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Care and Caring in the ICU: Family Members' Distress and Perceptions about Staff Skills, Communication, and Emotional Support

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Abstract

Purpose—Family members of intensive care unit (ICU) patients are sometimes highly distressed and report lower satisfaction with communication and emotional support from staff. Within a study of emotional responses to traumatic stress, associations between family distress and satisfaction with aspects of ICU care were investigated.

Materials and Methods—In 29 family members of trauma patients who stayed in an ICU, we assessed symptoms of depression and posttraumatic stress disorder (PTSD) during ICU care. Later, family members rated staff communication, support, and skills and their overall satisfaction with ICU care.

Results—Ratings of staff competence and skills were significantly higher than ratings of frequency of communication, information needs being met, and support. Frequency of communication and information needs being met were strongly related to ratings of support ($r_s = .75-.77$) and staff skills ($r_s = .77-.85$), and aspects of satisfaction and communication showed negative relationships with symptoms of depression ($r_s = -.31-.55$) and PTSD ($r_s = -.17-.43$).

Conclusions—Although satisfaction was fairly high, family member distress was negatively associated with several satisfaction variables. Increased understanding of the effects of traumatic stress on family members may help staff improve communication and increase satisfaction of highly distressed family members.

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Keywords

Intensive Care Units/standards; Family/psychology; Next-of-kin; PTSD; Depression; Satisfaction; Intensive Care/psychology

Excellence in health care is increasingly considered to include patient satisfaction with care. In critical care settings, quality of care also includes the satisfaction of family members who often take on responsibility for medical decisions on behalf of their incapacitated loved ones [1]. Although overall levels of satisfaction are generally high, studies have consistently shown that family members' levels of satisfaction are somewhat lower for aspects of communication and emotional support. Aspects of the hospital environment, such as the highly stressful nature of the work, and family members' considerable distress and uncertainty about their loved one's condition, can make it difficult for ICU staff and family members to communicate about the condition and care of the patient and provide emotional support to family members [2–5].

When asked about satisfaction with frequency of communication with ICU staff, family members in the U.S. [6], Australia [7], Israel [8], Brazil [9], and several European countries [10–13] expressed relatively lower satisfaction and were least satisfied with the amount of communication with doctors. Relatively low satisfaction was also expressed for the clarity, consistency, and completeness of information they received about the patients' condition and prognosis [9, 11, 12]. Not surprisingly, research on family members of ICU patients has found that many feel pressing needs for frequent communication with medical staff about the patient's condition and treatment [8, 13].

Families benefit greatly from receiving clear, continuous, and consistent information from a limited number of clinicians that is at an appropriate level and pace to allow for questions and ensure comprehension [9, 10, 14–17]. Family members also need emotional support, but several studies have reported that family members are dissatisfied with the emotional support they receive from ICU staff [11–13]. Family members' emotional distress may increase their need for and interfere with both communication and emotional support. Studies of ICU families indicate that family members often experience symptoms of posttraumatic stress disorder (PTSD), anxiety, and depression. The reported prevalence of anxiety, symptoms of PTSD, and despair among families of ICU patients has ranged from 30% to 100% [10, 18].

In the context of a study of emotional responses to traumatic stress in patients hospitalized for traumatic injury and family members of patients, we studied perceptions about ICU experiences and medical care in family members of patients receiving ICU care for their injuries. Given prior findings of problems in communication between staff and family members, we were interested in how perceptions about communication related to overall satisfaction and perceptions about support and staff skills. We also examined whether perceptions about communication, support, and skills were related to indicators of distress that have been observed in family members of traumatically injured ICU patients, such as depression and PTSD symptoms.

Materials and Methods

Participants

The study was approved by the institutional review panel for the protection of human subjects and written informed consent was obtained from participants. Participants were 29 spouses or first-degree relatives of severely injured patients treated at a Level 1 trauma center and admitted to a surgical ICU. All participants reported experiencing subjective distress in response to the event. Study participation was restricted to one family member per patient.

Measures

Family members completed the Family Satisfaction with Critical Care Questionnaire (FSCCQ) [19], which consists of 36 multiple choice and Likert-scale items. For this study, we focused on ratings of overall satisfaction with ICU care, frequency of communication (with ICU nurses and doctors), information needs being met (ease of obtaining and understanding information, honesty, completeness of information, and consistency of information), support (consideration of family needs, emotional support, spiritual support, and concern and caring), and staff skills (skill and competence of ICU nurses and doctors). The FSCCQ has demonstrated acceptable validity and reliability for use in family members of ICU patients.[19] FSCCQ items were scored 0 (“poor” or “very dissatisfied”), 1 (“fair” or “slightly dissatisfied”), 2 (“good” or “mostly satisfied”), 3 (“very good” or “very satisfied”), or 4 (“excellent” or “completely satisfied”).

Measures of PTSD and depression symptoms were administered as part of a larger study of risk factors for PTSD. For this study, scores on these measures were used as indicators of psychological distress in family members of ICU patients. The Beck Depression Inventory (BDI) is a measure of the severity of depression symptoms [20]. Numerous validation studies have shown that scores on the BDI are highly correlated with scores on other measures of depression [20]. The Short Form of the measure (BDI-SF) was used to reduce burden on participants. It is comprised of the first 13 items of the BDI, which assess cognitive-affective symptoms of depression [20]. A score of 9 has been recommended as the threshold for identifying medical patients with elevated levels of depression symptoms [21], and we used this score to identify those with elevated depression in this sample as we know of no established cutoff for a more similar sample. The Screen for Posttraumatic Stress Symptoms (SPTSS) was used to assess symptoms that are associated with PTSD and observed acutely following traumatic stress [22, 23]. The SPTSS is a self-report measure of re-experiencing, avoidance, and arousal symptoms which has demonstrated strong internal validity ($\alpha = .91$) and strong concurrent validity when correlated with other measures of PTSD symptoms [22, 24]. A score of 20 or higher on the SPTSS was used as an indicator of elevated symptoms as this cut-off has been found to accurately identify those whose symptoms meet diagnostic criteria for PTSD [25].

Procedures

Family members were part of a longitudinal study of emotional responses to traumatic stress, which is described in detail elsewhere [26]. Family members were recruited from the

patient's room or ICU waiting area one to fourteen days following the traumatically injured patient's ICU admission. A member of the research team consulted with ICU staff to confirm that a patient was no longer at imminent risk of dying before approaching relatives and informing them about the study. After obtaining informed consent, participants completed the first series of questionnaires, which included the SPTSS and BDI-SF. The FSCCQ was completed at home two months after the patient's ICU admission and returned through the mail in postage-paid envelopes.

Results

The average age of participants was 48 (median = 48.5), and 23 (79%) were female. Twenty-one (72.4%) participants identified themselves as White, seven (24.1%) identified as Hispanic, and one (4%) as Asian. Median years of education were 15; nine (31.0%) participants had a college degree, followed by nine (31.0%) with some college, five (17.2%) with post baccalaureate education, five (17.2%) with a high school diploma, and one (3.4%) with less than a high school diploma. Nine (31.0%) participants were the patient's mother, seven (24.1%) were wives, six (20.7%) children, two (6.9%) fathers, and three (10.3%) siblings. Pearson correlations and *t*-tests revealed no significant relationships between demographic variables and ratings of satisfaction or symptoms of PTSD and depression.

Average scores for overall satisfaction with ICU care, frequency of communication, information needs, support, and staff skills are shown in Table 1. Average ratings for some aspects of ICU care were quite high, with most in the "very good" or "very satisfied" range, but a substantial proportion of family members gave lower ratings of satisfaction: 17% rated themselves as "mostly satisfied" or "slightly dissatisfied" overall, and 17 to 20% rated frequency of communication, information needs being met, support, and staff skills as "good" or "fair". Staff skills were the most highly rated. In order to determine if ratings of staff skills were significantly different from ratings of the other variables rates, we conducted paired *t*-tests. Table 1 shows results of paired samples *t*-tests showing that staff skills were rated significantly higher than ratings of overall satisfaction, frequency of communication, information needs being met, and support.

Elevated levels of depression symptoms were indicated by a BDI score of 9 or more in 10.3% of participants, elevated levels of PTSD symptoms were indicated by an SPTSS score of 20 or more in 3.4% of participants, and 10.3% of participants had elevated levels of both depression and PTSD symptoms. One third to one half of individuals giving lower ratings on communication and support variables ("good" or "fair") had elevated levels of depression and PTSD symptoms. Table 2 shows significant and moderate to strong correlations between symptoms of depression and ratings of overall satisfaction ($r = -.57, p < .01$), frequency of communication ($r = -.55, p < .01$), information needs ($r = -.52, p < .01$), and staff skills ($r = -.53, p < .01$), and between PTSD symptoms and overall satisfaction ($r = -.39, p < .05$), frequency of communication ($r = -.43, p < .05$), and staff skills ($r = -.37, p < .05$).

Discussion

The family members we studied generally expressed high satisfaction with the care provided in the ICU, but relatively lower ratings were given for communication, information, and emotional support among 17 to 20% of participants. Staff competence and skills were most highly rated and were significantly higher than ratings of overall satisfaction, frequency of communication with doctors and nurses, information needs being met, and emotional support. Consistent with prior research [10, 18], elevated levels of depression or PTSD symptoms were reported by about one quarter of participants and by a large proportion of those giving low ratings for communication, information, and support. Analyses revealed very strong relationships among ratings for communication, information, support, and staff skills. Symptoms of depression and PTSD showed moderately strong negative relationships with communication, information, and staff skills.

While it's not clear whether our finding of significant differences between ratings of staff skills and satisfaction with communication, information, and support are clinically meaningful, lower ratings of the latter aspects of satisfaction have consistently been found across studies using a number of different measures [6, 7, 9]. Very likely, some family members are less satisfied with communication and information because of practical aspects of the situation. Ideally, families would receive information directly from the attending physician [6, 16, 17, 27, 28], but ICU doctors and nurses are responsible for the care of numerous critically ill patients, and they may need to attend to other patients at times when family members would like to speak with them. Families also tend to visit during evenings and weekends when the patient's attending physician and primary nurses are off duty. Moreover, the information that staff needs to communicate to family members is often unfamiliar and very complex, and family members who speak a different language or have limited education or minimal knowledge of medical issues and terms may have difficulty understanding the information [1]. Furthermore, different family members may have very different information needs in terms of the amount and level of complexity.

Lower satisfaction with emotional support may be due to a number of factors. First, the emotional needs of some family members may be high due to their high levels of distress. Such distress no doubt reflects distress about their loved one's risk of dying or permanent loss of function and sadness over losses already experienced [18]. Also, many family members may feel overwhelmed as they cope with complex medical and insurance systems. They typically face a raft of new problems and decisions brought about by the patient's injury. Financial problems due to loss of income or medical bills may also be exacerbating family members' distress [29]. Emotional distress from all of these sources can interfere with cognitive processes, further impairing family members' ability to understand, remember, and keep track of complex information about their loved one's condition and prognosis [30, 31].

Our finding that high levels of distress were relatively more common among family members giving lower ratings of satisfaction raises the possibility that some family members may blame medical staff for their own confusion and distress. Understandably, the complexity of the information, their impaired capacity to understand it, and the uncertainty

inherent in treatment of many critical injuries may sometimes leave family members feeling frustrated and distressed [5, 10]. Family members who do not realize that medical conditions and treatments are inherently complex and uncertain may think that medical staff are not making enough effort to explain the situation and should be more certain of prognosis. Emotional avoidance may be also contributing to problems with communication and emotional support of family members. On an emotional level, doctors and nurses may not want to deliver negative information about a patient's condition or prognosis and family members may not want to hear it. A review on physician communication with patients and family members in palliative care settings found that physicians tend to focus on medical and technical issues and to avoid discussing quality of life and emotional issues [3]. Research on physician-family communications in hospice settings found that family members are often ambivalent about what they want to know and have difficulty accepting "bad news" [32]. Alternatively, some family members who are having trouble tolerating uncertainty about a patient's condition or prognosis may persistently press medical staff for more definitive answers. Stress-related expressions of anxiety, guilt, anger, hostility, and denial from family members can also make it difficult for staff to be emotionally supportive [15, 16, 27, 33, 34]. Staff's own discomfort with uncertainty about treatments and prognosis, feelings of helplessness, and the natural inclination to avoid interacting with distressed people may cause them to avoid contact with family members, setting up an unfortunate cycle of distress and avoidance [4].

Inadvertent neglect of the emotional needs of family members can result from doctors and nurses focusing intently on medical care. Particularly within a highly demanding work environment such as an ICU, interacting with distressed family members, and "feeling their pain" can be emotionally distressing [2, 35] and interfere with cognitive functioning, limiting one's ability to effectively attend to patients' medical needs [31, 36]. Thus in order to perform work at a high level, staff members need to focus their attention and push away strong emotions. Family members may also be dissatisfied with the emotional support they receive because their emotional needs require mental health treatment that is beyond the scope of training that most doctors and nurses receive.

The moderately strong prospective associations between the symptoms experienced by family members during ICU care and their later ratings of satisfaction suggest a temporal relationship, yet a number of study limitations restrict the ability to draw definite conclusions about study findings. First and foremost, due to the relatively small size of our sample, study findings should be interpreted with some caution as they may not provide a fully accurate representation of the magnitude of relationships between study variables. Second, the observational, single-center design of the study limits generalizability of study findings. All participants were recruited from an ICU within a U.S. academic medical setting whose culture and processes of care may vary from other medical settings. Evidence of different patterns of distress symptoms among family members of ICU patients in the U.S. compared to India [37] suggest that family responses may differ depending on the cultural and economic environment. Additionally, the experiences and responses of family members whose loved one is in the ICU due to traumatic injury may differ from family members of patients admitted to an ICU for other reasons or a non-ICU setting [38]. Lastly, study findings do not take into account the potential impact of pre-existing mental illness

among family members. Family members with a pre-existing mental illness may have more difficulty coping and experience greater distress in response to their loved one's injury, so it is possible that the presence of pre-existing disorder may also impact relationships between distress and satisfaction. Further research with a larger sample and multi-center design should be conducted to confirm the results of the present study and improve generalizability of findings. Such a design could also elucidate the relationships between family member distress and satisfaction across medical settings and patient conditions (i.e., academic vs. community; ICU vs. non-ICU; ICU admission due to illness vs. injury). In addition, research that included an intervention aimed at lowering family members' distress could provide a more definitive answer to the question of whether distress is causing family members to experience negative perceptions and whether reducing distress would result in higher levels of satisfaction.

A range of approaches has been suggested to improve communication and emotional support of family members of ICU patients. Huffines and colleagues [14] developed and studied an evidence-based structured communication system aimed at improving family satisfaction with coordination of care and participation in decision-making on a surgical ICU. Specific communications to families at set times after admission and in response to particular clinical changes were found to improve satisfaction with coordination of care and involvement with decision-making. Another method to improve overall care and satisfaction with care is to find ways to increase involvement of family members in patient care [1]. When families get close to the patient and help with care, patients benefit through increased orientation, humanization, emotional support, and family members benefit from reduced uncertainty and fear about the patient's condition. Medical staff can also benefit from the assistance with care that more knowledgeable family members can provide [39, 40].

The association between family members' emotional distress and satisfaction with care found in the present study suggests that a greater focus on helping family members manage their distress could improve their experiences and satisfaction with care in the ICU. Evidence of better outcomes among traumatically injured patients who receive brief cognitive behavioral therapy soon after injury [41] suggest that distressed family members may also benefit from early provision of a similar early intervention. Furthermore, a brief dyadic intervention could be used to reduce patients' and family members' distress and perceptions of negative social support [42]. Improving understanding and disclosure between family members and patients may help to reduce the family members' feelings of distress, uncertainty about the patient's condition, and need for emotional support from staff. Emotional support for families can also be increased by fostering mutual support among families of ICU patients. For example, family members who are well adjusted to the ICU environment could play a role in supporting and reassuring those who are newer to the ICU setting [28]. Providing basic orienting information about hospital systems and processes can be very helpful to families who are new to the ICU and may reduce dissatisfaction with communication and information provided by staff. Providing information to new ICU families could give a sense of purpose to those who have already spent days or weeks the ICU waiting area. In addition, the emotional benefits of altruistic and compassionate behavior toward others are well established [43].

Some research has suggested that it can be important to identify and meet the *individualized* needs of families, as opposed to interacting with all families in the same way [10, 27, 28, 33, 44]. In particular, special attention should be given to the emotional needs of family members who are in extreme distress [10]. Requesting social work consults to assess, treat, and refer highly distressed family members can reduce pressure on medical staff stemming from family distress [1]. In addition, it is important to keep in mind that staff members' feelings of helplessness can have a negative impact on communication. In particularly difficult cases, staff members may be unintentionally communicating their own feelings of hopelessness to families by their choice of words, tone of voice, facial expression, and posture. Increasing staff's awareness of the possibility of a negative communication dynamic and providing staff with sources of emotional support and opportunities for emotional processing of their own feelings could improve communication [1]. Lastly, it could be beneficial to remind staff that in situations in which a patient's prognosis is uncertain, communicating in ways that foster hope balanced by realistic expectations can help reduce family members' emotional distress [1, 45].

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Table 1

Paired t tests Comparing Family Ratings of Staff Skills to Ratings of Overall Satisfaction, Frequency of Communication, Information Needs Being Met, and Support

	Mean ^a (SD)	<i>t</i>
Overall Satisfaction with ICU Care	3.28 (0.84)	2.91**
Frequency of Communication	2.93 (0.96)	5.62***
Information Needs Met	3.10 (0.97)	4.89***
Support	3.05 (0.89)	4.24***
Staff Skills	3.57 (0.79)	

= $p < .001$,

**
= $p < .01$

^a Scores of 0 = "poor" or "very dissatisfied," 1 = "fair" or "slightly dissatisfied," 2 = "good" or "mostly satisfied," 3 = "very good" or "very satisfied," and 4 = "excellent" or "completely satisfied."

Table 2
 Correlations Between Ratings of Overall Satisfaction, Frequency of Communication, Information Needs Met, Support, Staff Skills, and Baseline Levels of Depression and PTSD Symptoms

	Freq of Comm	Info Needs Met	Support	Staff Skills	Baseline Depress Symp ^a	Baseline PTSD Symp ^a
Overall Satisfaction with ICU Care ^b	.78***	.83***	.85***	.78***	-.57**	-.39*
Frequency of Communication ^b		.86***	.77***	.77***	-.55**	-.43*
Information Needs Met ^b			.75***	.85***	-.52**	-.26
Support ^b				.69***	-.31	-.17
Staff Skills ^b					-.53**	-.37*

*** = $p < .001$,

** = $p < .01$,

* = $p < .05$

^a Assessed 1 to 14 days after injury.

^b Assessed 2 months after injury.