

# Types of Information Needs among Cancer Patients:

## A Systematic Review

Kalyani Ankem, Ph.D.  
Associate Professor  
School of Library and Information Sciences  
North Carolina Central University  
Durham, NC 27707  
Email: kankem@nccu.edu

### **Abstract**

A systematic review of literature on the types of information important to cancer patients was conducted. The review included 18 studies. A synthesis of the ranking of the importance attached to various types of information by patients in individual studies showed that information about the disease itself and information about the treatment that follows are the most important types. A review of factors affecting the need for a particular type of information found that younger patients attribute more importance to information about sexual concerns and physical attractiveness than older patients. This type of information, however, was ranked least important by cancer patients overall. Also, the review indicates that highly educated patients may be similar to less educated patients in the types of information they need. As for the impact of patient situations on the need for a specific type of information, patients who prefer to be active in decision-making during illness want more information about their illness. Although some evidence existed to indicate that patients who are closer in time to their diagnosis need to understand the disease by wanting more information about their illness, the stage of cancer does not affect the type of information needed.

### **Introduction**

A diagnosis of cancer is a stressful life experience. The nature of the disease requires patients to learn about the illness, make difficult decisions regarding the ensuing treatment, and cope with the consequences of the illness. It has been found that having relevant

information not only helps patients understand the disease but also facilitates patients' decision-making and coping (Cassileth, Volckmar, & Goodman, 1980; Iconomou, Viha, Koutras, Vagenakis, & Kalofonos, 2002, p. 315).

Not all patients, however, are similar in their need for information. Patients' demographics and the situations they find themselves in during the illness have been found to affect their need for specific types of information. Graydon et al. (1997) have postulated five categories for information needs among breast cancer patients: 1) nature of disease, its process and prognosis, 2) cancer treatments, 3) investigative tests, 4) preventive, restorative, and maintenance physical care, and 5) patient's or family's psychosocial concerns. Degner et al. (1997) developed nine categories of information needs among cancer patients: 1) spread of the disease, 2) likelihood of cure, 3) treatment options, 4) side-effects of treatment, 5) effect on family and friends, 6) risk of disease to family, 7) impact on work, daily activities, and social life, 8) self-care issues, and 9) sexual concerns. Similar categories or items have been developed by other researchers.

The researchers have analyzed these various types of information that cancer patients need and, in the process, have also observed the effects of patient demographics and situations on the specific type of information needed. Such demographics as age, education, and gender have been found to have a possible differential effect on the need for a particular type of information. Also, situational factors, such as patients' preferred decision-making style during illness, time elapsed since diagnosis of cancer, stage of cancer, and type of treatment they are receiving, have been determined to potentially affect exactly what a patient may wish to know.

### **Aims of the Study**

For this article, the author systematically reviewed the literature regarding information needs among cancer patients to find (1) the ranking of importance that cancer patients attribute to specific information types, (2) the effect of such demographics as age, education, and gender on the need for a particular type of information among cancer

patients, and (3) the effect of such patient situations as time since diagnosis, stage of illness, type of treatment being received, and preferred role in decision-making on the need for a certain type of information. The objective of the systematic review was to synthesize results across studies to capture as a body of literature the meaning of all the relevant results.

## **Procedures**

A systematic review was conducted to synthesize the literature. A systematic review essentially presents the thought processes involved in the synthesis of disparate results from various studies pertinent to the research questions at hand and stops short of an actual mathematical amalgamation performed in a meta-analysis. A detailed description of systematic review as a research method can be found in an article by Carr (2002). To commence the review for this study, online databases—Medline and CINAHL—were searched to find studies published during the ten-year period 1993-2003 regarding the information needs of cancer patients. The first two searches were conducted using the heading neoplasm (with the explode function) and the term cancer patients (in the title, abstract, Mesh subject heading, and cas registry/ec number word). These searches were combined with the Boolean “or” to retrieve studies dealing with cancer patients. The resulting search was further combined with other separate searches using the following terms: information need(s), information seeking, information seeking behavior, information source(s), and information resource(s) (all in the title, abstract, Mesh subject heading, and cas registry/ec number word) to retrieve studies only on the information needs of cancer patients. The final search thus retrieved was limited to English, adults, and the years 1993-2003. Additionally, the search in CINAHL was limited to research. The final output of online searching was 196 studies in Medline and 283 studies in CINAHL.

First, the titles and abstracts of these studies were reviewed, and 110 publications that dealt with the information needs of cancer patients or the information sources used by cancer patients were selected. (The literature on information source use was retrieved for another

systematic review.) In the next step, the 110 studies were perused for inclusion based on these predetermined criteria: (1) analysis of information needs of patients diagnosed with cancer and/or information sources used by cancer patients, (2) inclusion of adults as subjects in the research study, and (3) application of quantitative research methods and relevant statistics. Relevant statistics were regarded as those applied to convey preference for certain types of information or use of information sources and inferential statistics, in particular, for studying the relationship between demographics (age, education, and gender) and information needs or information source use and, separately, the relationship between situations (time since diagnosis, stage of cancer, type of treatment being received, and a patient's preferred role in decision-making) and information needs or information source use. This led to the elimination of 35 papers that dealt with the following: qualitative studies on information needs, evaluation of general communication channels or site specific cancer information-oriented programs, breast cancer risk, hereditary breast cancer and genetic testing, prevention and screening, symptoms before diagnosis, information needs prior to breast biopsy, quality of life during cancer, coping during cancer, and impact of a particular information provider such as the Cancer Information Service (CIS).

The remaining 75 studies were carefully read to select candidates for the systematic review in order to ensure that they included data pertinent to the research questions proposed in this systematic review. At this point, studies were eliminated that dealt with the following: methods of information delivery, reading ability of patients, information presentation preferences, information provided by a particular information provider (e.g., CIS), desire for information, unmet information needs, models of information seeking, professionals' opinions, information needs of family and caregivers, patients' level of knowledge, patients' expectations and experiences, need for educational programs, information needs during breast reconstruction, satisfaction with information, role of information in decision making, comparison between different cancers, and instrument testing and evaluation solely to establish reliability and validity. An effort was also made to separate studies and/or results that dealt with information source use and the level of overall information

needs as opposed to the need for specific types of information. In selecting studies that dealt with specific information needs, those that presented an insufficient number of top-ranked information needs (two articles) and did not provide a clear picture of what was studied, those that presented too few or too many information needs (three articles) for comparison with information needs presented in other studies, and those that were too broad and encompassed patients' general needs were removed.

Before data extraction was undertaken, the articles were evaluated for quality. This process led to the elimination of three more articles due to unclear logical progression and/or inadequate explanation and presentation of statistical results that include reports of statistical tests conducted, test statistics derived, and probabilities reached. The final pool included 18 studies. No distinction was made among types of cancer. Studies retrieved through the literature search examined patients diagnosed with heterogeneous types of cancer. The publications selected were all peer-reviewed journal articles authored by researchers in oncology, nursing, public health, psychology, and psychiatry. Sample sizes in individual studies ranged from 33 to 2,331. The majority of sample sizes ranged from 70 to 250.

### *Instruments*

Notable instruments employed for measuring various information needs included Toronto Informational Needs Questionnaire – Breast Cancer (TINQ-BC) (Galloway et al., 1997; Graydon et al., 1997; Harrison, Galloway, Graydon, Palmer-Wickham, & Rich-van der Bij, 1997), Informational Needs Questionnaire–Breast Cancer (INQ-BC) (Harrison-Woermke & Graydon, 1993), Patient Learning Need Scale (PLNS) (Galloway, Bubela, McKibbin, McCay, & Ross, 1993; Galloway & Graydon, 1996), information preference cards (Hack, Degner, & Dyck, 1994), and Thurstone scaling of information needs developed by Degner and colleagues (Bilodeau & Degner, 1996; Davison, Degner, & Morgan, 1995; Davison et al., 2002; Degner et al., 1997; Luker, Beaver, Leinster, & Owens, 1996; Luker et al., 1995).

The INQ-BC is a precursor to TINQ-BC that measures on a five-point likert scale the

importance that patients attribute to different types of information. The five subscales of TINQ-BC—disease, investigative tests, treatment, physical, and psychosocial—measure five types of information. In seven comparable subscales, the PLNS similarly measures the importance of having information. The Hack et al. (1994) information preference cards are a precursor to the Thurstone scaling of information needs developed by Degner and colleagues. The information preference cards involve ranking of seven types of information related to diagnosis: illness, treatment alternatives, treatment procedures, side effects, and prognosis. The Thurstone scaling of information needs is a more complicated ranking method that uses nine categories of information: stage of disease, likelihood of cure, effect of treatment on social activity, effect of disease on family and friends, self-care needs, effect of treatment on sexual activity, types of treatment available, risk to a family member, and side effects of treatment. According to Bilodeau and Degner (1996), “In Thurstone scaling, each item produces a single number that reflects the degree of preference that a group of people have for that item” (p. 693). The researchers report reliability and validity for the TINQ-BC, the INQ-BC, the PLNS, and for the Thurstone scaling of information needs. Validity is reported for the Hack et al. information preference cards.

Other questionnaires administered also measured patients’ needs for comparable types of information on a likert scale. Among these other instruments, the Stewart et al. (2000) questionnaire is based on work conducted previously in developing information needs measures, including work by Cassileth et al. (1980) on the Information Styles Questionnaire and the more recent extensive work of Degner et al. (1997) on the Thurstone scaling of information needs. Both reliability and validity are reported for the Stewart et al. (2000) questionnaire. Jenkins, Fallowfield, and Saul (2001) indicate that the instrument they employed to measure information needs has been used widely in their studies in the UK and US. Although no specifics on reliability and validity are provided, Jenkins et al. state that their instrument is based on earlier work that includes the study by Meredith et al. (1996). Iconomou et al. (2002) provide reliability for their questionnaire, the Information

Needs Scale, and Raupach and Hiller (2002) indicate that the instrument used in their study has validity.

### *Data extraction*

To rank the top three information needs in the systematic review, rankings from individual studies were extracted and synthesized. Even though the items analyzed across studies were not precisely the same, they were comparable because they covered a variety of similar informational needs experienced by cancer patients. Studies that provided insufficient data to arrive at the top three needs were eliminated as were studies that presented too many (over 20) information needs without summarizing them or those that covered too few (fewer than 5) information needs and measured only a fraction of the needs measured by other studies.

Also, a scheme was devised to pull together the rankings from individual studies. As can be seen in tables 1-2, the rankings in individual studies were based mainly on percentages.

To collate the types of information cited as important by patients across studies, the Graydon et al. (1997) five information needs categories—1) nature of disease, its process and prognosis, 2) cancer treatments, 3) investigative tests, 4) preventive, restorative, and maintenance physical care, and 5) patient's or family's psychosocial concerns—were used as a guide in this systematic review. The information need that ranked first in a study was transcribed in the first column and ranked first in this systematic review (see Table 1). The information need that ranked second in the study was checked against the Graydon et al. categories to see if it belonged to a different category than the first. If it did, it was placed in column two and ranked second in this systematic review; otherwise, it was placed in column one under the first information need transcribed. The process was continued down the ranking list in each study until information needs were transcribed in column two and column three to arrive at the top three information needs in this systematic review.

For instance, Jenkins et al. (2001) ranked the item “Whether or not it is cancer” as first, and it was placed in column one in this review. The item ranked second in Jenkins et al., “What

all possible side effects of treatment are,” fell into a separate Graydon et al. category, i.e., treatments. As such, it was ranked second in the systematic review. If it had fallen under the Graydon et al. category *disease*, into which the first item fell, it would have been placed in column one under the first item. The item “What the chances of cure are” was ranked third in Jenkins et al. but fell under Graydon and colleagues’ description-of-the-disease category as did the first item. Guided by one of these items being ranked first in the Jenkins et al. (2001) study, both items were included as first in ranking in this systematic review (Table 1). The item “What all the possible treatments are” ranked fourth in Jenkins et al. but fell under the Graydon et al. treatments category and was placed in column two under the other item already placed in that column and ranked second in the review. The other items in Jenkins et al. also fell under the Graydon et al. disease or treatments categories and are not shown in Table 1.

This reorganization of terminology made categories and items across studies more comparable regardless of the instruments used. Because the highest ranked items and the lowest ranked items in the studies are shown in the tables, the reader should have a good idea of the ranked items covered in each study. There should, therefore, be no concern about synthesizing items covered in some studies and not in others. If other items appeared in other studies, they were ranked following the collating technique allowed by the Graydon et al. categories, and the reader can see in the tables the spread of vocabulary used. The lower frequency an item received in this review indicates that some researchers did not bother to study it.

To give the reader an idea of how items were originally ranked in a researcher’s individual study, the ranking from the study was entered in parentheses next to each item (Table 1). For example, in extracting data from the study by Jenkins et al. (2001), “Whether or not it is cancer” and “What the chances of cure are” were both ranked first in this systematic review while the researchers’ original ranking, one (1) and three (3) respectively, are included in parentheses next to the items (Table 1). The reader must, therefore, be cognizant that in the system review, all items appearing in the first column (Table 1)

concerning a study constitute type of information ranked first, and the numbers in parentheses are meant to provide the breadth and depth of the types of information examined in a given study.

To rank low information needs, the same process was applied but from the opposite direction of the rankings list in individual studies, that is, from the bottom of the ranking and moving upwards until the two least needed items were transcribed. To extract data on factors affecting types of information needs, any relationship between demographics and situational variables—age, education, gender, stage of disease, patient’s decision-making style, time since diagnosis, and type of treatment received—and any item representative of a type of information need among cancer patients were recorded. Relationships represented only in inferential statistics were entered.

#### *Data synthesis*

Data synthesized to summarize both the ranking of types of information needs and the effect of factors on specific information needs are presented in tables. Table 1 presents the research studies from which data were extracted, the three highest ranked information needs of cancer patients, the time during illness when the information needs were captured in the study, the type of cancer diagnosed in subjects, and the statistics used for ranking the types of information needs in the study. Table 2 presents similar data, except that the two least important information needs are presented; the least needed information is presented before the lesser needed information. Table 3 presents the following: the research studies from which the data were extracted, the relationship between demographics and types of information needed, the type of cancer diagnosed in subjects, the instruments employed to measure information needs, and the inferential statistics applied in the study. Table 4 is similar in presenting the influence of factors on the type of information needed; however, the relationship presented here is that between patient situations and the types of information needed. Tables 3-4 do not provide the time during illness when the information needs were studied because most of the studies included in these tables

appeared in earlier tables that provide the temporal dimension. One exception is Hack et al. (1994), included only in Table 4, which focused on patients 2-6 months after diagnosis. Data thus summarized in each table provide an overview of related research.

## **Results**

### *The three most important information needs among cancer patients*

The information ranked highest in need by patients emerged to be that related to the illness itself. A need for illness-related information was cited more frequently than any other type of information. Patients rated several aspects of their illness as most important: information about diagnosis, chances of cure, spread of disease, prognosis, and signs of recurrence (Table 1). All of these fall into Graydon and colleagues' description of information in the disease category that includes information about the nature of the illness, its process, and its prognosis (Galloway et al., 1997). However, as one can see, treatment-related information was the top priority for patients in some studies.

### [\[View Table 1\]](#)

Patients were in more agreement in rating information about treatment as a second priority. After expressing a need for information about the illness itself in order to understand the disease, patients across studies most frequently cited information about possible treatments, progress during treatment, and side effects as important to them (Table 1). No other information was cited in any studies as a second priority. According to Graydon and colleagues, information about treatment may include information on “various cancer treatments, how they work, how they are performed, sensations that may be experienced and possible side-effects” (Galloway et al., 1997, p. 61). The third priority for information need was less clear (Table 1). Among types of information other than those related to disease and treatment that have already been noted, information about the risk of a family member getting cancer and information about investigative tests appeared in studies as information of importance to patients (Table 1). One must, however, keep in mind that

each result was found across studies by the same group of authors. The importance of information related to family risk was found in studies by Degner and colleagues (Degner et al., 1997; Luker et al., 1996; Luker et al., 1995), and a need for information about investigative tests was noted in studies by Graydon and colleagues (Galloway, et al., 1997; Graydon et al., 1997; Harrison et al., 1999).

#### *The least important information needs among cancer patients*

Patients showed the lowest need in relation to information about sexual concerns, ranking this information as the least important in several individual studies (Table 2). Less frequently, information about psychological concerns and social activities was also noted in some studies as the least important. Among other types of information considered less important by cancer patients, information about self-care issues in dealing with disease and treatment was mentioned frequently (Table 2). The studies that found patients to have a low need for information about self-care issues were all conducted by the same group of researchers (Bilodeau & Degner, 1996; Davison et al., 2002; Degner et al., 1997; Luker et al., 1996). No other type of information was noted at this level by patients in more than two individual studies.

[\[View Table 2\]](#)

#### *Demographics and the type of information need*

Except for one (Luker et al., 1996), all of the studies that analyzed the effect of age found that the need for a particular type of information differed according to a patient's age. In general, younger patients were found to need more of certain types of information (Table 3). For example, younger patients of both genders wanted more information related to sexuality and physical appearance (Davison et al., 2002; Degner et al., 1997; Luker et al., 1995), the type of information that was found in the literature to be of least importance to this group of patients overall (Table 2). However, when compared to older patients, results in three studies (Davison et al., 2002; Degner et al., 1997; Luker et al., 1995) show a

significant difference. In addition, Jenkins et al. (2001) and Meredith et al. (1996) found that younger patients wanted more treatment-related information than older patients.

[\[View Table 3\]](#)

There was, however, minimal evidence to show that older patients have a greater need for certain information than do younger patients. Bilodeau and Degner (1996) found that older patients wanted more information related to self-care, while Luker et al. (1995) reported that they wanted more information about social life.

As for education, more evidence existed for the absence of a relationship between level of education and the need for a particular type of information. Degner et al. (1997), Luker et al. (1996), and Luker et al. (1995) all found no relation between level of education and type of information need. In contradiction, two other groups of researchers found relationships between level of education and the need for a particular type of information. In each of these studies, however, the type of information need was different (Table 3). Bilodeau and Degner (1996) found that those with lower levels of education wanted more information on self-care while Davison et al. (2002) found that these patients needed more information about hereditary risk of cancer. The influence of gender on information need, i.e., whether females wanted more of any particular type of information than males did, was left for future examination in the literature. Except for Meredith et al. (1996), who found that women wanted more information on all possible treatments than men, not much attention was given to gender.

#### *Situations and type of information need*

Four situations in which cancer patients find themselves during illness are 1) time since diagnosis, 2) stage of disease, 3) type of treatment received, and 4) patient's preference for a role in decision-making during treatment. These situations were the focus for summarizing the effect of patient situations on the type of information they need as reported in the literature.

[\[View Table 4\]](#)

Degner et al. (1997) and Harrison-Woermke and Graydon (1993) found that patients closer in time to diagnosis wanted more information on their illness. In one of these studies, Harrison-Woermke and Graydon found that patients at this time also wanted more information about investigative tests, treatment, and physical care (Table 4). A separate study by Raupach and Hiller (2002) found a tapering need among women as time passed. For example, they reported that women's need for information about sexuality and relationships decreased over time. The same researchers reported that patients' need for other types of information did not change over time, a finding that was supported for all types of information by Harrison et al. (1999), who found no difference in need for a type of information as time during illness progressed. Therefore, the results are mixed about patients' need for information over time. Cancer patients may need more of certain types of information earlier in time, or they may have the same need for all types of information as time progresses. Their need for some information may even increase with time. For example, Degner et al. found that the need for information about self-care actually increased over time although, as noted above, patients' need for information about the disease was greater early on.

The ambiguity concerning the effect of time on patient preference for a type of information may stem partly from the inconsistent methods of measuring time in individual studies. Degner et al. (1997) studied patient preferences during the first week of radiation therapy and upon completion of the therapy. Harrison-Woermke and Graydon (1993) examined information needs at six-month intervals from diagnosis to over 25 months from diagnosis; and Raupach and Hiller (2002) studied patients from six months after diagnosis, in five-month intervals, to 30 months from diagnosis.

No patterns were discerned for the effect of the type of treatment received by patients on their need for a particular type of information. Only one of the two studies analyzing the effect of type of treatment (Jenkins et al., 2001; Meredith et al., 1996) found that patients

who were radically treated needed more information on illness and treatment (Table 4). Patients' stage of cancer did not affect their need for any particular information.

As for the effect of patients' preference for a role in decision making on the type of information they need, patients who preferred to be active wanted to know more about their illness, especially about the diagnosis and chance of cure (Degner et al., 1997; Hack et al., 1994). That active patients also wanted more information about treatment was evident in only one of the two studies (Hack et al., 1994). Results contradictory to these were reported by Davison et al. (1995) who revealed that collaborative-passive instead of active patients wanted more information on both illness and treatment (Table 4). It is important to note, however, that the categorization of patients based on preferred roles in the Davison et al. (1995) study was different from that in the other two studies. Davison et al. (1995) compared six hybrid styles as opposed to two or three basic styles covered in the other studies, which would lead to variation in the number of people in each group and the styles they prefer.

## **Discussion and Conclusions**

Although the two most needed types of information (first and second priorities) and the least needed information were apparent among cancer patients in this systematic review, more consistent terminology and scope in studying the health information needs of cancer patients are required. The varying terminology and the scope and depth of the information needs examined rendered the synthesis difficult to accomplish.

The synthesis of the effects that demographics and patient situations have on patients' needs for a particular type of information was even more complex. The measurement of information needs has been discussed in an earlier section, and information needs, to some extent, were comparable across studies. The comparison of the other variables, however, presented problems. Age, as seen in Table 3, is presented in different ranges. An analysis of the results indicates that younger female patients who are in their forties and fifties wanted more information on sexuality and physical attractiveness than older female

patients. When male patients were studied in order to determine whether younger patients wanted more information on sexual concerns, men under 65 were compared with those over 65, leading to difficulty in conceptualizing younger versus older cancer patients' needs. The reader must also keep in mind that studies in which patients were diagnosed with breast or prostate cancer were overrepresented in this systematic review. Most studies in which patients were diagnosed with other types of cancer did not examine this type of information. The age ranges in results concerning other types of information were even more varied.

In particular, the methodological issues related to studying patient situations that were uncovered while conducting this systematic review can improve future research considerably. There was consistency in the way variables were conceptualized in individual studies; that is, similar variables appeared across studies in examining the effect on types of information needs among cancer patients. There were, however, inconsistencies in the scales of measurement or the categories used to measure the variables. As noted in the previous section, the variable time elapsed since diagnosis and the variable decision-making style preferred by patients were measured differently across individual studies. These variations in measurement make synthesis across studies difficult if not impossible. Also, test statistics and probabilities must be provided for both significant and nonsignificant results of all inferential tests. Several studies lacked such data.

The findings of this systematic review show that information about illness and information about treatment are the most important to patients and that age, time since diagnosis, and patient decision-making style affect the need for specific types of information. These findings can provide guidance in information provision. However, consistent and precise measurement of age, education, time, and patients' preferred style for involvement in decisions can provide more accurate and valuable indicators for information provision. With the knowledge of the types of information cancer patients need and the characteristics of patients who need certain information, better use of limited time during interactions in

all information provision settings can be made in fulfilling patient needs. Also, precise results concerning how much information patients require will aid in attending to their needs. The reasons behind a greater need for information in some patients and a lower need in other patients must be probed. The answers will assist in assessing need when patients are inhibited due to reasons other than fear of information overload during a stressful time.

## References

Bilodeau, B.A., & Degner, L.F. (1996). Information needs, sources of information, and decisional roles in women with breast cancer. *Oncology Nursing Forum*, 23, 691-696.

Carr, A.B. (2002). Systematic reviews of the literature: The overview and meta-analysis. *Dental Clinics of North America*, 46, 79-86.

Cassileth, B.R., Volckmar, D., & Goodman R.L. (1980). The effect of experience on radiation therapy patients' desire for information. *International Journal of Radiation Oncology, Biology, Physics*, 6, 493-496.

Davison, J.B., Degner, L.F., & Morgan, T.R. (1995). Information and decision-making preferences of men with prostate cancer. *Oncology Nursing Forum*, 22, 1401-1408.

Davison, J.B., Gleave, M.E., Goldenberg, S.L., Degner, L.F., Hoffart, D., & Berkowitz, J. (2002). Assessing information and decision preferences of men with prostate cancer and their partners. *Cancer Nursing*, 25, 42-49.

Degner, L.F., Kristjanson, L.J., Bowman, D., Sloan, J.A., Carriere, K.C., O'Neil, J., et al. (1997). Information needs and decisional preferences in women with breast cancer. *JAMA*, 277, 1485-1492.

Galloway, S.C., Bubela, N., McKibbin, A., McCay, E., & Ross, E. (1993). Perceived information needs and effect of symptoms on activities after surgery for lung cancer. *Canadian Oncology Nursing Journal*, 3, 116-119.

Galloway, S.C., & Graydon, G.E. (1996). Uncertainty, symptom distress, and information needs after surgery for cancer of the colon. *Cancer Nursing*, 19, 112-117.

Galloway, S., Graydon, J., Harrison, D., Evans-Boyden, B., Palmer-Wickham, S., Burlein-Hall, S., et al. (1997). Informational needs of women with a recent diagnosis of breast cancer: Development and initial testing of a tool. *Journal of Advanced Nursing*, 25, 1175-1183.

Graydon, J., Galloway, S., Palmer-Wickham, S., Harrison, D., Rich-van der Bij, L., West, P., et al. (1997). Information needs of women during early treatment for breast Cancer. *Journal of Advanced Nursing*, 26, 59-64.

- Hack, T.F., Degner, L.F., & Dyck, D.G. (1994). Relationship between preferences for decisional control and illness information among women with breast cancer: A quantitative and qualitative analysis. *Social Science & Medicine*, *39*, 279-289.
- Harrison, D.E., Galloway, S., Graydon, J.E., Palmer-Wickham, S., & Rich-van der Bij, L. (1999). Information needs and preference for information of women with breast cancer over a first course of radiation therapy. *Patient Education & Counseling*, *38*, 217-225.
- Harrison-Woermke, D.E., & Graydon, J.E. (1993). Perceived informational needs of breast cancer patients receiving radiation therapy after excisional biopsy and axillary node dissection. *Cancer Nursing*, *16*, 449-455.
- Iconomou, G., Viha, A., Koutras, A., Vagenakis, A.G., & Kalofonos, H.P. (2002). Information needs and awareness of diagnosis in patients with cancer receiving chemotherapy: A report from Greece. *Palliative Medicine*, *16*, 315-321.
- Jenkins, V., Fallowfield, L., & Saul, J. (2001). Information needs of patients with cancer: Results from a large study in UK cancer centres. *British Journal of Cancer*, *84*, 48-51.
- Luker, K.A., Beaver, K., Leinster, S.J., & Owens, R.G. (1996). Information needs and sources of information for women with breast cancer: A follow-up study. *Journal of Advanced Nursing*, *23*, 487-495.
- Luker, K.A., Beaver, K., Leinster, S.J., Owens, R.G., Degner, L.F., & Sloan, J.A. (1995). The information needs of women newly diagnosed with breast cancer. *Journal of Advanced Nursing*, *22*, 134-141.
- Meredith, C., Symonds, P., Webster, L., Lamont, D., Pyper, E., Gillis, C.R., et al. (1996). Information needs of cancer patients in west Scotland: Cross sectional survey of patients' views. *BMJ*, *313*, 724-726.
- Raupach, J.C., & Hiller, J.E. (2002). Information and support for women following the primary treatment of breast cancer. *Health Expectations*, *5*, 289-301.
- Stewart, D.E., Wong, F., Cheung, A.M., Dancey, J., Meana, M., Cameron, J.I., et al. (2000). Information needs and decisional preferences among women with ovarian cancer. *Gynecologic Oncology*, *77*, 357-361.

Table 1 - Three most important information needs among cancer patients

Study	Most important information needs			Type of cancer and time of information need	Statistic
	First	Second	Third		
Graydon et al. (1997, p.62)	Treatment	Disease	Investigative tests	Breast cancer Time: treatment	Percentage mean
Galloway et al. (1997, p. 1180)	Disease	Treatment	Investigative tests	Breast cancer Time: treatment	Percentage mean
Harrison et al. (1999, p. 221)	Disease	Treatment	Investigative tests	Breast cancer Time: treatment and post treatment	Percentage mean
Harrison-Woermke & Graydon (1993, p. 453)	Treatment	Physical	Diagnosis	Breast cancer Time: treatment	Mean
Galloway and Graydon (1996, p. 116) - pre-discharge group	Treatment and complications	Activities of living	Enhancing quality of life	Colon cancer Time: during hospital discharge	Percentage mean
Jenkins et al. (2001, p. 50)	Whether or not it is cancer (1)  What the chances of cure are (3)	What all the possible side effects of treatment are (2)  What all the possible treatments are (4)		Heterogeneous—breast, gastro-intestinal, hematological, lung, gynecological, urological, skin, CNS, head & neck, unknown primary, other Time: not specified	Percentage
Meredith et al. (1996, p. 725)	Whether illness is cancer (1)  What the chances of cure are (3)	What are all possible side effects of treatment (2)  What is week by week progress (4)		Heterogeneous—stomach, colon, lung, breast, cervix, ovary, bladder, prostate, other Time: not specified	Percentage
Stewart et al. (2000, p. 360)	Status and nature of cancer	Treatment concerns	Self-care and empowerment issues	Ovarian cancer Time: diagnosis, treatment, and follow-up	Percentage

Iconomou et al. (2002, p. 318)	Aftermath of chemotherapy (1) How chemotherapy worked (3) Duration of treatment (5)	Prognosis (2) Diagnosis (4)	How to deal with an emergency (6)	Heterogeneous—breast, lung, colorectal, genitourinary, other Time: treatment	Percentage
Davison et al. (1995, p. 1405)	Likelihood of cure (1) Advance of disease (2)	Types of treatment available (3) Effect of treatment on usual social activity (4)	Self-care needs (5)	Prostate cancer Time: 0-6 months post diagnosis	Thurstone scaling
Bilodeau & Degner (1996, p. 695)	Stage of disease (1) Likelihood of cure (2)	Treatment options available (3)	Physical and emotional (4)	Breast cancer Time: 0-6 months post diagnosis	Thurstone scaling
Davison et al. (2002, p. 47)	Prognosis (1) Stage of disease (2)	Treatment options (3) Side effects (4)	Sexuality (5)	Prostate cancer Time: after initial treatment consultation	Thurstone scaling
Degner et al. (1997, p. 1491) - overall and newly diagnosed groups	Chances of cure (1) Stage of disease (2)	Treatment options (3)	Risks of a family member getting breast cancer (4)	Breast cancer Time: newly diagnosed and treatment	Thurstone scaling
Luker et al. (1995, p. 138) - newly diagnosed group	Likelihood of cure (1) Spread of disease (2)	Treatment options (3)	Family risk (4)	Breast cancer Time: newly diagnosed	Thurstone scaling
Luker et al. (1996, p. 490) - newly diagnosed group	Likelihood of cure (1) Stage of disease (2)	Different types of treatment (3)	Family risk (4)	Breast cancer Time: newly diagnosed	Thurstone scaling
- follow-up group	Likelihood of cure (1) Stage of disease (3)	Family risk (2)	Different types of treatment (4)	Breast cancer Time: follow-up at home	Thurstone scaling
Galloway et al. (1993, p. 118) - pre-discharge group	Treatment & complications (1)	Enhancing quality of life (2)	Skin care (3)	Lung cancer Time: during hospital discharge	Percentage mean
- post-discharge group	Treatment & complications (1)	Enhancing quality of life (2)	Medication (3)	Lung cancer Time: after discharge at home	Percentage mean
Raupach & Hiller (2002, p. 293) - follow-up group	Information about recognizing a recurrence (1) Chances of cure (2)	Risk to family of breast cancer (3)	Tamoxifen and other antiestrogen drugs (4)	Breast cancer Time: post treatment	Percentages

Table 2 – Least important information needs among cancer patients

Study	Least important information needs		Type of cancer and time of information need	Statistic
	Lowest	Low		
Graydon et al. (1997, p. 62)	Psychological		Breast cancer Time: treatment	Percentage mean
Galloway et al. (1997, p. 1180)	Psychosocial		Breast cancer Time: treatment	Percentage mean
Harrison et al. (1999, p. 221)	Psychosocial		Breast cancer Time: treatment and post treatment	Percentage mean
Harrison-Woermke & Graydon (1993, p. 453)	Financial resources	Family	Breast cancer Time: treatment	Mean
Galloway & Graydon (1996, p. 116) - pre-discharge group	Community and follow-up	Skin care	Colon cancer Time: during hospital discharge	Percentage mean
Stewart et al. (2000, p. 360)	Financial issues	Sexuality	Ovarian cancer Time: diagnosis, treatment, and follow-up	Percentage
Iconomou et al. (2002, p. 318)	Medication at home	Diet/nutrition	Heterogeneous–breast, lung, colorectal, genitourinary, other Time: treatment	Percentage
Davison et al. (1995, p. 1405)	Effect of treatment on usual sexual activity	Effect of disease on family and close friends	Prostate cancer Time: 0-6 months post diagnosis	Thurstone scaling
Bilodeau & Degner (1996, p. 695)	Sexuality	Self-care issues	Breast cancer Time: 0-6 month post diagnosis	Thurstone scaling
Davison et al. (2002, p. 47)	Social activities	Home self-care	Prostate cancer Time: after initial treatment consultation	Thurstone scaling
Degner et al. (1997, p. 1491) - overall	Sexuality	Social activities	Breast cancer Time: newly diagnosed and treatment	Thurstone scaling
- newly diagnosed group	Sexuality	Home self-care	Breast cancer Time: newly diagnosed	Thurstone scaling

Luker et al. (1995, p. 138) - newly diagnosed group	Sexual attractiveness	Social life	Breast cancer Time: newly diagnosed	Thurstone scaling
Luker et al. (1996, p. 490) - newly diagnosed group	Sexuality	Self-care	Breast cancer Time: newly diagnosed	Thurstone scaling
- follow-up group	Sexuality	Self-care	Breast cancer Time: follow-up at home	Thurstone scaling
Galloway et al. (1993, p. 118) - pre-discharge group	Community and follow-up	Feelings about condition	Lung cancer Time: during hospital discharge	Percentage mean
- post-discharge group	Community and follow-up	Skin care	Lung cancer Time: after discharge at home	Percentage mean
Raupach & Hiller (2002, p. 293) - follow-up group	Breast reconstruction (1) Prostheses (3)	Sexuality and relationships (2)	Breast cancer Time: post treatment	Percentages

Table 3 – Effect of demographics on information needs among cancer patients

Demographics	Affect on type of information need	Type of cancer	Measure	Statistic
<b>Age</b>				
Jenkins et al. (2001, p. 49)	Patients < 70 wanted more information on medical name of illness, diagnosis, progress during treatment, chances of cure, possible treatments, side effects, and treatment working against illness than did patients > 70.	Multiple–heterogeneous	Designed by researchers	Chi-square
Meredith et al. (1996, p. 725)	Younger patients 15-64 wanted more information on all possible treatments than did older patients.	Multiple–heterogeneous	Designed by researchers	Chi-square
Bilodeau & Degner (1996, p. 695)	Women 65-83 wanted more information on self-care than did younger women.	Breast cancer	Thurstone scaling of information needs	T-test
Davison et al. (2002, p. 46)	Younger men ≤ 65 wanted more information on sexuality than did older men > 65.	Prostate cancer	Thurstone scaling of information needs	T-test
Degner et al. (1997, p. 1490)	Younger women ≤ 50 wanted more information on sexuality and physical attractiveness than did older women > 50.	Breast cancer	Thurstone scaling of information needs	Test for equality of proportions
Luker et al. (1995, p. 138)	Among the newly diagnosed, women < 40 and 40-60 wanted more information on sexual attractiveness than did women > 60, and older women > 60 wanted more information on social life than did younger women.	Breast cancer	Thurstone scaling of information needs	ANOVA Three groups compared
Raupach & Hiller (2002, p. 295)  - follow-up group	Women 50-69 wanted more information on sexuality and relationships, breast reconstruction, menopause and hormonal replacement therapy, and physical appearance than did women > 69. Women < 50 wanted more information on complementary and alternative therapies, menopause and hormonal replacement therapy, sexuality and relationships, and breast reconstruction than did women 50-69.	Breast cancer	Designed by researchers	Prevalence rate ratio (PRR)

Luker et al. (1996, p. 491)	No differences in need for any information based on age.	Breast cancer	Thurstone scaling of information needs	
<b>Education</b>				
Bilodeau & Degner (1996, p. 695)	Women with high school education wanted more information on self-care than did women with higher levels of education.	Breast cancer	Thurstone scaling of information needs	T-test
Davison et al. (2002, p. 47)	Men with high school education or lower wanted more information on hereditary risk of prostate cancer than did men with higher levels of education.	Prostate cancer	Thurstone scaling of information needs	T-test
Degner et al. (1997, p. 1490)	No differences in need for any information based on education.	Breast cancer	Thurstone scaling of information needs	
Luker et al. (1995, p. 139)	No differences in need for any information based on education.	Breast cancer	Thurstone scaling of information needs	
Luker et al (1996, p.491)	No differences in need for any information based on education.	Breast cancer	Thurstone scaling of information needs	
<b>Gender</b>				
Meredith et al. (1996, p. 725)	Women wanted more information on all possible treatments than did men.	Multiple–heterogeneous	Designed by researchers	Chi-square

Table 4 – Effect of situation on information needs among cancer patients

Situation	Affect on type of information need	Type of cancer	Measures	Statistic
<b>Time since diagnosis</b>				
Harrison-Woermke & Graydon (1993, p. 452)	Patients at T1 wanted more information on diagnosis, investigative tests, treatment, and physical aspects than did patients at T2.	Breast cancer	INQ-BC	T-test
Degner et al. (1997, p. 1490)	Closer to time of diagnosis, women wanted more information on chances of cure whereas further from diagnosis, women wanted more information on self-care.	Breast cancer	Thurstone scaling of information needs	Test for equality of proportions
Raupach & Hiller (2002, p. 295)  - follow-up group	With increasing time since diagnosis, women wanted less information on sexuality and relationships while their need for other types of information remained high.	Breast cancer	Designed by researchers	Mantel test for trend of odds
Harrison et al. (1999, p. 220)	No differences in need for any information over time.	Breast cancer	TINQ-BC	
<b>Type of treatment</b>				
Meredith et al. (1996, p. 725)	Patients receiving radical treatment wanted more information on chances of cure, possible treatments, and side effects than did patients receiving palliative treatment.	Multiple–heterogeneous	Designed by researchers	Chi-square Log rank test
Jenkins et al. (2001, p. 50)	No differences in need for any information based on type of treatment received.	Multiple–heterogeneous	Designed by researchers	
<b>Decision-making preference</b>				
Hack et al. (1994, pp. 284-5)	Active patients wanted more information on diagnosis, treatment options and risks, and treatment procedures than did passive patients.	Breast cancer	Information preference cards	Wilcoxon's rank sum test
Davison et al. (1995, p. 1405)	Collaborative-passive patients wanted more information on advance of disease, likelihood of cure, and types of treatment available than did active patients, passive patients, and other combination style patients.	Prostate cancer	Thurstone scaling of information needs	ANOVA Six groups compared

Degner et al. (1997, p. 1490)	Active patients wanted more information on chances of cure.	Breast cancer	Thurstone scaling of information needs	Test for equality of proportions
-------------------------------	---	---------------	--	----------------------------------