# Patient and family satisfaction with cancer-related information: A review of the literature

By Kim Chapman and Kathy Rush

#### **Abstract**

Individuals and families confronted with cancer experience many and varied educational needs. Cancer education is an important aspect of their care. Yet, over the past three decades, the literature has consistently identified that many patients and family members are dissatisfied with cancer education. This paper examines the literature relevant to one aspect of satisfaction with cancer education, patient and family member satisfaction with cancer-related information, according to patient, provider, and information factors. Gaps in the research are identified and discussed in relation to future research recommendations. The paper concludes with applications to clinical practice.

Education is considered important for anyone dealing with a health problem, but individuals and families dealing with cancer perceive education to be of paramount importance. Individuals with cancer and their families tend to want as much information as possible about the diagnosis, treatment, and other aspects of cancer care, whether this information is good or bad (Cassileth, Zupkis, Sutton-Smith, & March, 1980; Jones et al., 1999; Tattersall, Butow, Griffin, & Dunn, 1994; Turner, Maher, Young, Young, & Hudson, 1996). The need for new information and skills throughout the entire cancer experience is great. Individuals and families must deal with the varied phases of the experience, the pervasiveness of the illness, and the continuous, and often rapidly-changing needs.

A considerable body of research has focused on patient satisfaction with cancer care in general. Less attention has been devoted specifically to satisfaction with patient education. Yet, Sitzia and Wood (1998a) identified patient education as one of four components of satisfaction for cancer outpatients. While giving and receiving information is recognized as an important part of the educational process, there has been limited exploration of patient satisfaction with the information received.

Patient dissatisfaction with information provision dates back to the 1970s (Risser, 1975). Accumulating evidence since that time suggests that patients with cancer, irrespective of the type of cancer or the phase of the illness, are often dissatisfied with the information they receive (Northouse, Schafer, Tipton, & Metivier, 1999; Sitzia & Wood, 1998a, 1998b). The prevailing dissatisfaction heightens the importance of understanding the factors that influence patient satisfaction with information provision (Cassileth et al., 1980; Derdiarian, 1989; Fitch, Johnson, Gray, & Franssen, 1999).

The purpose of this paper is to examine research related to patients' and family members' satisfaction with cancer information. We will present a synthesis and analysis of the available literature related to patient and family satisfaction with cancer information. The paper will conclude by highlighting gaps in existing research and offering implications for clinical practice and future research.

## Factors influencing patients' and families' satisfaction with cancer information

We used the MEDLINE and CINAHL databases for this literature review because of their scope and capacity to target the research related to information satisfaction of patients with cancer and their family members. Research papers were selected from the early 1970s to August 2002 to capture all possible studies focusing on patient and family satisfaction with cancer-related information. Keywords used for the search included: satisfaction, expectations, perceptions, patient education, teaching, cancer, cancer information, and oncology. Of all the patient satisfaction literature reviewed, approximately one-quarter of the studies focused on patient determinants of satisfaction with cancer care; some were anecdotal and some research-based. Additional research papers were retrieved by manually searching reference lists included in the papers used for this review. For the purposes of this paper, only the empirical, research-based papers were included; both classic and more recent papers were incorporated into the review. Papers were selected irrespective of how satisfaction was defined. The authors (KC & KR) generated three categories from the reviewed empirical literature that reflected the major influences on patient satisfaction with cancer information: 1) patient-related factors, 2) provider-related factors, and 3) information-related factors. These inter-related categories served as an organizational framework for guiding the literature review, with no one category being perceived as more important than the others.

#### Patient- and family-related factors

Research supports patient- and family-related factors as important determinants of information satisfaction. A range of patient- and family-related factors that appear to influence satisfaction has been identified. These factors include expectations, preferences for type of information, information-seeking, anxiety, demographics, and compliance.

#### **Expectations**

The general satisfaction literature suggests that expectations influence patient satisfaction with care among patients from medical-surgical, gynecologic, and specialty inpatient units (Abramowitz, Coté, & Berry, 1987; Green, Coupland, & Kitzinger, 1990). How expectations interact with patient satisfaction in the cancer population is relatively unclear because there has been limited study of this

Kim Chapman, RN, MSc(N), is a Clinical Nurse Specialist, Oncology, with River Valley Health, Fredericton, NB.
Kathy Rush, RN, PhD, is a Professor, University of South Carolina, Spartanburg, Mary Black School of Nursing, Spartanburg, SC. At time of initial writing, Dr. Rush was a Professor at the University of New Brunswick in Fredericton, NB.

♦ CONJ • 13/3/03
RCSIO • 13/3/03
♦

relationship. Even less is known about the expectations for information of patients with cancer and the impact on satisfaction. In a classic 1984 study of cancer patients' expectations regarding overall care and satisfaction with information, Oberst (1984) reported that expectations of cancer patients (n=20) receiving ambulatory chemotherapy were positively correlated with satisfaction related to self-care (r=.626) and diagnostic/treatment information (r=.685). In 1988, Degner and Russell reported that patient satisfaction (n=60) with health care was directly linked to whether expectations of information were fulfilled. The completeness of information has been shown to significantly influence the extent to which expectations are met, a finding highly suggestive that adequacy of information relates to overall satisfaction with care (Oberst). Despite the pivotal role of expectations in understanding cancer patient satisfaction, further research building on this earlier work could not be found.

#### **Preferences for type of information**

Patient and family preferences for type of cancer information are an important, though poorly understood, variable in determining satisfaction with information (Degner & Russell, 1988). Contributing to this poor understanding are the varied usages of the term "patient preferences" found in the literature. The term has appeared explicitly in some studies, while in other studies related terms such as "learning needs", "perceived adequacy", and "usefulness of information" have been used.

Several studies have identified a range of patient preferences for types of information such as disease, tests, treatment options, expected outcomes, what to expect and what to do during a threatening event, and symptom relief (Cassileth, et. al., 1980; Derdiarian, 1986, 1987, 1989; Kutner, Foehner, & Steiner, 1999; Northouse et. al., 1999; Sutherland, Llwellyn-Thomas, Lockwood, Tritchler, & Till, 1989). Findings reporting the relationship between information preference and patient satisfaction have been inconclusive. For example, among a sample of recently-diagnosed men with cancer and their spouses, satisfaction increased commensurately for both patients and family members with the type and amount of information given in each of four categories – disease, personal, family, and social (p<.01) (Derdiarian, 1989). In contrast, in a more recent nationwide study of men's experiences with prostate cancer (n=621), almost one-fifth of the men voiced dissatisfaction with information received regarding emotional responses (19%), unconventional/alternative therapies (18.5%), how to talk with other men with prostate cancer (17.4%), available counselling services, and self-help and support groups (15.1%) (Fitch et al., 1999).

The majority of studies have examined patient and family preferences as a unit, making it difficult to determine the unique informational preferences of patients compared with their caregivers/families. Although Northouse and colleagues (1999) found that spouses highly desired information about the disease and treatment and wanted even greater amounts, spouses' specific informational satisfaction was masked by the use of an overall level of satisfaction with information. Recent research provides evidence that patients and their caregivers may have different preferences for type of cancer information (Aucoin-Gallant, 1999; Rees & Bath, 2000). Only one study was found that considered the informational preferences of caregivers (n=30) separately (Aucoin-Gallant). Although Aucoin-Gallant found that caregivers wanted disease- and treatment-related information, they identified psychosocial information among their top three informational needs. In particular, how to deal with negative social behaviours, the psychological impact of cancer and its treatment, and the probability of remission or recurrence were reported by over 80% of the caregivers. In light of Aucoin-Gallant's findings, studies analyzing patient and family data as a unit need to consider analysis of each study population separately.

#### **Information-seeking**

Studies have provided valuable insight regarding the relationship between patient satisfaction and information-seeking (Burish & Tope, 1992; Miller, 1987). Specific to the cancer population, Steptoe, Sutcliffe, Allen, and Coombes (1991) found in their sample of patients with metastatic cancer (n=77) that blunters (avoid or prefer minimal information) had a higher level of satisfaction with the cancer-related information they received, even though monitors (actively seeking information) had a higher level of factual knowledge. Findings suggest that blunters who reported good understanding of their condition and voiced satisfaction with information provided were satisfied, not because of high factual knowledge, but because of their coping style.

#### Anxiety

Anxiety as a main predictor of global satisfaction with health care has been consistently reported across patient populations (Oberst, 1984; Sitzia & Wood, 1998b; Steptoe et al., 1991; Waitzkin, 1984). Specific to the cancer population, a few studies have revealed similar findings. Oberst found that overall satisfaction in a sample of ambulatory patients receiving chemotherapy (n=20) was best predicted by patient anxiety (p<.001). Specific to cancer information, she further found that anxiety was weakly correlated with satisfaction with both diagnostic (r=-.241) and self-care information (r= -.336). Corroborating evidence by other researchers confirms a significant relationship between anxiety and satisfaction (Jones et al., 1999; Steptoe et al., 1991; Tattersall et al., 1994). Steptoe and colleagues found that those individuals who were highly satisfied with cancer information had lower trait anxiety (p<.05). Findings from Tattersall and colleagues' study revealed that the most significant predictor of both tape and letter satisfaction was patient anxiety before the consultation (p<.0001). They discovered that, as anxiety increased, satisfaction with the tape decreased.

#### **Demographics**

A number of demographic characteristics have been studied in relation to patient satisfaction with cancer information. Findings are inconclusive as to the effect of age, gender, education, socioeconomic status, religious beliefs, and treatment type on satisfaction with cancer information (Butow, Maclean, Dunn, Tattersall, & Boyer, 1997; Butow, Brindle, McConnell, Boakes, & Tattersall, 1998; Cassileth et al., 1980; Derman & Serbest, 1993; Steptoe et al., 1991; Tattersall et al., 1994). The confounding effect of studying multiple demographic variables simultaneously is the most likely explanation.

Findings from several other research studies suggest some association of patient demographics with cancer information satisfaction. Conflicting evidence has appeared regarding the relationship between age and satisfaction (Butow et al., 1997; Ong et al., 2000; Sitzia & Wood, 1998b; Steptoe et al., 1991; Tattersall et al., 1994). In a recent randomized, double-blind study of cancer patients attending their first consultation at outpatient clinics, age was found to interact with mode of information to influence patient satisfaction with information (Ong et al.). Younger patients were more satisfied than older participants (p<.01) with receiving a tape (mode of information). Other researchers (Jones et al., 1999) have found that patients under 60 voice more dissatisfaction with information given (type and amount) (p<.05). Men were found to be more dissatisfied with provided information in a survey conducted by Jones and colleagues (p<.05). In contrast, among Thai Buddhist patients with cancer undergoing radiation therapy, men expressed more satisfaction than women with nurse-provided education (Lundberg & Trichorb, 2001).

Though limited, evidence suggests that cancer type and marital status may influence satisfaction with cancer education. Researchers have reported cancer type as a confounding variable between the way information is delivered and satisfaction, suggesting an indirect relationship between the two variables (Dunn et al., 1993; Tattersall et al., 1994). The only study that addressed marital status found that patients who were never married were more satisfied with an audiotape compared with those who were married, divorced, or widowed (p<.01) (Tattersall et al.).

#### Compliance

Patient compliance (defined in the negative as stopping treatment) has been correlated directly with satisfaction with chemotherapy care (Sitzia & Wood, 1998b). In a comparative study of patients receiving chemotherapy, non-compliant patients were reported to be less satisfied with all aspects of nursing care, including patient information (p<.01). In particular, further analysis of specific areas of information revealed non-compliant patients to be significantly less satisfied with information related to practical management of side effects (p<.01). Earlier research highlighted that difficulty in managing side effects, not just their presence, contributed to noncompliance (Richardson, Marks, & Levine, 1988). Although it appears that non-compliant patients are less satisfied with information, whether compliance is a patient-related factor or an outcome of informational satisfaction is unclear.

#### Provider-related factors

Provider characteristics have been observed to influence patient and family satisfaction with information. There is a specific body of literature that describes a range of provider-related factors that influence patient/family satisfaction with cancer information. Factors from as broad as who provides the information to specific characteristics of the provider have been identified.

#### **Provider source**

A few, mainly descriptive, studies found that who provides the information seems to make a difference in patient satisfaction. Early work identified that patients with cancer preferred information from the physician and did not perceive nurses as informational resources (Oberst, 1984; Tishelman, 1994). However, a reversal in this pattern has been observed in more recent empirical work. A study of British patients attending an outpatient cancer clinic reported 85% satisfaction "all of the time" with information given by cancer nurses compared to 47% satisfaction with doctors' explanations (Hutchison, Addington-Hall, Bower, Austen, & Coombes, 1991). Similarly, Sitzia and Wood (1998b) reported increased patient satisfaction with information provided by nurses compared to physicians.

#### **Communication approach**

Communication has been identified as an important variable in patient satisfaction (Sitzia & Wood, 1998a). The approach used to communicate information is partly dependent on the approachability of the provider. Variability in how approachability is defined makes comparison of studies difficult. Pienschke (1973) defined approachability as openness to providing information or guardedness to restrict information. She found higher patient satisfaction when the provider used an open approach that explicitly informed the patient about the details of the diagnosis and prognosis. Provider approachability was the subject of two other studies (Kutner et al., 1999; Sitzia & Wood, 1998b). Sitzia and Wood (1998b) defined approachability as the interpersonal characteristics of the provider that encouraged patients to ask questions. They found a strong positive association between satisfaction with information on diagnosis and approachability of the consultant (p<.001). Kutner and associates described approachability in terms of decision-making

style. In their study, patients reported higher levels of satisfaction with information provided by physicians when a participatory decision-making style was used.

The specific relationship between communication approach and patient satisfaction with information has been difficult to isolate because patient factors appear to play an intermediary role. When Steptoe and colleagues (1991) interviewed medical oncology inpatients, they found greater satisfaction with provider communication among patients with low factual knowledge about cancer. Yet providing information in a way to promote recall has not been shown to affect level of satisfaction with care (Ley, 1982; Reynolds, Byrne, Sanson-Fisher, Poole, & Harker, 1981).

#### Provider behaviour/responses

Provider anxiety has been associated with patient satisfaction (Carter, Inui, Kukull, & Haigh, 1982; Hall, Roter, & Rand, 1981; Waitzkin, 1984). In the early 1980s, Carter and colleagues found that newly-diagnosed cancer patients' satisfaction increased when physicians expressed anxiety in their tone of voice. A few years later, Waitzkin suggested that patients were more satisfied with providers who demonstrated anxiety in their delivery of information.

Richardson and colleagues (1988) reported that patients' comments revealed that their perceptions of nurses' efforts to help manage side effects, whether side-effect outcomes were positive or negative, influenced their degree of satisfaction. Furthermore, Poroch (1995) suggested that the use of sensory and procedural descriptions by nurses gave patients the impression that the nurse had a credible understanding of, and empathy with, the experience upon which they were about to embark.

#### Information-related factors

Information factors such as information delivery mode, the degree of individualized information, and the amount and timing of information have been shown to influence satisfaction with cancer information (Poroch, 1995; van Wersch et al., 1997). Because information-related factors are integrally related to patient and provider factors, aspects of information factors have been addressed previously in relation to the other factors. The following section seeks to highlight unique dimensions of information-related factors that relate to patient satisfaction.

#### Mode of information delivery

Though limited, research supports the mode of information delivery as an important variable in cancer patients' satisfaction with the information they receive. A number of differing modes of communication have been explored including the log book, informational pamphlets/booklets, and audiotapes (Dunn et al., 1993; Hagopian, 1996; Tattersall et al., 1994; Vetto, Dubois, & Perez Vetto, 1996; Whelan et al., 1998).

Information booklets and pamphlets are used extensively in cancer education. Findings related to patient satisfaction with these widelyused information delivery modes have shown mixed results. Educational pamphlets distributed to 108 women with benign breast conditions resulted in higher overall reports of satisfaction (91%). Satisfaction significantly increased with the use of a file folder of information booklets and pamphlets among newly-diagnosed cancer patients (p<.0001) (Whelan et al., 1998). However, first-time chemotherapy patients were no more satisfied with use of a teaching book along with a 15-minute, individualized nurse-given patient education session compared with patients receiving the 45-minute standard didactic educational program (Porter, 1998). The one reviewed study which examined patient satisfaction with booklet/pamphlet characteristics found that five cancer booklets differing in content, emphasis, and origin were rated highly by patients with no significant differences found between books (Butow et al., 1998).

**♦** CONJ • 13/3/03

Research has suggested the efficacy of audiotapes in increasing cancer patient satisfaction (Dunn et al., 1993; Hagopian, 1996; Ong et al., 2000; Tattersall et al., 1994). Ong and colleagues found greater satisfaction with information among younger patients receiving an audiotape of the initial consultation compared with those in the control group who did not receive the audiotaped consultation. Increased satisfaction has been reported by patients listening to general informational tapes containing radiotherapy and side-effect information compared with a control group receiving standard care not including tape usage (Hagopian). It was unclear whether the increased satisfaction was statistically significant because of the difficulty with interpreting satisfaction scores as reported. Audiotaped information that is individualized and client-specific has been shown to further enhance patient satisfaction (Dunn et al.). In contrast, patients with cancer attending their first consultation with a medical oncologist were no more satisfied with information conveyed by an audiotape than with a summary letter (Tattersall et al.).

#### Individualized information versus general information

Across studies, it has been shown that individualizing information to clients' specific situations and cancer type increases satisfaction (Derdiarian, 1989; Dunn et al., 1993; Jones et al., 1999). Derdiarian (1989) found that recently-diagnosed men with cancer and their spouses who received individualized formal information, counselling, and referral were significantly more satisfied with information received than the control group who received non-individualized routine, informal information, counselling, referral, or follow-up care from the clinic's professional team. In a controlled, experimental study, Dunn and associates reported that the satisfaction of cancer patients attending their first consultation with a medical oncologist was significantly greater when information was conveyed by means of an individualized consultation audiotape (91%) compared with either a general audiotape (87.2%) describing cancer or no audiotape at all (85%) (p<.05). General information audiotapes appeared to confuse or distract patients from the specific facts of their own case (Dunn et al.). Using a different delivery mode, the computer, Jones and colleagues reported similar findings. Patients in their randomized trial of personalized computer-based information had a higher level of satisfaction when given personal information (mean difference 12%, 95% confidence interval 0.7%-23.9%).

Patients prepared for radiation therapy using structured and individualized preparatory patient education which incorporated sensory and procedural information (experimental group) were significantly more satisfied with the amount and specific information received than those prepared using the standard and unstructured hospital approach (control group) (p=.000) (Poroch, 1995). This level of satisfaction remained constant over time, from within a few days of commencing radiation therapy to the last week of each person's treatment (p<.001).

#### **Amount of information**

The relationship between patient satisfaction and amount of information has not been clearly defined. Dissatisfaction with the amount of information was indicated in a study by Turner and colleagues (1996) who found that 90% of post-treatment patients with Hodgkin's disease who had not received written information (62%) would have liked to receive written material. Yet, in another study, women with breast cancer who had received a "substantial" amount of information as part of a clinical trial were dissatisfied with the adequacy of information received (Reynolds et al., 1981).

Research has suggested that the amount of information fluctuates throughout the cancer experience, but results have been clouded by patients' preferences for information. Sitzia and Wood (1998b) reported greater patient satisfaction with enhanced information, but found that what the patient wanted to know was clearly an intervening variable. Another study reported that the type of information needed

by cancer outpatients in the treatment phase remained stable over time, but the amount of information requested decreased from the first to the second medical consultation (Butow et al., 1997).

#### **Timing of information**

The timing of cancer-related information is gaining increasing recognition as a factor influencing patient satisfaction with information. Only one comparative study was found that considered the timing of information (time sequence of provision of information) as an independent variable on satisfaction with information of patients undergoing radiotherapy (D'haese et al., 2000). Patients who received a step-wise approach to information provision (received booklet alone prior to stimulation followed by teaching sheets during the third to fourth day of treatment) were significantly more satisfied during the last week of treatment than the group receiving both booklet and teaching sheets simultaneously prior to stimulation (simultaneous group) (p=.001).

## Gaps in existing research and future research directions

The study of satisfaction with information in the cancer population has been largely atheoretical. While stress and coping theory and family systems theory have appeared in the general study of cancer patients'/families' informational needs, the theoretical basis specific to informational satisfaction has been lacking. Empirical work has not supported a strong theoretical base, with conceptual ambiguity characterizing the study of informational satisfaction. While a universal definition of patient satisfaction may be neither possible nor desirable, greater conceptual clarity is needed to aid theory development for guiding the study of patient satisfaction with information.

Theoretical models may be generated on the basis of continued empirical work to enhance understanding of both the determinants and outcomes of information satisfaction. Existing research points to the complex interplay of patient, provider, and information-related factors in determining patient/family satisfaction with information. The multifactorial nature of informational satisfaction requires that research be directed to understanding the relationships between and within factors/determinants. For example, the mediating influence of the patient's information-seeking style on patient preferences for amount and type of information and their expectations for information requires further examination. In addition, the ways in which these patient-related variables impact the amount, type, and timing of information (information-related variables) constitutes another important area of study. While various determinants have been studied, many others specific to the cancer population need to be explored, such as attentional fatigue, locus of control, and denial. Study of the impact of satisfaction with information on outcomes has been limited. One study established that satisfaction with the amount of information enhanced quality of life (Annunziata et al., 1998). Given the importance placed on quality of life for the cancer population, further exploration of how satisfaction with information affects this outcome is warranted.

Methodological weaknesses have characterized a number of studies. The majority of satisfaction studies have been quantitative in nature using paper-and-pencil formats. In a number of studies, psychometric information about the questionnaires had either not been obtained or was not reported [see Table One (pages 112-115) for summary]. When an overall satisfaction score is used, it has been found that high levels of dissatisfaction with information are masked by high levels of satisfaction on other aspects of care (Abramowitz et al., 1987; Steptoe et al., 1991).

Quantitative study designs have predominated in the study of informational satisfaction and have varied from descriptive to experimental. The inter-relatedness of patient, provider, and

RCSIO • 13/3/03

informational factors has made control of extraneous variables difficult in studies and has produced confounding and inconclusive results. More rigorous methodological designs need to be employed consistently. Further, exclusive use of crosssectional designs and longitudinal studies that have examined satisfaction over time during a single phase of the cancer experience have made it difficult to isolate how the phase of the cancer experience influences satisfaction with information. Longitudinal studies are needed to explore satisfaction with changing informational needs throughout the illness trajectory and across settings. Other variables such as time and/or family-friendhealth care team support need to be isolated and explored in relation to patient satisfaction with information. Qualitative studies have been lacking and, yet, have the potential for obtaining a deeper understanding of patients'/families' satisfaction with the information they receive.

Overall, sampling was generally seen to be a strength across studies, although limitations in approaches to sampling were noted. In particular, small sample sizes appeared among descriptive studies of patient-related factors, making for poor power to detect effects of person-related and setting-related characteristics on satisfaction (see Table One). Samples were drawn predominantly from single sites, making generalization problematic. Sampling patients and families separately would be helpful in identifying the unique determinants of informational satisfaction in these populations. Future studies could be enhanced through multi-site, random sampling and be extended to families and the pediatric population.

Although current research has enhanced understanding of patient satisfaction with the various types of cancer information needed, it still remains unclear what constitutes the adequacy and specificity of patient education. The timing of information, both in terms of the type and amount, bears further study, given that providing too much information too quickly and without appropriate discussion may be detrimental. Identifying the elusive balance between these information factors and their impact on patient satisfaction is an important topic for further research. Questions related to what information patients and family members want, when it should be provided, and by whom, remain unanswered. Answers to such questions may be better addressed through qualitative work.

#### Implications for practice

The findings from this overview of the literature related to patients' and family members' satisfaction with cancer information have several implications for practitioners. Practitioners need to be aware that patients and caregivers/spouses may have a high level of satisfaction with overall care, but have a lower level of satisfaction with cancer information. When patients/caregivers/spouses are satisfied with information, compliance is enhanced and outcomes improved. Patient and family satisfaction with information does not occur just because information is given (Jones et al., 1998). Nurses must consider characteristics of the patient/family, qualities they possess as providers of information, and the nature of the information itself in promoting patient/family satisfaction with the information they receive.

Nurses need to assess patients' expectations and preferences for information as well as their information-seeking style, so that information can be matched to the specific needs of patients. Patients who actively seek information, prefer disease- and treatment-related information, and have high expectations for the information they receive, will need to have teaching/educational approaches that are different from patients with low expectations, who want minimal information, and who prefer psychosocial information. As nurses understand patient/family informational expectations, preferences, and seeking behaviour, they will be better able to individualize the amount, type, and timing of the information they give. Nurses must assess the unique informational preferences of both patients and

caregivers/family to ensure that informational preferences are being appropriately addressed.

The side effects of cancer treatment can create considerable anxiety for patients and their families. When anxiety is high, satisfaction tends to be low. To enhance patient satisfaction, anxiety must be minimized, especially through effective management of side effects. Poor management of treatment side effects can lead to premature discontinuation of treatment. As treatment occurs over a period of time and side effects emerge and dissipate, nurses have the challenge of providing adequate information for patients to manage side effects while not contributing to patient anxiety. Clinicians must be aware of the need to modify their approach to the provision of cancer information as informational needs change over time (as treatment progresses).

Health care providers must also be aware that they too can influence patient satisfaction with information. The nurse's approachability influences patient satisfaction with information. It is important for practitioners to be sensitive to the degree to which they are open to sharing information and receptive to questions. Nurses need to consider the patient's information style in determining whether to be more open or guarded in their approach to information giving. A nurse who tends to be open in sharing information will need to taper the amount of information for a patient who prefers minimal information. Conversely, a nurse who is more guarded will need to strive for openness with patients who desire information.

Existing research reflects a broad multidisciplinary approach used with the cancer population that is highly valued by patients with cancer and their families. However, the multidisciplinary approach that characterizes cancer care poses the potential for the provision of contradictory information. Contradictory information has been associated with dissatisfaction. Practitioners can enhance patient satisfaction with cancer education in a number of ways: i) by being sensitive to informational inconsistencies; ii) by promoting communication among themselves and between themselves and patients and their families; and iii) by attending to empathetic and caring communication in the delivery of information.

Practitioners can choose from a variety of information delivery modes that appear to be equally effective in promoting patient satisfaction. Practitioners need to make the information they give as specific as possible to the individual patient/family situation. Practitioners should not rely solely on written information, such as pamphlets/booklets, in giving information because these modes tend to present information more generally. Although standardized written material is a good starting point, it must be accompanied by assessing individualized learning needs and tailoring the education accordingly. Audiotapes have been found to promote patient satisfaction. Practitioners might consider audiotaping informational sessions and making the tapes available to clients/families. Clients/families can be overwhelmed with information at a time of great anxiety, and having the tape gives them the opportunity to listen and review information they may have missed or did not hear during the informational session (Ong et al., 2000).

#### Conclusion

A clearer understanding of patient satisfaction with cancer education has emerged as interest in this area of research has grown. Research is evolving to the point that theoretical development will soon be possible. Research to date has identified multiple patient-, provider-, and information-related factors determining patient satisfaction with cancer education. The study of outcomes of satisfaction with education is in its infancy. There are various gaps in the research which need to be addressed. Nevertheless, the existing body of research does provide a basis for guiding care of the cancer population.

References follow Table One on page 116.



## Table One: Synthesis of the empirical literature on patient/family satisfaction with cancer information Patient and Family Factors

Author(s)	Year	Design	Sample	N	Satisfaction variables	Tool(s) to measure satisfaction
Lundberg & Trichorb	2001	Quantitative Descriptive	Patients with cancer receiving radiation. Convenience	200	Satisfaction with education & support	Patient Experience Questionnaire consisting of four parts developed for the study. Satisfaction measured on a 5-point Likert scale.
Ong et al.	2000	Quantitative Randomized double-blind	Patients with varied types of cancer.  Random	201 (105 experimental group, 96 control group)	Satisfaction with information received	Patient Satisfaction Questionnaire & Patient Satisfaction Questionnaire-III. Visual analogue scales. Reliability & validity not discussed in article
Aucoin-Gallant	1999	Quantitative & Qualitative Descriptive	Female caregivers of individuals with cancer undergoing chemotherapy or radiation therapy.  Convenience	30	Satisfaction with learning needs	Learning Needs Satisfaction Scale (1995) - 5-point Likert scale. Established content validity. Homogeneity & stability: 0.80 & 0.84 respectively.
Fitch et al.	1999	Quantitative Survey	Men with prostate cancer who had undergone one type of cancer treatment.  Convenience	621	Satisfaction with type of information provided	Fifty-two-item survey instrument designed for study by the members of the research team. Twelve appear to measure satisfaction. Reliability & validity not discussed in article
Jones et al.	1999	Quantitative Three group, prospective, time series, randomized trial	Patients with breast, cervical, prostate, and laryngeal cancer. Random	525	Satisfaction with information	Satisfaction score calculated from seven attributes addressed via a questionnaire. Reliability & validity not discussed in article.
Kutner et al.	1999	Quantitative Two group, randomized trial	Ambulatory patients with varied cancer diagnoses scheduled for return visits. Random	282	Satisfaction with physicians' explanations	Researcher-developed questionnaire with nine items addressing satisfaction on a 5-point Likert scale. Coefficient alpha 0.72 for relation subscale & 0.65 for demand subscale. Validity not discussed in article.
Northouse et al.	1999	Qualitative Descriptive	Patients with colon cancer Convenience	30 patients & spouses	Satisfaction with information received	Semi-structured interview with item, "As you think back, how satisfied were you with information received?" Face validity established.
Butow et al.	1998	Quantitative Exploratory	Patients receiving chemotherapy or who had recently completed chemotherapy.  Random	52 phase I 24 phase II	Patient satisfaction with, preference for & use of information booklets	Phase I: six Likert-type items Internal consistency 0.64-0.70; item-total correlations 0.27-0.87 Phase II: same scale as phase I + two more items. Internal consistency 0.86; item-total correlations 0.40-0.91 with a mean of 0.74.
Jones et al.	1998	Quantitative Survey	Patients with breast, cervical, prostate, & laryngeal cancer scheduled to receive radiotherapy.  Random	525	Satisfaction with information received	Questionnaire (not described in article). Reliability & validity not discussed in article

CONJ • 13/3/03 RCSIO • 13/3/03 \(\psi\)

Table One: Synthesis of the empirical literature on patient/family satisfaction with cancer information Patient and Family Factors (continued)

	Patient and Family Factors (continued)							
Author(s)	Year	Design	Sample	N	Satisfaction variables	Tool(s) to measure satisfaction		
Sitzia & Wood	1998b 1998b	Quantitative & Qualitative Descriptive, exploratory	Patients with varied types of cancer receiving chemotherapy.  Random	173	Satisfaction with chemotherapy-related information, explanation of procedures & treatment, information on side effects, regimens, prognosis/progress.	Worthing Chemotherapy Satisfaction Questionnaire Forty-seven-item self-report questionnaire with 27 satisfaction questions using VAS or 5-point adjectival scale. Established validity & reliability.		
Whelan et al.	1998	Quantitative Before/after design	Patients newly- diagnosed with varied types of cancer. Random	300	Satisfaction with a personal file folder	Self-developed questionnaire. Validity & reliability not discussed in article.		
Butow et al.	1997	Quantitative Descriptive, exploratory	Patients with varied types of cancer.  Random	80	Satisfaction with amount of information provided and communication skills used to deliver information.	Twenty-five-item, Likert scale. Internal reliability 0.92. Validity not discussed in article.		
Turner et al.	1996	Quantitative Descriptive	Adults with Hodgkin's Disease. Convenience	165	Satisfaction with amount of information provided.	Self-developed questionnaire. Validity & reliability not discussed in article.		
Tattersall et al.	1994	Quantitative Experimental	Patients with varied types of cancer.  Random	182	Satisfaction with & use of communication aids.	Eight items derived from a content analysis of patient comments. Used a 10-point linear analogue scale. Validity & reliability not discussed in article.		
Derman & Serbest	1993	Quantitative Descriptive	Patients with varied types of cancer receiving treatment.  Convenience	45	Satisfaction with information provided.	Forty-five-item, semi-structured interview. Validity & reliability not discussed in article.		
Dunn et al.	1993	Quantitative Randomized trial, three groups	Patients with varied types of cancer attending their first consult with a medical oncologist.  Random	142	Satisfaction with mode of delivery of information (tape). Satisfaction with amount & quality of information received.	Twenty-two items from Roter & Korsch et al.'s questionnaire. Validity & reliability not discussed in article.		
Steptoe et al.	1991	Quantitative Exploratory, correlational	Patients with varied types of cancer admitted to hospital for assessment/treatment.  Convenience	77	Satisfaction with information (about tests, symptoms & treatment).	Seven 5-point scales. Reliability & validity not discussed.		
Derdiarian	1989	Quantitative Quasi-exp., two group design	Men recently diagnosed with varied types of cancer & their spouses. Random	30 patients & spouses/ experi- mental & control groups	Satisfaction with information received.	Patient satisfaction & spouse satisfaction instruments. Twenty-four Likert-type items to measure satisfaction. Established reliability & validity.		

Patient and Fa		I	T			
Author(s)	Year	Design	Sample	N	Satisfaction variables	Tool(s) to measure satisfaction
Sutherland et al.	1989	Quantitative Correlational	Patients with varied types of cancer receiving chemotherapy & radiation.  Convenience	52	Satisfaction with details acquired.	Information Seeking Questionnaire. Eighteen linear analogue self-assessment scales; five of which explored satisfaction. Reliability established using Cronbach's alpha (value not provided). Validity examined using the Health Opinion survey.
Degner & Russell	1988	Qualitative Descriptive	Patients with cancer. Theoretical sampling	60	Satisfaction indirectly explored via preference for control for decision-making.	Eight written vignettes. Used a card sort procedure.
Oberst	1984	Quantitative Descriptive, correlational	Ambulatory patients with varied types of cancer receiving chemotherapy.  Convenience	20	Satisfaction with diagnostic & treatment information, self-care information, quality of medical & nursing care, and extent to which expectations of care were met.	Five visual analogue scales contained within a questionnaire focused on perceptions and adequacy of care. Reliability (internal consistency) not measured. Validity not discussed in article.
Reynolds et al.	1981	Quantitative	Patients with varied types of cancer.  Random	67	Satisfaction with amount of provided information.	Structured interview using 5-point scale. Number of items not identified. Reliability & validity not discussed in article.
Provider Facto	rs					
Author(s)	Year	Design	Sample	N	Satisfaction variables	Tool(s) to measure satisfaction
Aucoin-Gallant	1999	Refer to Patien	t and Family Factors sect	ion.		
Sitzia & Wood	1998(b)	Refer to Patien	t and Family Factors sect	ion.		
Poroch	1995	Quantitative Quasi- experimental prospective	Patients with varied types of cancer receiving radiation therapy.  Random	Standard teaching group = 25 Intervention group = 25	Satisfaction with information & preference for timing & presentation of information.	Six subscales modified from the Pienschke Patient Satisfaction Questionnaire (PPSQ). No published validity or reliability data for the PPSQ.
Tishelman	1994	Quantitative Descriptive	Patients with varied types of cancer. Random	First interview: 46 Second interview: 20	Satisfaction with nursing care & provision of information.	Semi-structured interview. Interview guide prepared by researcher. Number of items not identified. Reliability & validity not discussed in article.
Hutchison et al.	1991	Quantitative Survey	Patients with varied types of cancer. Convenience	93	Satisfaction with care & explanations received from medical & nursing staff.	Self-developed survey.  Most items were on a 5-point scale; two were on a 3-point scale.  Validity & reliability not discussed in article.

♦ CONJ • 13/3/03 RCSIO • 13/3/03 ♦

Author(s)	Year	Design	Sample	N	Satisfaction variables	Tool(s) to measure satisfaction		
Steptoe et al.	1991	Refer to Patient and Family Factors section.						
Oberst	1984	Refer to Patient and Family Factors section.						
Reynolds et al.	1981	Refer to Patien	t and Family Factors sect	ion.				
Pienschke	1973	Quantitative 2x2 factorial design	Hospitalized patients undergoing investigation or surgery for cancer. Random	32	Satisfaction with approach to revealing information and type/amount of information provided.	Patient Interview-Questionnaire (modeled after Johnson & Thielbar, 1971) Validity & reliability not discussed in article.		
Information Fa	actors							
Author(s)	Year	Design	Sample	N	Satisfaction variables	Tool(s) to measure satisfaction		
D'haese et al.	2000	Quantitative Quasi-exp. Two group time series	Patients with varied types of (solid tumour) cancer receiving radiation. Random	68 31 trial group 37 control group	Satisfaction with timing of providing written information.	Satisfaction defined & satisfaction scores reported but unclear how scores were obtained.  Validity & reliability not discussed in article.		
Ong et al.	2000	Refer to Patien	t and Family Factors sect	ion.				
Porter	1998	Quantitative Two group, prospective, quasi- experimental	Adult patients with varied types of cancer receiving their first chemotherapy treatment.  Random	240	Satisfaction with the professional, educational, & trusting roles of the oncology nurses.	Patient Satisfaction Scale (Risser, 1975). Alpha reliability = 0.92. Validity not discussed in the article.		
Whelan et al.	1998	Refer to Patient and Family Factors section.						
Butow et al.	1998	Refer to Patient and Family Factors section.						
Butow et al.	1997	Refer to Patien	t and Family Factors sect	ion.				
van Wersch et al.	1997	Quantitative Two group, prospective, experimental	Patients with head & neck cancer.  Random	Trial group Patients = 60 Health Care Professional (HCP) = 59 Control group Patients = 39 HCP = 35	Psychosocial functioning. Support. Psychosocial problems.	Self-developed questionnaire. Validity & reliability not discussed in article.		
Hagopian	1996	Quantitative Post-test-only control group	Patients with varied types of cancer receiving radiotherapy. <b>Random</b>	75	Satisfaction with mode of delivery of information (audiotape).	5-point Likert scale survey. Six of the subscales modified from the Pienschke Patient Satisfaction Questionnaire. Validity & reliability not discussed in article.		
Vetto et al.	1996	Quantitative Survey	Women with benign breast conditions.  Random	130	Satisfaction with pamphlet.	Survey containing four satisfaction questions. 10-point Likert scale. Validity & reliability not discussed in article.		
Poroch	1995	Refer to Provider Factors section.						
Tattersall et al.	1994	Refer to Patient and Family Factors section.						
Dunn et al.	1993	Refer to Patient and Family Factors section.						
Derdiarian	1989	Refer to Patient and Family Factors section.						
		Refer to Patient and Family Factors section.						

### References

- Abramowitz, S., Coté, A., & Berry, E. (1987). Analyzing patient satisfaction: A multianalytic approach. **Quality Review Bulletin**, **13**, 122-130.
- Annunziata, M., Foladore, S., Magri, M., Crivellari, D., Feltrin, A., Bidoll, E., & Veronesi, A. (1998). Does the information level of cancer patients correlate with quality of life? A prospective study. Tumori, 84, 619-623.
- Aucoin-Gallant, G. (1999). Description of the caregiver's educational needs and the degree of her dissatisfaction. Canadian Oncology Nursing Journal, 9, 170-174.
- Burish, T.G., & Tope, D.M. (1992). Psychological techniques for controlling the adverse side-effects of cancer chemotherapy: Findings from a decade of research. **Journal of Pain and Symptom Management**, 7, 287-301.
- Butow, P., Maclean, M., Dunn, S., Tattersall, M., & Boyer, M. (1997). The dynamics of change: Cancer patients' preferences for information, involvement and support. **Annals of Oncology**, **8**, 857-863.
- Butow, P., Brindle, E., McConnell, D., Boakes, R., & Tattersall, M. (1998). Information booklets about cancer: Factors influencing patient satisfaction and utilisation. Patient Education and Counselling, 33, 129-141.
- Carter, W.B., Inui, T.S., Kukull, W.A., & Haigh, V.H. (1982). Outcomebased doctor-patient interaction analysis: II. Identifying effective provider and patient behaviour. Medical Care, 20, 550-566.
- Cassileth, B.R., Zupkis, R.V., Sutton-Smith, K., & March, V. (1980). Information and participation preferences among cancer patients. Annals of Internal Medicine, 112, 832-836.
- Degner, L., & Russell, C. (1988). Preferences for treatment control among adults with cancer. **Research in Nursing & Health, 11**, 367-374.
- Derdiarian, A.K. (1986). Information needs of recently diagnosed cancer patients. **Nursing Research**, **35**, 276-281.
- Derdiarian, A.K. (1987). Informational needs of recently diagnosed cancer patients: Part II. Method and description. Cancer Nursing, 10, 156-163.
- Derdiarian, A. (1989). Effects of information on recently diagnosed cancer patients' and spouses' satisfaction with care. **Cancer Nursing**, 12, 285-292.
- Derman, U., & Serbest, P. (1993). Cancer patients' awareness of disease and satisfaction with services: The influence of their general education level. **Journal of Cancer Education**, **8**, 141-144.
- D'haese, S., Vinh-Hung, V., Bijdekerke, P., Spinnoy, M., Lochie, N., De Beukeleer, M. et al. (2000). The effect of timing of the provision of information on anxiety and satisfaction of cancer patients receiving radiotherapy. **Journal of Cancer Education**, **15**(4), 223-227.
- Dunn, S., Butow, P., Tattersall, M., Jones, Q., Sheldon, J., Taylor, J., & Sumich, M. (1993). General information tapes inhibit recall of the cancer consultation. Journal of Clinical Oncology, 11, 2279-2285.
- Fitch, M., Johnson, B., Gray, R., & Franssen, E. (1999). Survivors' perspectives on the impact of prostate cancer: Implications for oncology nurses. Canadian Oncology Nursing Journal, 9, 23-28.
- Green, M., Coupland, V., & Kitzinger, J. (1990). Expectations, experiences and psychological outcomes of childbirth: A prospective study of 825 women. **Birth**, 17, 15-24.
- Hagopian, G. (1996). The effects of informational audiotapes on knowledge and self-care behaviours of patients undergoing radiation therapy. **Oncology Nursing Forum**, **23**, 697-700.
- Hall, J.A., Roter, D.L., & Rand, C.S. (1981). Communication of affect between patient and physician. Journal of Health and Social Behaviour, 22, 18-30.
- Hutchison, G., Addington-Hall, J., Bower, M., Austen, M., & Coombes, C. (1991). **European Journal of Cancer Care, 1**, 15-18.
- Jones, R., Pearson, J., McGregor, S., Cawsey, A., Barrett, A., Craig, N., et al. (1998). Randomized trial of personalized computer based information for cancer patients. British Medical Journal, 319, 1241-1247.
- Jones, R., Pearson, J., McGregor, S., Harper Gilmour, W., Atkinson, J., Barrett, A., et al. (1999). Cross sectional survey of patients' satisfaction with information about cancer. British Medical Journal, 319(6), 1247-1248.
- Kutner, J., Foehner, K., & Steiner, J. (1999). Evaluation of the impact of a pre-visit questionnaire for addressing cancer patients' information needs. Journal of Cancer Education, 14, 248-253.
- Ley, P. (1982). Satisfaction, compliance, and communication. **British Journal of Clinical Psychology**, 21, 241-254.

- Lundberg, P., & Trichorb, K. (2001). Thai Buddhist patients with cancer undergoing radiation therapy. Cancer Nursing, 24(6), 469-475.
- Miller, S. (1987). Monitoring and blunting: Validation of a questionnaire to assess styles of information seeking under threat. **Journal of Personality and Social Psychology**, **52**, 345-353.
- Northouse, L.L., Schafer, J., Tipton, J., & Metivier, L. (1999). The concerns of patients and spouses after the diagnosis of colon cancer: A qualitative analysis. **Journal of Wound, Ostomy, and Continence Nursing, 26**, 8-17.
- Oberst, M. (1984). Patients' perceptions of care: Measurement of quality and satisfaction. Cancer, 10, 2366-2375.
- Ong, L.M., Visser, M.R., Lammes, J., van der Velden, B.C., Kuenen, B.C., & de Haes, J.D. (2000). Effect of providing cancer patients with the audiotaped initial consultation on satisfaction, recall, and quality of life: A randomized, double-blind study. Journal of Clinical Oncology, 18(16), 3052-3060.
- Pienschke, D. (1973). Guardedness or openness on the cancer unit. **Nursing Research**, **22**, 484-490.
- Poroch, D. (1995). The effect of preparatory patient education on the anxiety and satisfaction of cancer patients receiving radiation therapy. Cancer Nursing, 18, 206-214.
- Porter, H.B. (1998). Effectiveness and efficiency of nurse-given cancer patient education. Canadian Oncology Nursing Journal, 8, 229-234.
- Rees, C.E., & Bath, P.A. (2000). Exploring the information flow: Partners of women with breast cancer, patients, and health care professionals. **Oncology Nursing Forum, 27**(8), 1267-1275.
- Reynolds, P.M., Byrne, M.J., Sanson-Fisher, R.W., Poole, A.D., & Harker, J. (1981). Cancer and communication: Information-giving in an oncology clinic. **British Medical Journal**, 282, 1449-1451.
- Richardson, J.L., Marks, G., & Levine, A. (1988). The influence of symptoms of disease and side effects of treatment on compliance with cancer therapy. **Journal of Clinical Oncology**, **6**, 1746-1751.
- Risser, N. (1975). Development of an instrument to measure patient satisfaction with nurses and nursing care in primary care settings. Nursing Research, 24, 45-52.
- Sitzia, J., & Wood, N. (1998a). Patient satisfaction with cancer chemotherapy nursing: A review of the literature. **International Journal of Nursing Studies**, 35, 1-12.
- Sitzia, J., & Wood, N. (1998b). Study of patient satisfaction with chemotherapy nursing care. European Journal of Oncology Nursing, 2, 142-153.
- Steptoe, A., Sutcliffe, I., Allen, B., & Coombes, C. (1991). Satisfaction with communication, medical knowledge, and coping style in patients with metastatic cancer. **Social Science & Medicine**, **32**, 627-632.
- Sutherland, H.J., Llwellyn-Thomas, H.A., Lockwood, G.A., Tritchler, D.L., & Till, J.E. (1989). Cancer patients: Their desire for information and participation in treatment decisions. Journal of the Royal Society of Medicine, 82, 260-263.
- Tattersall, M., Butow, P., Griffin, A., & Dunn, S. (1994). The take-home message: Patients prefer consultation audiotapes to summary letters. Journal of Clinical Oncology, 12, 1305-1311.
- Tishelman, C. (1994). Cancer patients' hopes and expectations of nursing practice in Stockholm. Scandinavian Journal of Caring Science, 8, 213-222.
- Turner, S., Maher, E.J., Young, T., Young, J., & Hudson, G.V. (1996).
  What are the information priorities for cancer patients involved in treatment decisions? An experienced surrogate study in Hodgkin's disease. British Journal of Cancer, 73, 222-227.
- van Wersch, A., de Boer, M.F., der Does, E., de Jong, P., Knegt, P., Meewvis, C.A., et al. (1997). Continuity of information in cancer care: Evaluation of a logbook. **Patient Education and Counselling**, **31**, 223-236.
- Vetto, J., Dubois, P., & Perez Vetto, I. (1996). The impact of distribution of a patient-education pamphlet in a multidisciplinary breast clinic. **Journal of Cancer Education**, 11, 148-152.
- Waitzkin, H. (1984). Doctor-patient communication: Clinical implications of social scientific research. Journal of the American Medical Association, 252, 2441-2446.
- Whelan, T.J., Rath, D., Willan, A., Neimanis, M., Czukar, D., & Levine, M. (1998). Evaluation of a patient folder to improve the dissemination of written information materials for cancer patients. Cancer, 83, 1620-1625.

