

Family satisfaction with care in the intensive care unit: Results of a multiple center study*

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Objective: To determine the level of satisfaction of family members with the care that they and their critically ill relative received.

Design: Prospective cohort study.

Setting: Six university-affiliated intensive care units across Canada.

Methods: We administered a validated questionnaire to family members who made at least one visit to intensive care unit patients who received mechanical ventilation for >48 hrs. We obtained self-rated levels of satisfaction with 25 key aspects of care related to the overall intensive care unit experience, communication, and decision making. For family members of survivors, the questionnaire was administered while the patient was still in the hospital. For family members of nonsurvivors, the questionnaire was mailed out to the family member 3–4 wks after the patient's death.

Main Results: A total of 891 family members received questionnaires; 624 were returned (70% response rate). The majority of respondents were satisfied with overall care and with overall

decision making (mean \pm SD item score, 84.3 ± 15.7 and 75.9 ± 26.4 , respectively). Families reported the greatest satisfaction with nursing skill and competence (92.4 ± 14.0), the compassion and respect given to the patient (91.8 ± 15.4), and pain management (89.1 ± 16.7). They were least satisfied with the waiting room atmosphere (65.0 ± 30.6) and frequency of physician communication (70.7 ± 29.0). The variables significantly associated with overall satisfaction in a regression analysis were completeness of information received, respect and compassion shown to the patient and family member, and the amount of health care received. Satisfaction varied significantly across sites.

Conclusions: Most family members were highly satisfied with the care provided to them and their critically ill relative in the intensive care unit. Efforts to improve the nature of interactions and communication with families are likely to lead to improvements in satisfaction. (Crit Care Med 2002; 30:1413–1418)

KEY WORDS: family satisfaction; quality care; critical care

With requests for more accountability for the use of public funds and assurance that healthcare delivery is effective, hospitals and other healthcare organizations are actively engaged in quality-of-care assessments (1). A key domain of quality of care is satisfaction with care. Because desirable health status outcomes may not be attained after critical illness (2) and be-

cause mortality rates in tertiary referral intensive care units (ICUs) may approach 15% to 20% (3), satisfaction with care is important not only to patients but also to their families. Furthermore, given that the majority of critically ill patients (especially those at high risk for poor outcomes) are unable to participate in decision making about treatments, the family's perspective is central to understanding (and

measuring) satisfaction with care in the ICU.

In the critical care setting, studies on family satisfaction with care are few in number and limited in scope. One tool has been developed to measure family satisfaction with care in patients who die after hospital discharge (4). Other studies have evaluated the needs of families of critically ill patients and the extent to which those needs are met (5, 6). However, needs assessments are not synonymous with satisfaction because unmet needs do not always translate into dissatisfaction. In addition, meeting needs does not guarantee satisfaction. Satisfaction with care provided to the critically ill patient is an important construct that cannot be measured by traditional family needs assessments. For example, a recent survey of 76 families of critically ill patients suggested that up to one half of the families experienced inadequate communication with healthcare providers (7). This claim was based on assessments of

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the families' comprehension of what the physician communicated in family meetings. Although 54% of the families interviewed had poor comprehension of what was said, half of these families did not ask for more information. Furthermore, no measure of family satisfaction was assessed in this study. Whether lack of comprehension about what physicians say significantly affects satisfaction with care remains to be determined.

The purposes of this study were threefold: 1) to describe levels of family satisfaction with critical care, 2) to determine which key variables correlate most strongly with high degrees of satisfaction, and 3) to determine whether satisfaction with care varies across sites and, if so, the reasons for such variation. By using a questionnaire we developed and have shown to be valid and reliable (8), we evaluated family satisfaction with care provided to critically ill patients and their families in six centers across Canada.

MATERIALS AND METHODS

Design. This study was a multicenter prospective survey involving ICUs in six tertiary care hospitals in Canada. All ICUs admitted both medical and surgical patients, were affiliated with medical schools, and functioned as closed units. Participating ICUs varied in size from 8 to 24 beds, with an average bed occupancy ranging between 77% and 98% and an average nurse-to-patient ratio of 1:1. The majority of participating ICUs had support services from a social worker (five of six), pastoral care worker (six of six), and clinical ethicist (four of six) available.

Eligible Patients. The study population consisted of identified family members (next of kin or decision makers) of mechanically ventilated adult patients who had been in one of the participating ICUs for 48 hrs or more. We chose a minimum stay of 48 hrs in the ICU to be sure that the family member had adequate exposure to the ICU setting. The person who completed the questionnaire had visited the patient at least once during the patient's stay in the ICU. If more than one family member visited, we approached the one designated on the nurses' chart as next of kin. We excluded next of kin who could not comprehend the questionnaire because of language, cognitive, or cultural barriers.

Questionnaire. We developed a questionnaire to measure family satisfaction with care provided in the ICU. The details of the questionnaire development have been published elsewhere (8). In brief, items for the questionnaire were generated from conceptual frameworks of patient satisfaction, quality care at the end of life, research on needs of critically ill families, literature on family satisfaction or dissatisfaction with medical decision making,

and from our pilot study. As poor communication and decision making are frequently cited as the main causes of dissatisfaction with care (9, 10), 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 decision making.

The questionnaire was formatted in two sections. The first part broadly assessed overall quality of care and was patterned after the Conference Board of Canada's Measuring Up: Patient Satisfaction Survey (11). This questionnaire is a modified version of the Patient Judgements of Hospital Quality questionnaire, a well-tested, valid, and reliable instrument developed in the United States in the late 1980s (12). The same format and response options used in the Conference Board of Canada's 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. The intent of this section was to function as a screening tool, assessing the level of satisfaction over a broad range of domains, such as how the patient and family member were treated, the care provided by doctors, nurses, and other ICU staff, and the atmosphere in the ICU and waiting room. Where deficiencies or dissatisfaction existed, deeper, more thorough assessments would be needed in the future (using other tools) to define the exact nature and magnitude of the problems.

The second part of the questionnaire focused more on satisfaction with decision making. We developed questions to determine the extent to which families were satisfied with the content, completeness and consistency of information provided to them and their overall satisfaction with decision making. In our pilot study of 47 families of patients admitted to the Kingston General Hospital, we demonstrated that the questionnaire was a feasible, valid, and reliable tool to measure family satisfaction in the ICU setting (8).

Data Collection. A research assistant working in the participating ICUs prospectively identified consecutive eligible patients. When patients were ready for transfer or discharge from the ICU, the research assistant contacted the next of kin to solicit their involvement in this study. For willing participants, on discharge, 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.

For eligible patients who died in the ICU, we used an approach to recruiting participation from their family members that reflected respect and compassion for the bereaved. Three to 4 wks after the death of the family member, a letter signed by the president of the hospital (or designate) was mailed to the next-of-kin. The letter expressed sympathy, ex-

plained the study, and requested the next of kin's participation via a stamped, addressed return envelope. Four weeks later, a second questionnaire was sent to those who had not responded. In some centers, contact with eligible family members was made initially by phone and interested participants were then mailed the questionnaire. All participants were specifically told their results would be kept confidential and would not be communicated back to the doctors and nurses looking after the patient. Data on patient's baseline characteristics were abstracted from charts retrospectively (Table 1). At the time respondents completed the questionnaire, they were also asked to provide information about their own demographics (Table 2). Research ethics approval was obtained from all sites. Research ethics boards did not require that we obtain informed consent from respondents.

Data Analysis. We generated means, standard deviations, frequency tables, rates, and proportions to describe the patients, the respondents, and their answers. We determined the percentage of responses for each item and an item score, similar to a method used by Parkside Associates (13). In this method, scoring for each item was based on the following scale: excellent or completely satisfied = 100, very good or very satisfied = 75, good or mostly satisfied = 50, poor or slightly dissatisfied = 25, very poor or very dissatisfied = 0.

To assess the relative importance of various factors related to overall satisfaction, we developed multiple variable logistic regression models. Respondent evaluation of overall satisfaction was considered as a categorical dependent variable, whereas items of the ques-

Table 1. Demographic characteristics of study patients

Characteristic	Total (n = 624)
Mean age (sd)	61.6 (17.85)
Sex (%)	
Female	258 (42)
Male	366 (59)
Race (%)	
White	573 (92)
Black	2 (0.2)
Asian	22 (4)
Native	18 (3)
Other	5 (0.8)
Primary admission diagnosis (%)	
Cardiovascular	120 (20)
Respiratory	191 (32)
Neurologic	53 (9)
Sepsis	58 (10)
Trauma	52 (9)
Gastroenterology	86 (15)
Other	29 (5)
Number of co-morbid conditions (%)	
None	39 (6)
One	194 (31)
Two	149 (24)
Three or more	242 (39)
Mean APACHE II (sd)	22.17 (7.75)
Mean (sd) length of ICU stay (days)	13.7 (16.20)

APACHE, Acute Physiology and Chronic Health Evaluation; ICU, intensive care unit.

Table 2. Demographic characteristics of respondents

Characteristic	n	Responses
Mean age (SD)	539	54.24 (15.03)
Sex (%)	620	
Female		430 (69)
Male		190 (31)
Relationship to patient (%)	613	
Parent		56 (9)
Partner		301 (49)
Brother/sister		82 (14)
Son/daughter (or in-law)		161 (26)
Other		13 (2)
Lives with patient (%)	624	
Yes		372 (60)
No		252 (40)
Location of home (%)	615	
In the city where hospital is		241 (39)
Out of town		374 (61)
Level of education (%)	585	
High school		94 (16)
Less than high school		232 (40)
Post-secondary education		259 (44)
Satisfaction with previous ICU experience (%)	579	
Completely satisfied		127 (22)
Very satisfied		96 (17)
Mostly satisfied		63 (10)
Slightly dissatisfied		15 (3)
Very dissatisfied		15 (3)
Not applicable		263 (45)
Satisfaction with previous care in hospital (%)	580	
Completely satisfied		135 (23)
Very satisfied		126 (22)
Mostly satisfied		85 (15)
Slightly dissatisfied		37 (6)
Very dissatisfied		26 (4)
Not applicable		121 (30)

ICU, intensive care unit.

tionnaire, respondent, patient, and site characteristics (including variables listed in Tables 1 and 2) where considered the independent covariates. In consideration of the markedly skewed distribution of responses and the failure of the parallel slopes' assumption of ordinal regression, an ordinary logistic regression model of the percentage of "completely satisfied" (vs. any lesser degree of) satisfaction was developed. Similarly, for most independent covariates, because responses tended toward one end of response options, we reduced the number of responses from five to three. These modified and other categorical variables were offered to the model building process as sets of dummy variables. Only the age of the respondent and the Acute Physiology and Chronic Health Evaluation II score of the patient were considered to be continuously distributed.

Model building was by means of a forward selection process of covariates (on the basis of their additional contribution to overall model fit, as assessed by a chi-square for covariates statistic) followed by a reassessment of the residual statistical significance of covariates that entered the model previously. We finalized the model when limited data and multicollinearity threatened the stability of the model. Dummy variables with near identical

levels of association were combined to determine the best model.

Crude analysis (i.e., with site as a single variable of interest) of possible differences in distribution of responses between centers was by means of contingency tables, with chi-square statistical assessment of significance, and also by logistic regression models containing five dummy variables (corresponding to $n - 1$, where $n = 6$ is the number of sites). These logistic regression models were further developed into multiple variable models to answer the question as to whether the initial significant differences observed between the sites could be explained by concomitant variation in other covariates.

RESULTS

Questionnaires were given to 611 family members of eligible surviving critically ill patients; 458 completed surveys were returned (response rate, 75%). Questionnaires were mailed to 280 family members of eligible nonsurviving critically ill patients; 166 completed surveys were returned (response rate, 59%). The overall response rate was 70% (624 of 891). Tables 1 and 2 outline the demo-

graphics of study patients and respondents. There were no significant differences in baseline or respondent characteristics between survivors and nonsurvivors (data not shown).

The majority of respondents were satisfied with overall care and with decision making (mean item score and SD, 84.3 ± 15.7 and 75.9 ± 26.4 , respectively). Families reported the greatest satisfaction with nursing skill and competence (92.4 ± 14.0), the compassion and respect given to the patient (91.8 ± 15.4), pain management (89.1 ± 18.3), and coordination of care (89.0 ± 16.5). They were least satisfied with the waiting room atmosphere (65.0 ± 30.6) and frequency of physician communication (70.7 ± 29.0). The item, domain, and overall scores are shown in Table 3 and 4.

The percentage of respondents who considered their overall satisfaction to be excellent varied significantly across sites. Responses to additional items in the questionnaire also varied significantly across sites (Table 5).

Results of Regression Analysis. The greatest amount of variability in an overall assessment of complete satisfaction could be explained by variables (in hierarchical order) concerned with 1) the completeness of information provided by the ICU staff, 2) the courtesy and compassion received by the patient, 3) the courtesy and compassion received by the respondent, and 4) the degree of respondent satisfaction with the level or amount of health care provided to the patient. Respondents who rated the completeness of information provided by ICU staff as excellent or very good were much more likely to give an overall rating of their ICU experience as completely satisfactory (Odds Ratio [OR], 16.0; 95% confidence interval [CI], 5.8–43.9; and OR, 5.3; 95% CI, 1.9–14.8; respectively). Respondents who rated the courtesy, compassion, and respect shown to the patient by ICU staff as excellent were much more likely to give an overall rating of their ICU experience as completely satisfactory (OR, 4.9; 95% CI, 2.6–9.5). Respondents who reported they were completely satisfied with the amount or level of care the patient received in the ICU were much more likely to give an overall rating of their ICU experience as completely satisfactory (OR, 4.6; 95% CI, 2.8–7.3). Respondents who rated the courtesy, compassion, and respect shown to them by ICU staff as excellent were much more likely to give an overall rating of their

Table 3. Responses to questionnaire (part 1): Family satisfaction with intensive care unit (ICU) experience

	n	Excellent, %	Very Good, %	Good, %	Fair, %	Poor, %	Item Score, %	Item SD, %
Care of family								
Consideration of needs	617	57	30	9	2	2	84.52	21.69
Emotional support	607	50	32	13	3	2	81.18	23.4
Spiritual support	430	47	31	16	4	2	79.12	24.54
Coordination of care	605	65	28	7	0	1	89.04	16.49
Concern and caring for family	618	59	31	7	2	2	85.92	20.53
Care of patient								
Concern and caring for patient	624	73	23	3	1	1	91.79	15.38
Pain management	605	65	29	6	1	1	89.09	16.68
Breathlessness management	583	66	26	6	1	1	88.98	18.23
Agitation management	583	58	30	9	2	1	85.03	21.04
Professional care								
Nursing skill and competence	619	74	23	3	1	0	92.37	13.98
Nursing communication	618	60	28	8	3	1	85.68	21.19
Physician skill and competence	616	63	27	8	1	1	87.82	18.64
Physician communication	616	36	31	19	10	5	70.65	29.05
Pastoral care	354	47	29	17	3	3	78.39	22.5
Social work	361	43	30	13	0	6	74.38	29.37
ICU environment								
Atmosphere of the ICU	617	48	32	17	2	1	80.43	22.5
Atmosphere of the waiting room	600	29	28	24	12	7	65.04	30.57
Overall satisfaction	624	54	33	10	1	2	84.29	15.72

Table 4. Responses to questionnaire (part 2): Family satisfaction with decision making

	n	Excellent, %	Very Good, %	Good, %	Fair, %	Poor, %	Item Score, %	Item SD, %
Information needs								
Ease of getting information	617	58	32	7	2	2	85.53	20.85
Understanding information	617	52	36	9	3	1	83.75	20.21
Honesty of information	618	54	32	9	3	2	83.5	22.34
Completeness of information	617	54	31	10	3	2	82.86	22.99
Consistency of information	608	44	34	15	4	4	77.47	25.83
Satisfaction with level or amount of care	612	54	34	9	1	2	84.68	20.41
Overall satisfaction with decision making	595	41	34	17	4	4	75.88	26.35

Table 5. Variation in responses across sites: Percentage of patients scoring excellent

	Site						p Values
	A	B	C	D	E	F	
Overall satisfaction	65	59	57	55	48	36	.001
Courtesy, respect, and compassion patient was given	81	75	75	76	76	53	.001
Courtesy, respect, and compassion respondent member was given	71	55	65	65	56	37	.001
Completeness of information	62	51	57	62	64	32	.001
Satisfaction with level or amount of care	62	55	55	59	44	41	.024

ICU experience as completely satisfactory (OR, 3.5; 95% CI, 2.1–6.0). In the final model, no other site, patient, respondent characteristics, or survey items were significantly associated with overall satisfaction with care.

Although there were statistically significant differences between the sites in the crude proportions of respondents who reported an overall rating of their ICU experience as completely satisfactory (chi-squared, $df = 24.88$, $p < .001$) once the significant associations described

above were accounted for, there was no residual overall site effect ($\Pi^2_{5, df} = 5.10$; $p = .40$).

DISCUSSION

In this multiple center study involving over 600 families, we found that the majority of respondents were satisfied with overall care in the ICU. Fifty-four percent of families considered their level of satisfaction with care to be excellent, with a mean item score of 84.3. Forty-one per-

cent scored their satisfaction with decision making to be excellent, with a mean item score of 75.9. As was expected, satisfaction varied across items and across institutions. The high proportion of patients satisfied with care may be influenced by the fact that our questionnaire was not anonymous. The strengths of our questionnaire relate to the comprehensive conceptualization of satisfaction and the rigor by which the questionnaire was pretested and validated (8). Items we included were derived from existing litera-

ture on patient satisfaction, quality of care near the end of life, the needs of families of critically ill patients, and on satisfaction with decision making. Despite its length, the high response rate (70%) to this questionnaire attests to the feasibility of this questionnaire for future research and quality improvement initiatives.

When examining individual item scores, satisfaction with nursing skill and competence and the compassion and respect given to the patient scored highest, whereas satisfaction with the waiting room atmosphere and frequency of physician communication scored lowest. However, attempts to improve the atmosphere in the waiting room may not lead to an improvement in overall satisfaction. The results of the regression analysis suggest that the main determinants to overall satisfaction have more to do with how providers treat and communicate with patients and their families and the amount of care the patient receives (a byproduct of that communication) than the waiting room atmosphere. The variables significantly associated with overall satisfaction in a regression analysis were completeness of information received, respect and compassion shown to the patient and family member, and amount of health care received. In fact, the variation in satisfaction across sites was largely explained by the variation in scores related to these items.

Recent studies of patient/family satisfaction with end-of-life care also suggest that factors related to communication and decision making are strongly associated with satisfaction. In the United States, Tilden et al. (14) interviewed 32 family members of 12 patients who died in an ICU while undergoing withdrawal of treatment. Emergent themes that correlated with satisfaction with care were feeling included in the decision-making process, avoiding prolongation of death, explication of families' role in decision making, facilitating family consensus, and quality, quantity, and timeliness of information. In another survey conducted in United States, bereaved family members of older patients who died at home, in a 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 (9). In Switzerland, Malacrida et al. (10) 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. In France, Azoulay et al. (7) interviewed family members after the family had met with the physician to evaluate the family members' comprehension of what was said in the meeting. In 54% of cases, the family member failed to comprehend the diagnosis, prognosis, or treatment of the patient. Abott et al. (15) interviewed 48 families of patients previously hospitalized in the ICU in the United States who had been considered for withdrawal or withholding life-sustaining treatments. They found that many families (46%) perceived conflict during their family member's stay; the majority of these conflicts related to inadequate communication or perceived unprofessional behavior. Finally, Wasser et al. (16) recently reported the results of their developmental and validation work with a critical care family satisfaction survey. The psychometric properties of this instrument look promising, and we look forward to empirical results based on the use of this tool.

To efficiently improve quality of care in the ICU, clinicians and managers can target domains of low satisfaction for patient and family centered quality improvement initiatives. Best scores from all sites can serve as an important benchmark or target for such improvement projects. To improve satisfaction with overall care in the ICU in the most efficient manner, efforts should be directed

toward improving physician communication with families and improving the manner in which healthcare providers interact with patients and their families. What specifically can be done to improve physician interactions and communications with families? This depends on the root of the problem. In Figure 1, we provide a conceptual framework describing the nature of a physician-patient interaction. There may be patient (surrogate decision maker), provider, environmental factors, or some combination of the three that contribute to the problem. To improve family satisfaction, the way forward will depend on which of these variables contributes the most to satisfaction or dissatisfaction. Clearly, some physicians will have suboptimal communication or professional skills that will negatively impact family satisfaction (7, 15). Education and training in these humanistic skills are possible (17, 18) and may lead to changes in performance and improved satisfaction, although data supporting this latter assertion are lacking. Alternatively, physicians may have the skills, but they work in a healthcare system with barriers to the provision of sufficient time necessary to meet the needs of families. Finally, physicians may be skilled communicators and take sufficient time to talk with families; however, if these discussions are too emotionally difficult for families, they may not recall content or only remember feeling dissatisfied sec-

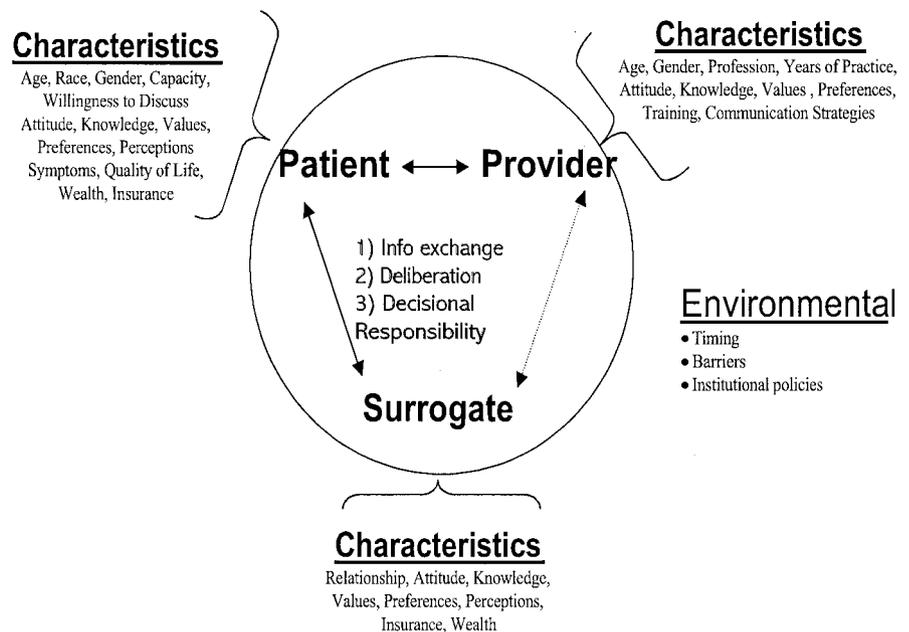


Figure 1. Conceptual framework of a patient-physician interaction.

Increasing the quality and quantity of physician-patient communication may lead to the greatest increase in the satisfaction of family members whose loved ones are cared for in the intensive care unit setting.

ondary to the “bad news.” Often, more than one family-physician encounter may be required (19). Working with physicians, support services from clinical nurse specialists, pastoral care workers, social workers, and others working in a interdisciplinary model of care may be helpful. Further research is required to better evaluate whether diagnosing the root of the communication problem and their proposed solutions actually lead to an increase in family satisfaction.

CONCLUSIONS

Use of a validated and reliable questionnaire to assess family satisfaction and the multiple center perspective obtained in our survey enhances the validity and generalizability of our findings to similar settings. Overall, most families in this study were satisfied with care provided to them and their critically ill relative; however, opportunities for improvement exist. Increasing the quality and quantity of

physician-patient communication may lead to the greatest increase in the satisfaction of family members whose loved ones are cared for in the ICU setting. Measuring and understanding satisfaction with care provided in ICUs will likely enhance the effectiveness of (scarce) resources used in this critically ill patient population.

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