

# Getting to know oncology inpatients and their families: A continuous quality improvement approach

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## Abstract

*Given the overall magnitude of cancer, a climate of stretched health care resources, and the political activism of cancer survivors and families, it is becoming increasingly clear that local service providers need to assess and reassess the care they provide. A qualitative design was used to seek the patient and family's perspectives on whether or not their needs were being met while in hospital. Direct feedback from a convenience sample of 19 oncology patients and families was elicited through a semi-structured interview.*

*Qualitative data analysis revealed eight important aspects of care for oncology patients and their families. These included: communication between patients and caregivers, caregiver availability and concerns about health care cutbacks, coordination and continuity of care, physical care and comfort, psychosocial care, caregiver sensitivity, caregiver competence, and the physical environment of the hospital.*

*Challenges faced by individuals and their families affected by cancer are highlighted as they navigate through our health care system. Respondents provide positive reinforcement for use of appropriate interventions by caregivers, while clearly outlining areas needing improvement.*

## Introduction

One in three Canadians will develop some form of cancer during his lifetime (National Cancer Institute of Canada [NCIC], 1997). Additionally, the population is aging and the incidence of cancer is higher in older age groups (Ministry of Health Ontario [MHO], 1993; NCIC, 1997). Caring for an aging population with specific needs is becoming a serious and pressing health care issue. Cancer is a major health problem both for those with the disease, as well as for their families and communities.

Often, the diagnosis of cancer is the beginning of a long-term or chronic condition. Affected individuals can face a lifelong relationship with the health care system for various aspects of the disease. Cancer treatment usually involves complex treatment modalities from multiple disciplines in a variety of settings (Conkling, 1989; Ferrell & O'Neil-Page, 1993). For this reason, cancer patients are often at particular risk for receiving fragmented care that does not meet their complex medical, social and psychosocial needs (Conkling, 1989; Fletcher et al., 1984; Lauria, 1991). As the incidence of cancer continues to increase over the next 20 years (MHO, 1994), so too will the

complexity of care delivery, and the number of agencies and sectors involved with the provision of services to this population.

This report documents a phase of needs assessment regarding the care of oncology inpatients at an urban teaching hospital. It is intended to provide foundational information in evaluating care. The activity was part of the ongoing quality improvement activities.

## Method

### Study participants

A convenience sample of individuals diagnosed with cancer admitted to one of eight inpatient units over a three-month period was invited to provide feedback regarding their care. Family members and significant others were invited to participate. A total of 19 patients and 13 family members were interviewed.

### Procedure

Patients and families were asked by an interviewer if they would spend 15 to 20 minutes discussing their hospitalization. Respondents were informed that the interviewer was interested in understanding if their needs were being met, in order to improve the provision of care. Confidentiality was assured.

Semi-structured interviews were conducted using a standard approach by two oncology nurses. Interviews took place in the patients' rooms for privacy and convenience and lasted 15 to 20 minutes. The interviews were not taped, however detailed notes were taken during the interviews which were used to reconstruct the interviews immediately following the sessions. Interviews were based on the following lead questions: (a) Was your stay at the hospital what you expected? (b) What were you pleased with? (c) Were there any areas where you felt your needs were not met? and (d) Is there anything else you would like to tell us that could help in providing better care for cancer patients at the hospital?

### Qualitative analysis

A qualitative content analysis (QCA) was performed on the interview data. QCA is an inductive strategy which essentially involves examining, comparing and categorizing data. This type of analysis results in the identification of themes present in the data



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(Altheide, 1987; Crabtree & Miller, 1992; Strauss, 1987). The interviews were typed into a word processing program. Interview transcripts were assigned a unique numerical identifier with no identifying personal information. Copies of the transcripts were then distributed to the two nurse researchers and two researchers from the clinical epidemiology unit for independent open coding. After the four researchers assigned their own codewords to categories or themes which began emerging in the transcripts, they met and compared, consolidated and came to consensus on coding categories and their definitions. Using the codewords (and categories) agreed upon, the transcripts were indexed using the academic word processing software Nota Bene version 4. The passages assigned to each codeword were then retrieved and examined by the researchers to determine if each passage had been assigned the appropriate codeword. When necessary, passages were recoded by consensus. The transcripts were re-indexed and the passages generated by codeword were again reviewed for consistency. The transcripts were re-indexed one last time becoming the data reported on here. The unit of analysis for this report is each text unit or passage, not the respondent.

## Results

The types of cancers experienced by the sample are summarized in Table One. The sample consisted of 13 female and six male patients who ranged in age from 38 to 85 years (median = 60 years) and 13 of their family members.

The qualitative analysis revealed eight important aspects of care for oncology patients and their families. In descending order of frequency, comments raised most often related to: (a) communication between patients and caregiver (50 comments made by 14 individuals), (b) caregiver availability and concerns about health care cutbacks (47 comments made by 15 individuals), (c) coordination and continuity of care (45 comments made by 14 individuals), (d) physical care and comfort (41 comments made by 16 individuals), (e) psychosocial care (33 comments made by 16 individuals), (f) caregiver sensitivity (31 comments made by 13 individuals), (g) caregiver competence (15 comments made by seven individuals), and (h) the physical environment (13 comments made by nine individuals). Each of these aspects of care is summarized below and preceded by quotes which are representative of the comments made by patients and their families.

### Communication between patients and caregivers

*Before I knew it, there stood a nurse tech in front of me. She was dressed in a mask, big goggles and a funny coloured apron. She carried a cardboard tub that said BIOHAZARD with a symbol on it that looked like a bat. It reminded me of Hallowe'en and ghosts. I was terrified! The next thing I saw was the nurse removing a very large syringe from that box. Talk about fear! And all this one day after being told that I might have only six days to live. Gowned, masked, with goggles and carrying a tub that*

*says BIOHAZARD gives me a LETHAL MESSAGE. I feel like I'm in a foreign country. Please explain to me what all these things mean. Why are they necessary? Explain the whole procedure to me. (60-year-old male with AML)*  
*Most of the time the doctors have been attentive and caring. But sometimes they don't seem to listen to what I have to say. Sometimes I feel I can't get a word in edgewise. I know they are all very busy, but it would be helpful if they would take the time to sit down, even for a minute, and listen to my concerns. (56-year-old female with squamous cell lung cancer)*

Three distinct categories of communication issues emerged. Patients wanted: (a) information and explanations, (b) opportunity to talk and interact with caregivers, and (c) to be listened to by caregivers.

**Information seeking and wanting things explained.** Patients wanted information about their condition, treatment and prognosis. They indicated frustration when things were not explained to them. When explanations were provided, patients described a sense of control over what was happening to them. This reduced uncertainty and stress.

**Talking and interacting with caregivers.** Patients desired an opportunity to talk with their caregivers. Many patients equated the lack of opportunity to talk with caregivers with being treated impersonally or "as objects". When dialogue did not occur, they perceived their caregivers as "cold and clinical".

**Listening to patients.** Patients wanted to be listened to and by this they meant heard. They perceived that when listening occurred, their caregivers were responding to their needs. Patients talked about the frustration they felt when their caregivers did not hear what they were saying.

### Caregiver availability and concerns about health care cutbacks

*There are not enough nurses. They are too busy. We understand that emergencies come up. The other day, the nurse did not come in for a very long time. We found out later that someone had an ulcer that was bleeding very bad. There is only so much they can do. (Son of a 67-year-old female with CLL)*

The theme of caregiver availability and concerns about cutbacks related to patients' perceptions of the availability of caregivers. Patients wanted caregivers to be readily available to respond to their needs despite the fact that they perceived staff as being busy or overworked. Lack of caregiver availability was attributed to health care cuts. The need to involve family and friends in care provision was identified as an important strategy to deal with this issue. Four categories emerged within this theme: (a) perception of staff as being unresponsive to patient needs, (b) appearance of staff being busy/overworked, (c) awareness of cuts, and (d) need for family involvement.

**Responding to needs.** Patients valued prompt response to their needs by their caregivers. Clearly, patients were dissatisfied when their needs were not addressed in a timely fashion.

**Appearance of staff being busy/overworked.** Half of the patients indicated that they were keenly aware that nurses were very busy and overworked. Some of the comments revealed that patients rationalized that caregivers were too busy to provide the amount or type of care they would have liked to receive.

**Awareness of cuts.** Patients and their families attributed perceived compromises in the level and quality of care to declining resources. Not only did patients believe that these cutbacks directly impacted the physical care they received, but they also believed that it indirectly affected them because of the resulting caregiver stress.

**Need for family involvement.** Perceptions that patient care was seriously threatened by cutbacks was evident in the comments of a relatively small number of patients. These comments revealed that family members believed that they had to become personally involved in their relative's physical care in hospital since professional caregivers were unable to meet all of their loved one's needs.

**Table One: Sample characteristics**

Primary cancer	Number of patients
breast	5
colon	3
leukemia	3
lung	3
lymphoma	2
cervical	1
ovarian	1
multiple myeloma	1

### Coordination and continuity of care

*I was really happy to see the same nurse on the second night that I spent in the hospital. I was looking forward to having her again, she knew my requirements and I didn't have to tell her the whole story all over again. (47-year-old male with cancer of the colon, liver mets)*

*Last year I had to go in to the emergency department for blood (during the week I can go in to the special procedure unit to get it - they are great in there). They were not organized for me in emergency, nobody was able to open my Hickman for the longest time. I should have been in and out, but it took forever. (38-year-old female with breast cancer, lung and brain mets)*

The theme of coordination referred to the organization of care and the structure of the health care system within the hospital. It reflected the interaction and interconnection of the components and services making up the system. Waiting was one of the major outcomes of lack of coordination. Patients wanted coordinated care. For patients who were seriously ill, waiting was frustrating and for some infuriating. Many patients were painfully aware that their life expectancy was short. They did not want to spend 45 minutes repeating their histories or waiting long hours in hospital corridors.

Continuity of care also emerged as being highly valued by patients. Continuity of care involved having the same caregivers (nurses and doctors) managing and coordinating care. Patients wanted to get to know their caregivers and they wanted their caregivers to get to know them.

### Physical care and comfort

*We don't get back rubs any more because the nurses are too busy. I really miss that part of my care. (56-year-old female with squamous cell lung cancer)*

Many patients referred to physical care and comfort. The majority of these comments were related to physical needs that patients felt went unmet such as wanting to be checked on more often at night, wanting help to get into more comfortable positions, wanting back rubs, and wanting more appetizing meals. When considered in the context of why these patients are in hospital, it is understandable why these seemingly minor concerns become so important to patients and their families.

In contrast, several patients' comments indicated there was general satisfaction with the care they were receiving. It should be noted that while few patients mentioned they were pleased with how promptly they received their medications, none complained about not receiving pain medications.

### Psychosocial care

*They (the nurses) had an awareness of, and the ability to deal with all the non-medical stuff. They responded to a tear. These were nurses who were experienced, qualified. They were able to listen and be sensitive to a situation. I think the medical people tend to look only at the patients' stats like my blood counts and temperature. They don't seem to be aware of the whole human being as a person. The psychological, emotional and spiritual aspects seem to get lost. (60-year-old male with AML)*

Many patients commented on their psychosocial care. Comments highlighted the importance of psychosocial support for patients and their families. The majority of these comments were positive in nature. However, one-third of the comments suggested patients' social and psychological needs were not being addressed at all or to the patients' satisfaction. Patients indicated that they expected caregivers to respond to their psychosocial as well as their physical needs.

### Caregiver sensitivity

*The kids and I were with him when he was admitted at 0230 a.m. We waited outside while five nurses got him settled. Each nurse who came out of that room*

*acknowledged us and spoke to each one of us. They showed us how to get a cup of tea or juice. They made us feel comfortable right away. I was told that if I felt worried I should feel free to phone the nurses' desk at any time. The nurse not only said to my husband, "Are you all right?", she asked me too if I was all right. (Wife of a 42-year-old male with end stage Hodgkin's lymphoma)*  
*What upsets me most is when the doctors stand outside my door discussing cases. I can often hear what they are saying. It's frightening to listen to because you always wonder if they are talking about you. (62-year-old male with multiple myeloma)*

This theme consisted of comments which identified the absence or presence of caregiver sensitivity to patient needs and concerns. A number of comments reflected the appreciation patients felt when caregivers are perceived to be thoughtful and respectful. For example, several comments illustrated how "little" things such as introducing oneself or taking time to speak with the patient's family impact positively on patients. In many of the cases, caregiver sensitivity was actually about courteousness and politeness.

### Caregiver competence

*Competence is something I look for in all my caregivers. I want a nurse who knows how to deal with all my machines, tubes and medications. For my first chemo I was very lucky to have a very perceptive nurse. I didn't have to say to myself, "Can I trust this person with all these potent, lethal things?" In fact, I had only four nurses over those few days when I was so ill. I got to know and trust each one. I didn't have to repeat everything each time the shift changed... I need to know that my nurse is competent, that she knows about my disease... People can be with you for a very short time and inspire confidence by explaining what they are doing and showing that they are competent. (60-year-old male with AML)*

Comments related to patients' feelings of confidence in their caregivers were positive and negative; some mentioned trusting and feeling safe with their caregivers while others did not feel this trust. When patients did not perceive their caregivers as competent, they lost trust in them and in some cases even feared them. For some, caregiver competence was measured not only in terms of technical proficiency but also by the caregiver's ability to attend to psychosocial issues. The simple task of explaining procedures and practices to patients resulted in increased patient confidence in the caregiver's competence. Some comments suggested that high levels of stress amongst nurses were perceived to result in decreased competence.

### The physical/therapeutic environment

*I don't get much sleep in the hospital. Then I end up tired and weak. It's a vicious cycle. The doors in the two utility rooms bang and click all night long, surely that could be prevented. Once I was in a room with a lady who was dying of cancer. She moaned and groaned continually, day and night. She should have been in a single room. If you can't sleep, I think it delays your progress and that, in turn, leads to added days of hospitalization. (56-year-old female with metastatic breast cancer)*  
*Do they sterilize the commode chairs between patients? I don't think so. How would you like to use a dirty commode? (78-year-old female with metastatic colon cancer)*

There were a number of comments related to the physical environment of the hospital; most of these types of comments were about problems or concerns that patients had about their physical surroundings. Comments related to cleanliness of bathrooms, climate control (excessive heat in summer on some of the wards), and dry air which produced dry lips and throats. Patients also mentioned a number of factors which they felt contributed to poor sleep, including lighting, noise, drafty windows and other patients.

## Implications for nursing

Respondents indicated that they wanted to know their plan of care, specifically information about treatment, procedures and prognosis. Patients felt valued when given opportunities to discuss their treatment plan with their caregivers in a relaxed, unhurried atmosphere. Many patients described frustration with poor coordination of their care, which inevitably resulted in waiting. The use of critical paths or care maps is becoming a popular initiative designed to enhance the provision of cost-effective care that meets the needs of the client (Hofmann, 1993). The development of unit-specific care maps for high-volume, high-cost treatments or procedures with predictable outcomes may facilitate the communication of the multidisciplinary plan of care for patients and their families.

Patients felt that continuity of care was compromised with the lack of consistent caregivers. Clearly, the implementation of primary nursing as a care delivery system should enhance continuity in the nurse-provider relationship which is fundamental to the development of a therapeutic relationship (Procter, 1995).

A number of patients identified unmet physical care issues such as positioning and back rubs. In some instances, family and friends wanted to be involved in the provision of these basic care needs. Nurses can facilitate family involvement in physical care by assessing their desire to be involved and addressing any educational needs.

Aspects of care that patients and families felt extremely positive about were related to the manner in which the health care team dealt with them. Some examples include nurses showing compassion, empathy, "really caring", introducing one's self, acknowledging the family, and having a sense of humour. Patients and families wanted to

## References

- Altheide, D.L. (1987). Ethnographic content analysis. *Qualitative Sociology*, 10(1), 65-67.
- Conkling, V. (1989). Continuity of care issues for cancer patients and families. *Cancer*, 64, 290-294.
- Crabtree, B., Miller, W. (Eds.). (1992). *Research methods in primary care* (Vol. 3). Newbury Park, CA: Sage.
- Ferrell, B.R., O'Neil-Page (1993). Continuity of care. In S. Groenwald, M. Fogge & C. Yarbro (Eds.), *Cancer nursing: Principles and practice* (3rd ed.) (pp.1346-1359). Boston: Jones & Bartlett.
- Fletcher, R.H., O'Malley, M.S., Fletcher, S.W., Earp, J.A., Alexander, J.P. (1984). Measuring the continuity and coordination of medical care in a system involving multiple providers. *Medical Care*, 22(5), 403-411.
- Hofmann, P.A. (1993). Critical path method: An important tool for coordinating clinical care. *Journal on Quality Improvement*, 19, 235-246.
- Lauria, M.M. (1991). Continuity of cancer care. *Cancer*, 67, 1759-1766.
- Ministry of Health Ontario. (1994). *Life to gain: A cancer strategy for Ontario*. Toronto: Queen's Printer for Ontario (Cat #2226232).
- Ministry of Health Ontario. (1993). *A healthier Ontario: Progress in the '90s*. Toronto: Queen's Printer for Ontario (Cat #4225539).
- National Cancer Institute of Canada. (1997). *Canadian cancer statistics 1997*. Toronto, Canada.
- Ontario Cancer Treatment and Research Foundation. (1994, May). *Providing supportive care for individuals living with cancer*. Toronto, Canada: Author.
- Procter, S. (1995). Planning for continuity of care in nursing. *Journal of Nursing Management*, 3(4), 169-175.
- Strauss, A. (1987). *Qualitative analysis for social scientists*. Cambridge: Cambridge University.
- Strauss, A., Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage Publications.
- Taylor, C. (1995). Rethinking nursing's basic competencies. *Journal of Nursing Care Quality*, 9(4), 1-13.

be made to feel welcome, to be called by name and to be listened to. Patients wanted to be treated with respect, empathy and courteousness. They wanted to be treated as individual persons, not as a "number" or a "case". Psychosocial care was sometimes compromised by caregiver insensitivity.

Needs identified in this study fit within the practical, spiritual, psychosocial, informational, emotional and physical needs paradigm of the Supportive Care Framework (Ontario Cancer Treatment and Research Foundation [OCTRF], 1994). The appropriate approach for addressing a person's supportive care needs demands a partnership with the patient (OCTRF, 1994, p.14). Determining supportive care needs should be included in ongoing nursing assessments of these clients so that appropriate interventions can be tailored to meet their needs.

This study highlights the importance of responding to basic human needs with sensitive care from caregivers with interpersonal competence. Interpersonal competence may be defined as the ability to establish and maintain caring relationships that facilitate the achievement of valued goals while simultaneously affirming the worth of the participants in the relationship (Taylor, 1995). Taylor (1995) argues that nurses have struggled to meet the scientific and technical challenges inherent in the professional practice which has resulted in the diminishment of nursing's historical excellence in the interpersonal domain. Strategies for enhancing interpersonal competence include the creative use of look, speech and touch to communicate respect and enhance the patient's sense of worth; skilled use of presence and conversation to demonstrate empathy and to obtain sufficient knowledge about the patient to personalize care and serve as an effective advocate; and responsible, competent attentiveness to the holistic needs of patients such that trust is built and patients experience comfort or security (Taylor, 1995).

These findings highlight some of the challenges faced by individuals affected by cancer and their families as they navigate through our health care system. Nurses caring for cancer patients and their families need to be sensitized to the issues identified. Providing sensitive care that meets individual needs is not costly to implement. ♦

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