

# Measuring Family Satisfaction With Care in the Intensive Care Unit: The Development of a Questionnaire and Preliminary Results

Daren K. Heyland and Joan E. Tranmer, for the Kingston General Hospital ICU Research Working Group

**Purpose:** To develop and test the feasibility of administering a questionnaire to measure family members' level of satisfaction with care provided to them and their critically ill relative.

**Materials and Methods:** To develop the questionnaire, existing conceptual frameworks of patient satisfaction, decision making, and quality of end-of-life care were used to identify important domains and items. We pretested the questionnaire for readability, clarity, and sensibility in 21 family members and 16 professionals. To assess validity, we measured the correlation between satisfaction with overall care and satisfaction with decision making. To assess the reliability of the questionnaire, we administered the questionnaire to next of kin of surviving patients on discharge and 7 to 10 days later.

**Results:** Questionnaires were mailed out to 33 family members of nonsurvivors; 24 were returned completed but only 22 (66%) were usable. Twenty-five family members of eligible surviving critically ill patients participated in the test-retest part of this study. Of the 47 respondents, 84% were very satisfied with overall care and 77% were very satisfied with their role in the decision making. There was good correlation between satisfaction with overall care and satisfaction with decision making (correlation coefficient = .64). The assessment of overall satisfaction with care was shown to be reliable (correlation coefficient = .85).

**Conclusions:** This questionnaire has some measure of reliability and validity and is feasible to administer to next of kin of critically ill patients.

Copyright © 2002 by W.B. Saunders Company

THE EFFECTIVENESS of critical care units has traditionally been evaluated by examining severity-adjusted measures of mortality, length of stay, and other measures of administrative efficiency. Increasingly, patient- and family-centered outcomes are being recognized as important outcome measures. From a quality care perspective, satisfaction with care is an important domain, especially for critically ill patients because desirable health status outcomes may not be attainable.<sup>1</sup> As the public demands more accountability for the use of public funds and assurance that the health care system is performing effectively, hospitals and other health care organizations are actively engaged in measurement of their performance, including the measurement of patients' satisfaction with care.<sup>2</sup> Although there is nascent understanding of the important determinants of patient satisfaction with care,<sup>3</sup> we do not know if these de-

terminants or aspects of care are relevant to families, particularly when their family members are critically ill and hospitalized in a complex intensive care environment.

The purpose of this project was to develop a tool to measure family members' satisfaction with the care provided to their seriously ill family member during their stay in intensive care. We focused on the intensive care setting because patients admitted to the ICU are experiencing life-threatening illnesses and, given the nature of care in a complex, multidisciplinary, technologically driven environment, there are many aspects of care that potentially may be dissatisfying. In this context, in which substitute decision makers play a large role in decision making, it is the perspective of the substitute decision maker (or family member as we will refer to in this article) that is most relevant.

Further justification for this project comes from recent studies that document that conscious patients dying in the hospital suffer moderate to severe pain and spend significant periods of time in an intensive care unit (ICU) on life supports before dying.<sup>4,5</sup> Concerns have been raised in both the lay press and scholarly journals about inadequate services for dying patients,<sup>6</sup> overtreatment of terminal patients,<sup>7,8</sup> and poor communication between patients and providers near the end of life.<sup>9-11</sup> These findings raise questions about the level of satisfaction with care provided to dying, critically ill patients and their families.

---

From the Departments of Medicine and Nursing, Kingston General Hospital; and the Department of Community Health and Epidemiology, and the School of Nursing, Queen's University, Kingston, Ontario, Canada.

Dr. Heyland is a Career Scientist with the Ontario Ministry of Health.

Supported in part by the Canadian Intensive Care Foundation.

Address reprint requests to Daren K. Heyland, MD, MSc, FRCP(C), Angada 3, Kingston General Hospital, Kingston, Ontario, K7L 2V7, Canada.

Copyright © 2002 by W.B. Saunders Company

0883-9441/01/1604-0004\$35.00/0

doi:10.1053/jcrc.2001.30163

Finally, existing literature documents variation across institutions in family satisfaction with terminal care.<sup>12</sup> This finding supports the notion that family satisfaction may be a worthwhile target for quality improvement initiatives. To be held as a standard by which ICUs are judged and as a target for quality improvement, measurements of family satisfaction need to be valid and reliable. To date, there has been little published research in this area.<sup>12</sup> Herein, we describe the development of a questionnaire to assess the family’s satisfaction with care provided in a critical care setting.

**METHODS**

**Instrument Development**

*Item Generation*

Items for the questionnaire were generated from existing conceptual frameworks of patient satisfaction, quality end-of-life care, existing research on needs of critically ill families, existing literature on family (dis)satisfaction with medical decision making, and from our pilot testing.

*Patient Satisfaction*

Patients’ perceptions of the quality of services provided is an important outcome indicator of organizational and clinical

effectiveness. The satisfaction literature generally reports that there are certain aspects of care that are important to a positive patient experience.<sup>3,13</sup> We have categorized these as: direct care, respect, coordination, communication, and environment (see Table 1). These categories are not exclusive but are meant to summarize and group selected care items (ie, skill and competence) to aspects of care that are important to patient satisfaction.

Most satisfaction measures will include specific, patient-defined expectations or standards (ie, aspects of care identified in Table 1) and a judgment of the relative degree of positive evaluation of the experience with the care (ie, satisfied or not satisfied). The critical challenge is to select the most appropriate attributes and methods to measure key components of patient satisfaction with service quality in a timely, accurate, and valid manner, recognizing that this is only 1 outcome measurement, of many, that should be collected and determined during an episode of care. With respect to the intensive care experience, we hypothesized that, similar to patients, family members expect care for the patient to be skilled, respectful, coordinated, and provided in a comfortable environment. They would also expect similar care for themselves.

*Quality End-of-Life Care*

There have been several attempts to develop a conceptual framework or taxonomy for quality of end-of-life care.<sup>14-17</sup> Three of these taxonomies are derived from expert medical opinion,<sup>15-17</sup> 1 is based on qualitative research with chronically ill patients.<sup>14</sup> Based on these taxonomies, there are several key

**Table 1. Patients’ Expectations About Their Care**

Aspect of Care	Descriptors of Aspect of Care
Direct Care: Care is skilled, knowledgeable, supportive, therapeutic, and comforting and provided in a timely manner	Skill and competence Response and attentiveness of condition Physical and emotional care and comfort (eg, pain and symptom management) Assistance with activities of daily living
Respect: Care is respectful of patients’ and families’ values, preferences, expressed needs, and is provided in a humanistic, caring, kind, and courteous manner	Courtesy and respect Positive attitude Friendliness Dignity Privacy and confidentiality Patient and family needs and autonomy respected
Coordination: There is confidence in the coordination, integration, accessibility, availability, and continuity of care	Coordination of clinical care (ie, someone is in charge) Coordination of support services (ie, discharge, admission, testing) Coordination of front line care (ie, patients and families know who to talk to) Accessible and available services (ie, operating room time, clinic visit waits, available staff)
Communication: Communication is informative, timely, honest, complete, and understandable and is provided in a manner that respects confidentiality, privacy, and participation	Information on clinical status, progress, and prognosis Information about the processes of care—ie, test results, available treatment options (including benefits and risks) Information and education to facilitate autonomy, self-care, and recovery—ie, discharge instructions Patient and family involvement in decisional processes
Environmental: Care is provided in safe, clean, comfortable, accessible, and calm patient surroundings	Hospital and surroundings are clean, comfortable, and accommodating to patient and family Belongings are safe Food and support services

indicators or domains that will define *quality* care near the end of life (see Table 2): symptom control, meeting hopes and expectations, maintaining overall well-being (physical, emotional, spiritual, and so forth), control or participation in decision making, strengthening relationships, burden on family, and provider skill. We recognize that the majority of ICU patients are not near the end of life. However, for those who do not survive, satisfaction with overall care is likely to correlate with these aspects of quality end-of-life care.

*Family Needs Assessments*

Because it pertains specifically to the critical care setting, considerable research has been conducted to define the needs of critically ill families.<sup>18</sup> These needs have been translated into questions and incorporated into a questionnaire designed to measure how well family needs are met.<sup>19</sup> These needs/questions constitute important elements of quality of care and were also used to generate items for our questionnaire measuring family satisfaction.

*Satisfaction with Decision Making*

Limited research has been performed to assess family satisfaction with decision making in the critical care setting. Guyatt et al<sup>20</sup> generated a list of items relevant to family satisfaction with medical decision making in the chronic-care setting based on a literature review and interviews with patients, relatives, and health care providers. In Oregon, Tilden et al interviewed 32 family members of 12 patients who died in an ICU while undergoing withdrawal of life support.<sup>21</sup> Themes that emerged and seemed to correlate with satisfaction with care included: feeling included in the decision-making process, avoiding prolongation of death, explication of families' roles, facilitating family consensus, and quality, quantity, and timeliness of information provided. In a survey conducted in North Carolina, bereaved family members of elderly patients who died at home,

at the hospital, and at a nursing home were interviewed. To improve quality of care at the end of life, family members emphasized the need for better communication, greater access to physicians, and better pain management.<sup>22</sup> In Switzerland, Malacrida et al<sup>23</sup> surveyed the relatives of patients who died in the ICU and found that a high percentage of respondents (83%) were satisfied with the care their family members received. Those who expressed criticisms primarily complained about the information received and the way it was communicated.<sup>23</sup>

Based on our literature review, which shows that the majority of poor quality care may stem from poor communication/decision making,<sup>22,23</sup> we constructed a questionnaire with the purpose of providing a broad overview of satisfaction with care and a specific, more detailed assessment of satisfaction with end-of-life decision making.

**Questionnaire Construction**

The study instrument was designed in 2 sections. The first section broadly assesses overall quality of care and largely stems from the Conference Board of Canada's "Measuring Up: Patient Satisfaction Survey".<sup>24</sup> This questionnaire is a modified version of the Patient Judgement's of Hospital Quality Questionnaire, a well-tested, valid, and reliable instrument developed in the United States in the late 1980s.<sup>25</sup> The same format/response options used in this hospital-based questionnaire were maintained, but the exact nature of the questions were changed to reflect the ICU setting and the fact that substitute decision makers would be responding. For each item, respondents chose 1 option from excellent, very good, good, fair, poor, or not applicable. The purpose of this section was to function as a screening tool, assessing the level of satisfaction over a broad range of domains. In areas in which deficiencies or dissatisfaction exist, deeper, more thorough assessments may be needed (using other tools) to define the exact nature and magnitude of the problems.

**Table 2. Taxonomy of Quality of End-of-Life Care**

Journal of the American Geriatrics Society Statement <sup>16</sup>	Institute of Medicine Committee <sup>17</sup>	Emanuel and Emanuel <sup>15</sup>	Singer et al <sup>14</sup>
Physical and emotional symptoms	Overall quality of life	Physical symptoms	Receiving adequate pain and symptom management
Support of function and autonomy	Physical well-being and functioning	Psychologic and cognitive symptoms	Avoiding inappropriate prolongation of dying
Advanced care planning	Psychosocial well-being and functioning	Social relationships and support	Achieving a sense of control
Aggressive care near death	Spiritual well-being	Economic demands and caregiving needs	Relieving burden
Patient and family satisfaction	Patient perception of care	Hopes and expectations	Strengthening relationships
Global quality of life	Family well-being and perceptions	Spiritual and existential beliefs	
Family burden			
Survival time			
Provider continuity and skill			
Bereavement			

In the second section of the questionnaire, we measured aspects of family satisfaction with decision making. We have organized the sequence of questions based on the work of Charles et al<sup>26</sup> who defined 3 distinct analytic components to the decision-making process: information exchange, deliberation about treatment options, and deciding on which treatment option (the outcome of the deliberation process). We developed questions that incorporated these items and other proposed by Tilden et al<sup>21</sup> into the framework of information exchange, deliberation, and deciding. In addition, we added additional questions to assess the preferred and actual role of the substitute decisions makers in the decision-making process.<sup>27</sup>

### Pretesting

We administered drafts of the questionnaire to 16 health care workers and 21 family members of critically ill patients. We asked the respondents 3 questions: (1) Do the questions make sense? (2) Are they written clearly? and (3) Are there other questions or issues you think we should ask about? Revisions were made based on feedback received before the questionnaire was further tested.

### Validity

The validity of the questionnaire used in this study stems from the fact that questions selected for inclusion in this questionnaire were derived from the literature and are principally based on the domains and concepts presented in the previous section on item generation (*content validity*). To further explore the validity of the questionnaire, in this feasibility study we assessed the degree to which satisfaction with overall care correlated with satisfaction with decision making. A priori we expected to find a high degree of correlation between satisfaction with care and satisfaction with decision making.

### Reliability

To assess the reliability of the questionnaire, we administered the questionnaire to 37 eligible family members when the patient was discharged from the ICU. Seven to 10 days later, we readministered the same questionnaire to the same family member while in the hospital. Given the logistical difficulties in contacting family members of deceased patients, only family members of surviving ICU patients were involved in the test-retest assessment.

### Study Population

This study was conducted at the Kingston General Hospital in Kingston, Ontario, Canada. Our ICU is a 21-bed combined medical and surgical unit. The study population consisted of identified family members (next of kin or decision makers) of mechanically ventilated adult patients who had been in the ICU for 48 hours or more. The person who completed the questionnaire had visited the patient at least once during their stay in the ICU. If there was more than 1 family member, we approached the one designated on the nurses' chart as next of kin. We chose a minimum of 48-hours stay in the ICU to be sure that the family member would have adequate exposure to the ICU setting. We excluded next of kin who may not have comprehended the questionnaire (in English) secondary to cognitive, psychiatric, or cultural issues.

### Data Collection

A research assistant working in the ICU identified eligible patients. For survivors of critical illness, at the time of discharge from the ICU, the research assistant contacted next of kin to solicit their involvement. Informed consent was obtained for the reliability assessment. For willing subjects, the research assistant left a copy of the questionnaire (to be self-administered) and made arrangements to pick it up the next day. Completed questionnaires were retrieved from the family member while the patient was still in the hospital. Seven to 10 days later, the research assistant again approached the same family member to fill out a repeat questionnaire. If the patient was discharged or the family member was not available, questionnaires were mailed to the family member.

For eligible patients who died, we used an approach to recruiting participation from their family members that reflected respect and compassion for the grieving individuals. On the patient's death, the family member received a booklet titled, "*Guidelines for the Bereaved*." Inserted in the booklet was a leaflet that informed the bereaved that they would receive a letter and a questionnaire in the next few weeks. A letter signed by the president of the hospital explaining the study and asking for their participation and the questionnaire (with a stamped, addressed return envelope) was mailed 3 to 4 weeks after death. Four weeks later, a second questionnaire was sent to those who had not responded.

### Data Analysis

The analysis of this study is largely descriptive. We determined the percentage of responses for each item and an item score, similar to a method used by Parkside Associates Inc. (Parkridge, IL).<sup>28</sup> Scoring for each item was based on the following scale: excellent = 100, very good = 75, good = 50, poor = 25, very poor = 0. We generated means, standard deviations, frequency tables, rates, and proportions to describe the patients, the respondents, and their answers. Internal consistency of the questionnaire was measured by calculating Cronbach's alpha (the average interitem correlation) for each domain. Spearman's correlation test was used to assess the degree of correlation between satisfaction with overall care and satisfaction with decision making and satisfaction with overall care on repeated assessments.

## RESULTS

Questionnaires were mailed out to 33 family members of nonsurvivors; 24 were returned completed but only 22 (66%) were usable. Thirty-seven family members of eligible, surviving, critically ill patients were approached to participate in the test-retest part of this study; 34 agreed to participate but only 25 (73%) completed both questionnaires in a usable fashion. Table 3 outlines the baseline demographics of study patients. Of respondents to the questionnaire, 67% were spouses, 15% were offspring, 9% were siblings, and 9% were parents. The item and overall scores are shown in Tables 4 and 5.

**Table 3. Demographic and Baseline Characteristics of Study Patients**

Characteristic	Survivors (n = 25)	Nonsurvivors (n = 22)	Total (n = 47)
Mean age (SD)	59.3 (20.6)	64.0 (12.1)	61 (17)
Women (%)	8 (32%)	2 (9%)	10 (21%)
Admission diagnosis (%)			
Cardiac	8 (32%)	5 (23%)	13 (28%)
Respiratory	6 (24%)	9 (41%)	15 (32%)
Neuro	3 (12%)	2 (9%)	5 (11%)
Sepsis	1 (4%)	1 (4.5%)	2 (4.3%)
Trauma	4 (16%)	0 (0%)	4 (8.5%)
Surgical	2 (8%)	3 (14%)	5 (11%)
Other	0 (0%)	1 (4.5%)	1 (2.1%)
Mean APACHE II (SD)	18.3 (7.08)	23.6 (7.8)	20.6 (7.8)
Mean (SD) length of ICU stay [days]	9.9 (9.5)	4.6 (4.9)	7.5 (8.1)

Abbreviation: APACHE II, Acute physiology and chronic health evaluation score.

In Table 4, for the domains, “Care of Family,” “Care of Patient,” “Professional Care,” and “ICU Environment,” the Cronbach’s alpha coefficients were .95, .97, .91, and .74, respectively. In Table 5, for satisfaction with decision making, the Cronbach’s alpha coefficients were .93 and .87, respectively, for the domains “Information Needs” and “Deliberation.”

There was good correlation between satisfaction with overall care and satisfaction with the role in

decision making (correlation coefficient = .636). Across the 2 time periods, the assessment of overall satisfaction with care was shown to be reliable; the Spearman’s correlation coefficient was .847.

**DISCUSSION**

The purpose of this study was to develop and pilot test a tool to systematically measure family satisfaction with care during their family member’s in-

**Table 4. Family Satisfaction With Care**

Aspect of Care	n	Responses					Scores*	
		Excellent %	Very Good %	Good %	Fair %	Poor %	Item Score	Item SD
<b>Care of family</b>								
Consideration of needs	46	74	15	7	2	2	89.13	22.14
Emotional support	47	64	21	4	6	4	83.51	27.72
Spiritual support	43	58	16	18	5	2	80.81	26.63
Coordination of care	47	58	30	9	4	0	85.11	20.62
Concern and caring for family	46	72	13	9	2	4	86.41	26.19
<b>Care of patient</b>								
Concern and caring for patient	47	70	19	6	2	2	88.29	22.02
Pain management	43	58	26	12	2	2	83.72	23.71
Breathlessness management	40	55	33	8	5	0	84.37	20.94
Agitation management	43	54	30	7	7	2	81.39	25.64
<b>Professional care</b>								
Nursing skill and competence	47	72	21	2	2	2	89.9	20.63
Nursing communication	47	62	21	9	4	4	82.98	27.14
Physician skill and competence	46	63	24	7	4	2	85.32	23.90
Physician communication	45	36	29	18	4	13	67.22	34.05
Social work	43	53	20	10	10	8	75.00	33.01
Pastoral Care	43	58	15	23	3	3	80.63	26.14
<b>ICU Environment</b>								
Atmosphere of the ICU	46	60	20	18	0	2	83.88	23.32
Atmosphere of the waiting room	46	39	36	11	11	2	74.43	27.22
Overall satisfaction	46	67	17	9	4	2	85.87	27.22

\*Calculation of scores: excellent = 100; very good = 75; good = 50; poor = 25, and very poor = 0.

**Table 5. Family Satisfaction With Decision Making**

Aspect of Decision Making	n	Responses					Scores*	
		Excellent %	Very Good %	Good %	Fair %	Poor %	Item Score	Item SD
<b>Information needs</b>								
Ease of getting information	47	53	30	6	11	0	81.38	24.71
Understanding information	47	55	23	13	9	0	81.38	24.71
Honesty of information	46	57	22	15	10	0	82.06	23.96
Completeness of information	47	60	21	13	2	4	82.44	26.54
Consistency of information	46	43	26	15	11	4	73.37	30.00
<b>Deliberation</b>								
Inclusion in decision making	47	66	15	15	2	2	85.11	24.26
Supported during decision making	44	27	59	5	7	2	75.56	22.54
Control over care	46	36	27	22	11	4	69.44	29.62
Enough information	46	45	32	15	9	0	91.30	24.27
Overall satisfaction with decision making	45	47	33	18	0	2	76.11	29.66

\*Calculation of scores: excellent = 100; very good = 75; good = 50; poor = 25, and very poor = 0; yes = 100, no = 0.

tensive care experience. Compared with other instruments to measure family satisfaction,<sup>12,29</sup> the strengths of our questionnaire relate to the comprehensive conceptualization of satisfaction and the rigor by which the questionnaire was developed and pretested. Items in the questionnaire were derived from existing literature on patient satisfaction, quality care near the end of life, the needs of families of critically ill patients, and satisfaction with decision making. As we expected, there was good correlation between satisfaction with overall care and satisfaction with decision making. Our response rate with family members of both survivors (73%) and nonsurvivors (66%) suggests that our data collection process was feasible. Based on our results to date, this questionnaire seems to have some reliability and validity and is feasible to administer to next of kin of critically ill patients.

Consistent with other published studies,<sup>12</sup> the majority of families surveyed in this study seem to be satisfied with the care provided to them and to their family members. Ninety-three percent (n = 43/45) reported that overall care was good, very good, or excellent. One of the predominant concerns with patient satisfaction surveys is that patients, or in this case, families, are reluctant to criticize care because of their perceived vulnerability in the patient role.<sup>30</sup> In this study, families were surveyed after discharge from the ICU or, in the case of nonsurvivors, after death. In addition, family members were ensured that responses were confidential and in no way would influence future care.

Although families did report overall satisfaction, the satisfaction scores for aspects of care varied. Families were most satisfied with the nursing care (score = 90) and least satisfied with the frequency of physician communication (score = 67). These findings are consistent with other studies in which satisfaction with nursing care is high and a significant contributor to overall satisfaction with care, whereas satisfaction with aspects of communication often score lower.<sup>12</sup> This validated the incorporation of the second part of the questionnaire that determined patient satisfaction with decision making (ie, communication).

In the critical-care setting, assessments of family satisfaction with care provided are limited. Some studies have evaluated the needs of families of critically ill patients and the extent to which those needs are met.<sup>19</sup> Although these are related concepts, needs assessments are not synonymous with satisfaction because unmet needs do not always translate into dissatisfaction. Nor does meeting needs guarantee satisfaction. Satisfaction with care provided to the critically ill patient is an important construct that is not measured in family needs assessment. For example, a recent survey of families of critically ill patients suggested that up to one half of families experience inadequate communication with health care providers.<sup>11</sup> This claim was based on assessments of the families' comprehension of what the physician communicated in family meetings. Although 54% of the 76 families interviewed had poor comprehension of what was said, half of

the families did not ask for more information. Furthermore, no measure of family satisfaction was assessed. Whether lack of comprehension of what the physician said significantly affects satisfaction with care remains to be determined.

Perhaps the most comprehensive assessment of family satisfaction with the care provided to seriously ill patients comes from the Study to Understand Prognosis and Preferences for Outcomes of Risks of Treatments (SUPPORT).<sup>12</sup> In 5 hospitals in the United States, 767 family members responded to an 8-item questionnaire regarding the circumstances around their relative who died within 6 months after admission to the hospital. Respondents were asked whether they agreed with or disagreed with 2 statements related to patient comfort and 6 statements related to communication. With this very narrow focus on satisfaction (not appropriate for an ICU setting), they found 84% of respondents were satisfied with the patient's comfort and 70% were satisfied with communication and decision making. Moreover, they found that satisfaction varied across the 5 participating institutions, suggesting that satisfaction varies with the institutional structure and practice patterns of participating hospitals. It would appear that there are opportunities to improve satisfaction and overall quality of care at some institutions.

In the second part of the survey we focused on the specific process of communication and decision making. There was good correlation between family satisfaction with decision making and satisfaction with overall care. This supports the hypothesis that communication and decision making are important components of the family member's experience in the ICU. Families were less satisfied with the "consistency of information provided," but were satisfied with the timing and amount of information provided. This finding is important and worthy of further study because, quite often, interventions to improve communication focus on the provision of more information and not on the process of how the

information is shared. Can we meet the families' expectations of providing consistent information in a busy ICU with multiple caregivers? Is this a realistic expectation? Perhaps to enhance communication effectiveness we need to encourage providers to communicate among themselves more before they communicate with families.

Given the paucity of existing data on family satisfaction and the limitations with existing tools, we justify the development of this new questionnaire to measure family satisfaction in the critical care setting. Although other tools exist and are used commonly in hospitalized settings, the unique characteristics of an intensive care unit suggest that a tool specific for critical care would be required. We have developed such a tool to measure family members' satisfaction with the care provided to their seriously ill family member during their stay in intensive care. We found that this questionnaire has some measure of reliability and validity and is feasible to administer to next of kin of critically ill patients.

We caution making strong inferences from these results given the small, select sample. A future step in our research program would be to collect data in a larger population across many sites. Furthermore, given that family satisfaction has been used as an outcome measure in interventional studies,<sup>31,32</sup> it would be important to determine whether this questionnaire is responsive to changes in levels of satisfaction. Finally, it remains to be seen if use of this tool leads to illumination of quality problems, which, when remedied, result in improved satisfaction. The first part of the questionnaire, which was conceptualized as a "screening tool," may be too general and lack specificity to show remediable problems in the care delivered in the ICU.

#### ACKNOWLEDGMENTS

The authors are grateful to members of the Kingston General Hospital ICU Research Working Group who provided valuable comments in the development of this questionnaire and to Drs. Graeme Rucker, Jim Kutsiagianis, and Peter Dodek for their comments on the manuscript.

#### REFERENCES

1. Stewart AL, Teno J, Patrick DL, et al: The concept of quality of life of dying persons in the context of health care. *J Pain Symptom Manage* 17:93-108, 1999
2. Ontario Hospital Association: Hospital Report 1999: A balanced scorecard for Ontario acute care hospitals. Toronto, Ontario, Ontario Hospital Association
3. Geretis M, Edgman-Levitan S, Daley J: Through the patient's eyes: Understanding and promoting patient centered care in Delbanco (eds). 1993 San Francisco, Jossey-Bass Publishers, 1993
4. The SUPPORT Investigators: A controlled trial to improve care for seriously ill hospitalized patients. *JAMA* 274:1591-1598, 1995
5. Benson J, Cantor J, Lynn J, et al: A national perspective on dying in America: Does place of death matter? Presented at

the New York Symposium on Health Services Research, New York, NY, December 10, 1995

6. The Final Journey. Toronto Star, Toronto, Ontario. December 2, 2000

7. Ahronheim JC, Morrison S, Baskin SA, et al: Treatment of the dying in acute care hospital. *Arch Intern Med* 156:2094-2100, 1997

8. Solomon MZ, O'Donnell L, Jennings B, et al: Decisions near the end of life: Professional views on life-sustaining treatments. *Am J Public Health* 83:14-23, 1993

9. Tulskey JA, Chesney MA, Lo B: How do medical residents discuss resuscitation issues with patients? *J Gen Intern Med* 10:436-442, 1995

10. Hanson LC, Danis M, Garrett J: What is wrong with end of life care? Opinions of bereaved family members. *J Am Geriatr Soc* 45:1339-1344, 1997

11. Azoulay E, Chevret S, Leleu G, et al: Half the families of intensive care unit patients experience inadequate communication with physicians. *Crit Care Med* 28:3044-3049, 2000

12. Baker R, Wu AW, Teno J, et al: Family satisfaction with end-of-life care in seriously ill hospitalized adults. *J Am Geriatr Soc* 48:S61-S69, 2000 (suppl)

13. Charles C, Gould M, Chambers L, et al: How was your hospital stay? Patients' reports about their care in Canadian hospitals. *CMAJ* 150:1813-1872, 1994

14. Singer PA, Martin DK, Kelner M: Quality end-of-life care. Patients' perspectives. *JAMA* 281:163-168, 1999

15. Emanuel EL, Emanuel LL: The promise of good death. *Lancet* 351:21-29, 1998 (suppl 2)

16. Measuring quality of care at the end of life: a statement of principles. *J Am Geriatr Soc* 45:526-527, 1997

17. Field MJ, Cassel CK (eds): For the Institute of Medicine: Approaching Death: Improving Care at the End of Life. Washington, DC, National Academy Press, 1997

18. Hickey M: What are the needs of families of critically ill patients? A review of the literature since 1976. *Heart Lung* 19:401-415, 1990

19. Johnson D, Wilson M, Cavanaugh B, et al: Measuring the ability to meet family needs in an intensive care unit. *Crit Care Med* 26:266-271, 1998

20. Guyatt GH, Mitchell A, Molloy DW, et al: Measuring patient and relative satisfaction with level or aggressiveness of care and involvement in care decisions in the context of life threatening illness. *J Clin Epidemiol* 48:1215-1224, 1995

21. Tilden VP, Tolle SW, Garland MJ, et al: Decisions about life-sustaining treatment. Impact of physician's behaviors on the family. *Arch Intern Med* 155:633-638, 1995

22. Hanson LC, Danis M, Garrett J: What is wrong with end of life care? Opinions of bereaved family members. *J Am Geriatr Soc* 45:1339-1344, 1997

23. Malacrida R, Bettelini CM, Degrade A, et al: Reasons for dissatisfaction: A survey of relatives of intensive care unit patients who died. *Crit Care Med* 26:1187-1193, 1998

24. Patient Satisfaction Survey Team: Measuring up: Patient satisfaction survey. The Conference Board of Canada, April, 1998

25. Ware JE, Berwick DM: Patient judgments of hospital quality: Report of a pilot study. *Medical Care* 28:S39-S44, 1990 (suppl)

26. Charles C, Gafni A, Whelan T: Decision-making in the physician-patient encounter: Revisiting the shared treatment decision-making model. McMaster University Centre for Health Economics and Policy Analysis, Working Paper Series #98-2, May 1, 1998

27. Degner LF, Kristjanson LJ, Bowman D, et al: Information needs and decisional preferences in women with breast cancer. *JAMA* 277:1485-1492, 1997

28. Patient Satisfaction Survey Team: Canadian Inpatient Hospital Survey, Kingston General Hospital Report 1999. Parkridge, IL, Parkside Associates Inc

29. Wasser T, Pasquale MA, Matchett SC, et al: Establishing the reliability and validity of the critical care family satisfaction survey. *Crit Care Med* 29:192-196, 2001

30. Health Services Research Group: A Guide to direct measures of patient satisfaction in clinical practice. *CMAJ* 146:1727-1731, 1992

31. Henneman EA, McKenzie JB, Dewa CS: An evaluation of interventions for meeting the information needs of families of critically ill patients. *Am J Crit Care* 1:85-93, 1992

32. Engelman RM: Mechanisms to reduce hospital length of stay. *Ann Thoracic Surg* 61:S26-S29, 1996