Oncology patients’ and nurses’ perceptions of caring

by Patricia Poirier and Ann Sossong

Abstract
The concept of caring is central to the practice of nursing. Recent focus on patient-centred care highlights the importance of viewing caring from the patient’s perspective. A comparative descriptive cross-sectional study was conducted to determine if there was a difference in oncology patients’ and nurses’ perceptions of caring. The Caring Behaviors Inventory-Elders (CBI-E) directly derived from Watson’s Theory of Human Caring was administered to patients and nurses from in-patient medical-surgical units. This paper reports on a subset of 19 patients and 15 nurses from the oncology unit. There were significant differences between patients’ and nurses’ perceptions on overall caring and on several individual behaviours. In order to provide true patient-centred care, innovative approaches to addressing these differences are needed.

Background
Caring is a concept adopted in the early 1800s by Florence Nightingale. Since that time, it is generally acknowledged worldwide that the concept of caring is central to the practice of nursing. There is, however, no single definition of what it means to care (Beck, 1999; Dyson, 1996). To borrow from McCaffery’s (1972) widely accepted definition of pain, caring is whatever the person experiencing it says it is (p. 8). Caring theories generally identify two general categories of caring behaviours: those that reflect activities or technical competence and those that reflect attitudes and behaviours or the affective aspects of caring (Wilkin & Slevin, 2004).

In a dyadic study of patients with cancer and their nurses, that patients regarded the subscales “accessible” and “explains and facilitates” as more important than the nurses thought they did. Burstron, & Sjoden, 1994). Widmark-Petersson et al. (2000) found, in a qualitative study of patients’ and relatives’ perspective on good and not so good care, that the nature of the care provided and the interpersonal qualities of caring were the major themes. Henderson et al. (2007) found, through both observation and direct questions, that patients felt cared for when nurses responded to specific requests. Studies of nurses have shown that nurses consistently emphasize the humanistic side of the caring relationship rather than the technical aspects (Bassett, 2002; Bertero, C., 1999; Dyson, 1996; Wilkin & Slevin, 2004; Yam & Rossiter, 2000).

Studies comparing oncology nurses’ and patients’ perceptions of caring have found both similarities and differences (Chang, Lin, Chang, & Lin, 2005; Larsson, Widmark-Petersson, Lampic, von Essen, & Sjoden, 1998; von Essen, Burstrum, & Sjoden, 1994; Widmark-Petersson, von Essen, & Sjoden, 2000). Larsson et al. found, in an inpatient oncology unit, that nurses stressed the emotional aspects of caring more than did patients and that patients rated the informational aspects of caring higher than did nurses. However, in another study employing matched pairs of cancer patients and nurses, there was no difference in the task-oriented dimension of caring (von Essen, Burstrum, & Sjoden, 1994). Widmark-Petersson et al. (2000) found, in a dyadic study of patients with cancer and their nurses, that patients regarded the subscales “accessible” and “explains and facilitates” as significantly more important than the nurses thought they did.

Although much has been studied about the concept of caring in nursing, much remains to be investigated. There has been a recent focus in health care toward true patient-centred care, as an indicator of quality. The Institute of Medicine (IOM) was chartered in 1970 by the United States government as an independent advisor to improve the nation’s health. The IOM (2001), in its report Crossing the Quality Chasm, defined patient-centred care as care in which treatment recommendations and decisions are respectful of and responsive to patients’ preferences, beliefs, and values. Focus on patient-centred care requires adaptation to patient perceptions. True patient-centred care then requires congruency in patients’ and nurses’ perceptions of care.

Perceptions relatives au caring chez les patients et les infirmières en oncologie

Abrégé
Le concept de caring est un élément fondamental de la pratique infirmière. L’intérêt croissant porté aux soins axés sur le patient souligne l’importance d’examiner les soins depuis la perspective du patient. Une étude transversale à la fois comparative et descriptive a été menée afin de déterminer une différence sur le plan de leurs perceptions du caring entre les patients en oncologie, d’une part, et les infirmières en oncologie, d’autre part. L’instrument Caring Behaviors Inventory-Elders (CBI-E) [Inventaire de comportements de caring-Aînés] directement influencé par la théorie du caring de Watson a été administré aux patients et aux infirmières d’unités d’hospitalisation en médecine chirurgie. Cet article examine un sous-ensemble de 19 patients et de 15 infirmières liés à l’unité d’oncologie. Des différences significatives ont été relevées entre les perceptions des patients et celles des infirmières concernant le caring considéré dans son ensemble et plusieurs comportements particuliers. Si on veut dispenser des soins réellement axés sur le patient, on doit cerner des approches novatrices en vue d’aborder ces divergences.

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Purpose
The purpose of this study was to determine if there were differences in patients' and nurses' perceptions of caring in an inpatient oncology setting.

Conceptual framework
The conceptual framework for this study was Watson's Theory of Human Caring. This theory focuses on the vital nature of the interpersonal process between the caregiver and the care receiver (Watson, 2002; Watson, 1996). Watson, in support of the theory, argued that "if human caring-healing is not sustained as part of our collective values, knowledge, practices, and global mission, the survival of humankind is threatened" (1996, p. 147). The Caring Behaviors Inventory-Elders (CBI-E) used to measure caring in this study was directly derived from the Theory of Human Caring and stresses the interaction of nurses and patients in therapeutic relationships (Fawcett, 2005; Wolf et al., 2004; Wolf, Zuzelo, Goldberg, Crothers, & Jacobson, 2006).

Methods
Design and sample
In order to evaluate similarities and differences in patients' and nurses' perceptions of caring, a comparative cross-sectional descriptive research design was used. A cross-sectional design was used to reflect the current standards of short hospital lengths of stay. This report is on the subset of oncology nurses and patients obtained from a larger study conducted on the in-patient medical-surgical units of a large medical centre in rural United States. Fifteen registered nurses were recruited from the in-patient oncology unit. This represented a 54% response rate from full- and part-time nurses on the unit. Nineteen patients were recruited over a four-day period. The average daily census of oncology patients on the unit ranges from 10 to 17. All patients were 18 years of age and older and had been in the hospital for at least 48 hours. Patients were excluded if they had evidence of cognitive impairments, as determined by the neurological assessment on the initial nursing assessment. Using these samples sizes, findings revealed a medium effect size with power of .92 based on Cohen’s (1988) power tables.

Instruments
Caring Behaviors Inventory-Elders (CBI-E). The CBI-E was developed by Wolf et al. (2004, 2006) to measure perceptions of nurse caring reported by older individuals and the nurses caring for them. Several versions of the CBI exist. In discussion with the developer of the instrument, the CBI-E was chosen as it best represented the anticipated age demographics of the study participants. The CBI-E consists of 28 items that use a three-point Likert format scale. Participants are asked to rate caring words and phrases on a three-point scale: 1 = rarely; 2 = sometimes; and 3 = often. Total scores may range from 28 to 84. Patient and nurse versions differ by direction and according to role with items corresponding by item (Wolf et al., 2006). For example, patients were asked “How often did the nurse caring for you give you your treatments and medications on time?” The corresponding question for nurses was “How often did you feel that you gave patients their treatments and medications on time?”

The CBI-E measures overall caring behaviours and five subscales representing the technical and emotional aspects of caring: a) attending to individual needs, b) showing respect, c) practising knowledgeably and skillfully, d) respecting autonomy, and e) supporting religious/spiritual needs. To accommodate elderly participants the CBI-E is printed in a 14-font type size with sufficient open space (Wolf et al., 2004, 2006). Readability level of the overall instrument, including directions, individual items, and demographic data was 4.5 according to the Flesch-Kincaid grade level.

The CBI-E demonstrated acceptable reliability and validity in previous studies (Wolf et al., 2004, 2006) with combined Cronbach’s alpha 0.936, the elders 0.941, and the caregivers 0.823. The CBI has been described as being valuable in determining perceptions of caring in both patients and nurses (Andrews, Daniels, & Hall, 1996, as cited in Watson, 2002). Cronbach standardized alpha coefficients were 0.891 for the combined sample, 0.687 for oncology nurses and 0.892 for oncology patients in the present study.

Demographic data form. The demographic data form for patients included type of living arrangements, age, gender, ethnicity, marital status, religion, and education. The demographic data form for nurses included age, gender, ethnicity, marital status, religion, and type of nursing education.

Procedures
Following approval by the university and medical centre institutional review boards, the researchers presented the study to the nurses on the oncology unit for their cooperation, participation and consent. Registered nurses caring for the patients screened patients for neurological impairment using the institution’s initial nursing assessment. Patients who did not have neurological impairment and who had been on the unit for at least 48 hours were asked if they were willing to have the investigators speak with them about completing the CBI-E. The investigators or designated research assistants then obtained informed consent and administered the CBI-E. All participants were assured of confidentiality. Patients took an average of 11 minutes and nurses took an average of six minutes to complete the CBI-E.

Data analysis
SPSS 12.0 for Windows was used to analyze the data. Descriptive statistics were used for the demographic data forms. Responses to the questions on the CBI-E were generally high with the distribution of responses highly negatively skewed. Thus, the non-parametric Mann-Whitney U test was used to compare nurses and patients perceptions on the CBI-E (Munro, 2005).

Results
Sample
Nurses who participated in the study were relatively young compared to national averages. Seventy-three per cent of the nurses were less than 40 years of age, with 33.3% less than 30 years of age. The majority of the nurses were female and married or living with a partner. Seventy-three point three per cent of the nurses had a bachelor’s degree in nursing, and 26.7% an associate’s degree, which is a two-year community college degree. No advanced practice nurses participated in the study. Patients who participated in the study ranged in age from 24 to 88 (M = 64.33, SD = 18.65). The sample was fairly evenly divided between male and female. Nearly 53% of

| Table 1. Differences between nurse and patient scores on selected items |
|-----------------|---------|---------|-----|
| Item            | Nurse   | Patient | Difference |
| Checking on you | 2.93    | 2.58    | .35* |
| Responding quickly to your call | 2.73    | 2.37    | .35* |
| Knowing how to give you needles, enemas, treatments, etc. | 3.0     | 2.68    | .32* |
| Managing your pain | 3.0     | 2.68    | .32* |
| Standing up for your interests | 2.93    | 2.74    | .32** |
| Appreciating you as a unique person | 2.93    | 2.63    | .30* |

*p = < .01; **p = < .05
patients were married or living with a partner. Approximately one-quarter of patients had less than a high school education. All patients and nurses in the sample were Caucasian.

Perceptions of caring
Overall, nurses rated their caring behaviours higher than did patients. The difference between the two groups was statistically significant with the overall mean for patients 2.70 and the overall mean for nurses 2.90 (Mann Whitney U/Z = -2.222, p = .026). Patients perceived that nurses caring for them met their technical needs to a significantly greater degree than their emotional needs (Wilcoxon Signed Ranks Z = -7.408, p = .000). There were no statistically significant differences in patients’ or nurses’ perceptions of caring by any of the demographic characteristics, such as age, gender or education.

Differences were noted among individual items on the CBI-E. Table 1 identifies items where nurses’ ratings were .3 or greater than patients’ ratings. There were several items where both nurses and patients rated nurses caring highly, greater than the mean for patients or nurses (> 2.9): helping you feel comfortable, being pleasant with you, protecting your privacy, watching out for your safety, being honest with you, helping you to feel at home, adjusting to your limitations, and trying to relieve your ailments. There were several other items where both nurses and patients rated nurses’ caring low, below the mean for patients or nurses (< 2.7): helping you and your family make decisions, assisting you to meet your religious needs, and appreciating your life story.

Discussion
The findings were positive with both nurses and patients giving nurses high marks for caring behaviours. Nurse caring was rated high on interpersonal skills such as being pleasant and helping a patient to feel at home. This is consistent with Watson’s Theory of Human Caring, which emphasizes the interpersonal relationships between patients and nurses. However, as found in previous studies, there were differences in patients’ and nurses’ perceptions of overall caring and of specific caring behaviours. Thus, there continues to be a lack of congruency in patients’ and nurses’ perceptions of caring. Innovative strategies need to be found to address this lack of congruency in order to provide true patient-centred care.

Practice implications
Patients rated nurses’ technical skills lower than did the nurses. The young age of nurses working on the oncology unit suggests that these nurses may be relatively inexperienced. They may not yet be comfortable with the complex treatments and protocols required of oncology patients. This may be perceived by patients as lacking technical competence. Institutions may need to expand their orientation programs to adjust to the needs of inexperienced nurses. The increased use of simulation technology in health care facilities may provide nurses opportunities to practise unfamiliar skills. In addition, specialty nursing organizations such as the Oncology Nursing Society (ONS) and the Canadian Association of Nurses in Oncology (CANO) have a wealth of educational resources available to support practising nurses.

Oncology patients have unique characteristics that may demand more of nursing such as difficult venous access, complicated treatment protocols, and the emotional strain of a cancer diagnosis. Bassett (2002), in a review of the literature, suggested that perceptions of care and caring may be very context dependent. Patients who are in pain or acutely ill may be more focused on tasks and having their immediate needs met. Patients in long-term care or in an terminal stage of illness may be more focused on the interpersonal relationship with the nurse (Bassett). Thus, oncology nurses need to be aware that patients may have different perceptions of caring depending on the stage of their illness. Nurses need to continue to validate with patients what care is important to them. Larsson et al. (1998) suggested that nurses need to learn to ask patients specific questions about their perceptions of care rather than depend on the nurses’ own assumptions or on non-specific information volunteered by patients or their families.

Policy implications
Nurses frequently cited time and staffing constraints as impediments to their providing care. Knebel (2003), in a report to the IOM’s summit on educating health professionals, identified the demands of nurses’ caring for many patients at a time as a barrier to providing patient-centred care. Focus on patient-centred care needs to be a key component of any policy decisions regarding nurse-patient staffing.

Limitations
Findings may have been influenced by the small sample size. Patients and nurses who chose to participate in the study may not be representative in demographics or perceptions of those who chose not to participate. Another limitation is the homogeneous ethnic and racial make-up of the sample; participants were 100% Caucasian. This limits the ability to generalize to diverse populations. The reliability index for the CBI-E for nurses was relatively low. Although the CBI-E had been validated with those caring for older individuals, the focus of oncology nurses was more likely on the cancer-related rather than age-related needs of their patients. This suggests that further validation of the CBI-E in the general oncology setting is warranted.

Recommendations for further research
Caring is a complex concept that is often context and culturally defined. The IOM (2001), in its discussion of patient-centred care, highlights the necessity of cross-cultural awareness and competence. It is important to continue to explore patients’ and nurses’ perceptions of caring in more diverse populations and settings. Replication of the study in the clinic setting will be important, as much of oncology care is given as an out-patient, where nurses and patients may have different perceptions of caring than those in the in-patient setting.

The congruency of low scores on decision-making, spirituality, and appreciating a patient’s life story suggest that perhaps in today’s health care environment these concepts may be difficult to address. However, the oncology literature continues to validate the importance of these concepts in cancer care. Both the Oncology Nursing Society (2009) and the Registered Nurses’ Association of Ontario (RNAO) (2006), in their position statements, emphasize that a key component of patient-centric care is involvement in making health decisions. A practice guideline from the RNAO to support decision-making is to spend time with clients in order to understand the situation from their perspective. Stacey, Samant, and Bennett (2008) found, through a review of randomized trials, that effective approaches to increase patient involvement in clinical decisions include training of health care providers in shared decision-making, incorporating patient decision aids into clinical discussions, and decision coaching by nurses and other allied health professionals. Spirituality is also considered to be a key component in nursing. A study by Taylor (2006) found, in a sample of 156 out-patient radiation oncology patients and in-patient medical oncology patients, that having “nurses help with spiritual needs consistently indicated varied and tempered enthusiasm” (p. 733). Being an in-patient and perceiving cancer as incurable were correlated with desire for nurses’ help with spirituality. Codes of ethics for nursing identify respect for the inherent dignity, worth, and uniqueness of every person (American Nurses Association, 2001; Canadian Nurses Association, 2002; International Council of Nurses, 2000). Anecdotally, both patients and nurses in the present study identi-
ried time as the major constraint in appreciating a patient's life story. Thus, research on patient’s perceptions of the importance of these concepts, decision-making, spirituality, and life story, is needed. Intervention studies need to be designed that identify approaches nurses can use to meet patient needs within the current time and staffing constraints.

Conclusions
This study provided insight into the perceptions of nurse caring by both patients and nurses that are present in today’s complex health care environment. Although both patients and nurses rated nurses’ caring highly, there were differences in individual items. There were also concepts that were rated low by both patients and nurses that are key concepts in oncology such as decision-making and spirituality. Additional research further addressing patients’ perceptions of caring needs to include intervention studies and diverse treatment settings. Patients’ needs and perceptions must be considered in any policy decisions regarding nurse-patient staffing. Changes in education of new oncology nurses may be needed to meet the directives for patient-centred care. As health care facilities continue to move forward in providing high-quality, cost-effective, patient-centred care, it will be vital to consider patient perceptions and ensure there is congruency in patients’ and nurses’ perceptions of caring.

References