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Patient and Family Experience: Targets for Improvements in Care and Communication in the ICU

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Abstract

This process improvement project sought to further explore the experience of patients and family members within an intensive care unit (ICU) hospital setting to develop specific interventions that can be executed to provide better patient-centered outcome. We surveyed 103 family members using the satisfaction with care subscale of Family Satisfaction with the ICU survey (FS-ICU) (validated ICU experience survey). 103 patients also completed FS-ICU subscale with a modification to make it applicable to patients. Additional questions explored their interest in supportive services and factors contributing to distress with the goal of understanding the gaps in multidisciplinary care and supportive services. Overall, the findings of this project emphasize the importance of (1) understanding patients' experience and satisfaction with care, in addition to families', (2) gathering data with measurement tools that is specific enough to the care environment allowing for unique feedback and areas for improvement, and (3) identifying psychological needs and faith-based support to intervene on challenging experiences.

Keywords

Patient experience, behavioral health, patient/relationship-centered, patient feedback, quality improvement, communication, caregiving

Introduction

An intensive care unit (ICU) is a dedicated geographic area with an organized system for the provision of care to critically ill patients.[1] The care delivered in ICU, is increasingly recognized as more than just survival.[2-4] Patient's experience is a unique metric, and has been defined as " …the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care"[5] and correlates with the quality-of-care patients receive.[6] Given the severity of illness in the ICU, patient's family members play an important role in a patient' care team and understanding their experience.

Previous reviews explored the satisfaction with care for families of patients in an ICU, which focus recommendations on areas such as visitation, communication, and perception of the care the patients receive.[7,8] The well-being of both patients and family is integral to optimal care of the critically ill.[9] Ineffective communication (eg, use of jargon, inconsistency across providers) with families is cited as the primary driver of dissatisfaction with care.[10] Clinical guidelines for patient-centered care and family support for ICU patients have been developed to address this issue.[11] Symptoms of anxiety and posttraumatic stress disorder in ICU patients and their families during their admission to the ICU[12,13] are important factors to attend to given there impact on the patient's experience.

Post-intensive care syndrome (PICS) and posttraumatic stress disorder symptoms (eg, nightmares, hypervigilance,

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etc) for patients and families is associated with the trauma of being critically ill, but also due to unintended harm inflicted by medical teams.[14] With high rates of psychological symptomology in both patients and families, marshalling resources to address those symptoms is vitally important to improve their experience. The majority of patient experience data is performed retrospectively after discharge from the hospital, thus impacted by recall bias.[15] This limits the quality of data, does not provide specific feedback to improve care and families rather than patients themselves often provide feedback on the patient's experience. This process improvement project assessed patient and family experience with care within a mixed medical-surgical intensive care and sought to identify resources to improve their experience with care. We hypothesize that exploring patient and family experience across domain specific to critical care units could provide granular data to develop specific interventions to improve patient-centered outcomes.

Methods

Participants were recruited from an adult mixed medical-surgical intensive care unit at a level 1 trauma center between September 2021 and January 2023. The inclusion criteria for patients included admission to the ICU for >48 h, alert, oriented, lack of delirium, and extubated. Patients with traumatic brain injury, developmental delay, altered mental status/encephalopathy, or those that were unable to effectively communicate or involved in the current legal system were excluded. Adult family members were recruited if their family member had been in the ICU for >48 h and visited the patient at least twice. Patient and family members were not recruited in dyads. Project procedures were approved by an Institutional Review Board.

The satisfaction with care, subscale of the Family Satisfaction with ICU Survey (FS-ICU), was used to assess family members satisfaction with care, including management of symptoms specific to critically ill patients, communication, and the ICU environment. The FS-ICU is well-established, psychometrically-sound.[16,17] The satisfaction subscale, rather than the full measure, was utilized to limit burden on the participants. For the patient participants, the satisfaction with care subscale of the FS-ICU questions was modified to apply to the patient, rather than family.

Exploratory questions were included to better understand both groups' interest in supportive services, factors that brought emotional distress, communication, and open response items related to areas of improvement. Patient's data was extracted from the electronic health record and all respondents provided demographic information.

The results of the data were reported as frequencies (percents) for categorical variables and means (SD) for continuous variables. Analysis examining relationships between satisfaction with care and other patient and family factors were run using the independent t test.

Results

About 344 patients and family members were approached for enrollment. About 103 patients and 103 family members were enrolled. Descriptive information is presented in Table 1. There were no significant correlations between satisfaction with care and any of the demographic and hospital characteristics for patients or family members (Table 2). The Cronbach's alpha value for the satisfaction with care, subscale of the FS-ICU, was 0.943 for family members and 0.959 for patients.

For symptoms specific satisfaction scores, a higher percentage of family members than patients were very satisfied with the assessment and treatment of pain (97 vs 87), breathlessness (89 vs 83), and agitation (85 vs 64). 55.9% of patients and 74.5% of families were completely satisfied with their understanding of ICU staff explanations when assessed by the modified FS-ICU survey. 20% of patients and 9% of family members agreed that they were overwhelmed with the amount of medical information shared. Furthermore, 8% of patients and 6% of family members reported strongly agreeing with feeling overwhelmed with the amount of medical information provided. Yet, a high percentage of patients (85.3%) and family members (92.1%) reported being very satisfied or completely satisfied with their overall ICU stay.

Both groups felt the most reported resources they could benefit from during an ICU stay was a psychologist, chaplain services, social workers, and/or the use of video calls to connect with their family. For both samples, the three most reported factors that contributed to distress were thoughts of how their critical illness would impact the patient's future health, limited visitation, and worries related to the patient's critical status. Of note, the next most reported distressing factor for both groups was their ability to emotionally manage the ups and downs of the patient's hospitalization.

For open-ended questions, additional themes identified were comfort, communication and continuity of care. When asked about to improve their experience, patient's shared "more information throughout treatment to alleviate some anxiety'" and "rotation of doctors (weekly) and nurses (daily) with different standards of care." Family members reported being frustrated with the perception of conflicting information provided by caregivers. In addition, there were comments related to orienting families to the norms of the intensive care unit, including who is involved in care and best times to call to avoid long wait times. Families noted that by making their day-to-day activities more streamlined it may remove some of the stressors. Further it was requested to have improved waiting rooms, more comfortable furniture in patients' rooms, and compensation for parking and meals. Additionally, the number of specialties and providers that comprise the ICU team made it difficult to recall names and faces of team members and their role. Families also shared that lack of continuity in care due to changing team members made it difficult for them to feel comfortable.

Table 1. Patient and Family Member Characteristics.

	Patient		Family Member	
Variable	N		N	
Age (Mean/SD)	100	60.21 (14.71)	101	54.84 (14.64)
Gender Identity % (n)	101		101	
Female		42. 6 (43)		66. 3 (67)
Gender Queer		0 (0)		1.0 (1)
Male		57.4 (58)		32.7 (33)
Race/Ethnicity % (n)	102		102	
BIPOC		32.4 (33)		28.4 (29)
White		67.6 (69)		71.6 (73)
Highest Level of Education % (n)	102		102	
HS Diploma or less		46.1 (47)		31.4 (32)
Some college		34.5 (25)		34.3 (35)
College graduate		21.6 (22)		19.6 (20)
Postgraduate		7.8 (8)		14.7 (15)
COVID diagnosis % (n)	101	17.8 (18)		7.8 (8)
Prior ICU Experience (% yes)	102	32.4 (33)	102	39.2 (40)
ICU LOS (Median/IQR)	101	5 (3–9)		
Days Overall Hospital LOS (Median/IQR)	101	13 (8–20)		
SOFA score (Mean/SD)	101	5.09 (3.12)		
% Mortality	100	10 (38–15.3)		
Relationship to patient			102	
Spouse				51.0 (52)
Significant other (fiancé, girlfriend)				2.9 (3)
Mother				6.9 (7)
Father				2.9 (3)
Child				22.5 (23)
Sibling				9.8 (10)
Extended family				2.0 (2)
Additional Response				2.0 (2)
ICU Admission Reason	102	From EMR	103	Self-reported
Cardiovascular		52.9 (54)		28 2 (29)
Respiratory		22.5 (23)		28.2 (29)
Sepsis/Shock		0 (0)		4.9 (5)
Neurologic		0 (0)		5.8 (6)
Other		24.5 (25)		28 2 (29)
Unknown		0 (0)		4.8 (5)

Discussion

This project explored patient and family experience, interest in supportive services, and factors of distress in a mixed medical-surgical intensive care unit. While many patients and families were satisfied with overall care, a significantly lower proportion of participants were specifically satisfied with the explanations and communication surrounding the care that was provided. The results suggest that families and patients can feel overwhelmed with the amount of medical information provided and find it difficult to navigate the large number of medical providers on the care team.

Race of the patient and/or family, geography, or insurance did not lead to a significant difference in the satisfaction with care which is consistent with previous research.[18] Overall, family members rated higher satisfaction across many of the domains assessed, which suggest the importance of assessment of patient's experience, rather than relying on family members, which a major of the literature focuses on.

There is a growing body of literature supporting the clinical level of psychological symptoms that patients and family experience during and after an ICU admission.[19-21] Psychologists and licensed clinical social workers can complete assessments and provide interventions for the emotional distress of patients and family members, which could positively impact patient experience, engagement with care, relationships with families, and possibly reduce time at the bedside for medical providers. To improve communication skills, critical care units could take an interdisciplinary approach, including specialists such as psychologists.to enhancing interpersonal effectiveness skills within their providers. Furthermore, faith-based providers were also identified as a resource for families during moments of distress, as connecting with faith can be an important coping mechanism. A question related to interest in faith-based services could be included as part of a bedside nursing checklist. The richness of the qualitative data suggests that a mix of

Table 2. Correlation Between the FS-ICU Patient and Family Satisfaction Subscale (FS-CARE).

Factor	Variables	N	FS-Care Mean (±SD)	P-value
Patient Satisfaction				
Gender	Female	43	87.46 (14.18)	0.197
	Male	57	82.58 (23.15)	
Race	BIPOC	32	78.80 (23.53)	0.064
	White	69	87.63 (17.32)	
Admission	Cardiac	40	85.80 (21.55)	0.647
	Non-Cardiac	60	83.93 (18.79)	
Transferred patient	Transfer	59	84.43 (19.24)	
	Non transfer	42	85.40 (20.82)	
Family Member Satisfaction				
Gender	Female	33	89.85 (16.15)	0.791
	Male	65	89.03 (10.49)	
Race	BIPOC	29	86.67 (16.52)	0.188
	White	71	90.84 (13.23)	
Admission	Cardiac	13	93.33 (7.95)	0.608
	Non-Cardiac	70	88.99 (15.37)	
	Uncertain	17	89.44 (13.68)	

scaled and open-ended responses can be beneficial when exploring complex constructs like satisfaction with care

Limitations

Those who are dissatisfied with the care may have been less likely to agree to participate in this project, which may have led to significant bias. Due to staffing resources, not every patient and family that met inclusion criteria was approached. The FS-ICU satisfaction with care subscale language was changed to explore the patient's satisfaction with care, which has not previously been validated. Families, whose preferred language was Spanish were approached; however, none consented to participate, and they may have had different experiences with the care they received, which was not captured. There were changes to procedures in hospitals due to the COVID-19 pandemic, that may have impacted satisfaction with care.

Conclusions

Within the fast-paced and often chaotic intensive care environment, determining how to improve patient's and family member's experience is an ongoing area of improvement. Based on data from the current project, we developed a brochure that outlines care expectations, visiting hours, augmentative and alternative communication tools for patients who are unable to phonate, and recommendations for navigating care in the ICU. Overall, these findings emphasize the importance of (1) understanding the experience and satisfaction with care for critically ill patients and families, (2) gathering data via valid measurement tools that are specific to the intensive care environment allowing for targeted feedback and areas for improvement, and (3) identifying psychological needs and faith-based support to intervene on challenging experiences.

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Author Contributions

CL, NP, and NL modified the survey; CAL, CB, ED, NL, TM, PP, and NP participated in study recruitment; CL, CB, KH, ED, NL, NP had access to data, analyses, and interpretation; all authors contributed to the development of the hypotheses, analytic plan, and manuscript drafting and revision, as well as approving the version for publication and agreeable to accountability

Consent to Participate

Informed consent was obtained from all individual participants included in the study

Consent for Publication

Not applicable

Data Availability Statement

Data can be provided by the corresponding author upon request.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical Considerations

This project was approved on 08/09/2021 by Cooper Health System Institutional Review Board IRB# 21-166. The authors certify that all procedures performed in this project were in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

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Supplemental Material

Supplemental material for this article is available online.

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