disease Treatment Cancer spread Side effects Management of side effects	Likelihood of cure Disease [spread] treatment
Citation					
Cowan, C. & Hoskins, R. (2007)	X				
Galloway et al., (1997)		X			
Gopul, R., Beaver, K., Barnett, T. & Ismail, N. (2005)			X		
Graydon et al., (1997)		X			
Lee et al., (2004).				X	
Luker et al., (1995)					X
Harrison et al., (1999)		X			