



DEFINING THE MEDICAL INTENSIVE CARE UNIT IN THE WORDS OF PATIENTS AND THEIR FAMILY MEMBERS: A FREELISTING ANALYSIS

By Catherine L. Auriemma, MD, Sarah M. Lyon, MD, Lauren E. Strelec, BS, Saida Kent, BS, Frances K. Barg, PhD, and Scott D. Halpern, MD, PhD

Background No validated conceptual framework exists for understanding the outcomes of patient- and family-centered care in critical care.

Objective To explore the meaning of *intensive care unit* among patients and their families by using freelistings.

Methods The phrase *intensive care unit* was used to prompt freelistings among intensive care unit patients and patients' family members. Freelistings is an anthropological technique in which individuals define a domain by listing all words that come to mind in response to a topic. Salience scores, derived from the frequency with which a word was mentioned, the order in which it was mentioned, and the length of each list, were calculated and analyzed.

Results Among the 45 participants, many words were salient to both patients and patients' family members. Words salient solely for patients included *consciousness*, *getting better*, *noisy*, and *personal care*. Words salient solely for family members included *sadness*, *busy*, *professional*, and *hope*. The words *suffering*, *busy*, and *team* were salient solely for family members of patients who lived, whereas *sadness*, *professionals*, and *hope* were salient solely for family members of patients who died. The words *caring* and *death* were salient for both groups.

Conclusions Intensive care unit patients and their families define *intensive care unit* by using words to describe sickness, caring, medical staff, emotional states, and physical qualities of the unit. The results validate the importance of these topics among patients and their families in the intensive care unit and illustrate the usefulness of freelistings in critical care research. (*American Journal of Critical Care*. 2015;24:e47-e55)

Patient- and family-centered care (PFCC) has become an important research priority in the United States,^{1,2} partly because of evidence that such care is associated with better outcomes and patient satisfaction.^{3,4} PFCC has become integrated into the definition of health care quality of the Institute of Medicine⁵ and has become a component of reimbursement in value-based purchasing.⁶ However, no validated conceptual framework exists for understanding the outcomes of PFCC in critical care. Such a framework is essential to efforts to improve measurement and analysis of critical care interventions in order to advance research and practice in patient-centered fashions.

Patient- and family-centered care is associated with better outcomes and patient satisfaction.

The Synergy Model, a linkage of patients' characteristics with nursing competencies, is perhaps the best existing framework for understanding PFCC in the intensive care unit (ICU).⁷ However, this model, which was developed in the late 1990s, is limited in its selective focus on nurses' contributions to patient

care, and its applicability to analyzing the full spectrum of critical care interventions is uncertain. Similarly, frameworks developed by Slatore et al⁸ and Downey et al⁹ focus exclusively on nursing roles in communication or in assessing the needs of patients' families.

Although nurses are undoubtedly in key positions for delivering and evaluating PFCC, an integrated framework including all ICU team members and ICU interventions does not exist. Furthermore, these frameworks describe PFCC from the perspective of the medical teams, not the perspective of the patients or patients' family members. The Family Satisfaction in the Intensive Care Unit survey¹⁰ and the Critical Care Family Needs

Inventory,¹¹ used to measure satisfaction and needs of patients' family members, also exclude patients' perspectives.

Qualitative studies of patients' ICU experience have involved topics ranging from memories¹² and perspectives on nursing care¹³ to interactions with technology¹⁴ and the ICU physical environment.¹⁵ In a review of research studies published on patients' ICU experiences, Stein-Parbury and McKinley¹⁶ noted that patients recalled positive experiences such as a sense of safety and negative experiences including pain, difficulty sleeping, and anxiety. These studies,¹²⁻¹⁶ although informative, primarily involved focused—and potentially leading—questions on specific topics proposed by research teams and did not include the experiences of patients' family members. Studies that included patients' family members focused specifically on palliative care,¹⁷ questions for the medical team,¹⁸ or long-term follow-up.¹⁹ Although each of these studies¹²⁻¹⁹ provides valid information about specific research topics, none allowed patients or patients' family members to generate the basis of the research question.

We examined language used by patients and their family members to describe the ICU by using the open-ended technique of freelisting. Anthropologists use freelisting to enable members of a group to define a concept in the members' own words. Freelisting has been used to help researchers understand what aspects of an experience resonate with the members of a specific group and to identify shared illness experiences from a group's point of view.²⁰⁻²⁵ To the best of our knowledge, freelisting has never been used with critical care patients and their families. Understanding how these patients and their families define the ICU may reveal what experiences and elements of care are most important, thereby helping shape future research to promote more effective delivery of PFCC.

Methods

This study was conducted in accordance with the amended Declaration of Helsinki and was approved

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by the appropriate institutional review board. Limited results were presented in abstract format²⁶ at the American Thoracic Society meeting in May 2014.

Study Design

Patients and patients' family members were recruited from a 24-bed medical ICU at the University of Pennsylvania, Philadelphia, Pennsylvania. Recruitment was targeted to represent the full range of race, age, sex, and primary outcomes of a medical ICU stay and hospitalization (death, transfer, or discharge home) noted in the ICU's electronic registry during a 1-year period preceding the collection of data for this study. Potential participants were identified prospectively by using daily admission data. Eligible participants were 18 years or older, English speaking, and either a patient or a primary family member of a patient with an ICU stay of at least 4 days. Throughout the study, recruitment focused on individuals with characteristics underrepresented in the then-current sample in order to achieve full diversity in the final study population. This method of purposive sampling is commonly used in anthropological studies to ensure sampling of the breadth of diverse demographics. Any patient for whom study recruiters or interviewers were members of the patient's medical team was not considered eligible.

Data Collection

A researcher approached eligible patients during their ICU stay for consent to access their medical records and contact them 7 to 60 days after discharge from the hospital to schedule an interview. This time frame provided time for initial home adjustment and yet ensured that the ICU stay was still sufficiently recent to permit recollection. For any patient without the capacity to provide consent, consent was requested from the patient's family member who was serving as surrogate decision maker. The surrogates were recruited to participate in the family cohort. Separate consent was requested from family members to contact them at least 7 days after a patient's hospital discharge or at least 30 days after a patient's death. Interviews were scheduled during the contact after discharge at the participant's earliest convenient date, and a second consent was obtained from those who agreed to an interview before the interview began.

Freelisting is a standard interviewing technique²⁷ used to identify a particular domain (in this study, the ICU) and to determine relative salience or importance of words defining the domain.²⁸⁻³⁰ Freelisting was chosen for its simplicity, reproducibility, and capacity to identify the most fundamental commonalities between participants' definitions of the ICU. After participants were acclimated to the exercise with an unrelated practice round and their

questions were answered, they were asked to list all words that "come to mind when [you] think about the intensive care unit" and/or "what words intensive care unit brings to mind." Participants were given as much time as desired before stating they could not add any more words to their lists. Interviewers could repeat the prompt but did not encourage participants in any other way. All interviews were conducted by 1 or 2 interviewers and were collected as sound recordings. Most participants recorded their list with pen and paper, but 5 stated lists verbally because of physical disability. The verbal lists were professionally transcribed. All interviews were private. Patients and patients' family members were interviewed separately.

For 39 of the 73 patients initially recruited (53%), first-person consent was not possible in the ICU. Written informed consent to contact patients was provided by a surrogate for these patients. Later, at the time of freelisting, all participants provided individual, written informed consent.

Data Analysis

Using cultural consensus analysis,³¹ members of the research team examined freelists, standardized word forms, and identified and grouped terms with similar meaning. All groupings of terms were reviewed by the entire research team, which included 2 critical care physicians, 1 medical anthropologist with substantial experience in using this method and a background in nursing, 1 medical student, and 2 research assistants who provided a lay perspective in accordance with their limited medical knowledge. Terms that were obvious synonyms or variations of the same word (eg, pain and suffering or nurse and nurses) were first combined. Then terms that seemed to fit into a larger category were grouped together (eg, needles, tubes, and machines into medical equipment). Finally, for the remaining terms, 2 researchers independently grouped the terms and compared results with each other. For the few discrepancies, discussion among the entire team was used to reach consensus on optimal grouping.

The resulting cleaned freelists were entered into Anthropac, version 4.0 (Analytic Technologies), a software program designed to analyze freelists. For each word, the program calculated a salience score (the Smith S).³⁰ The salience score is a function of the frequency with which a word is mentioned, the average position on the list where the word falls, and the length of each list. The formula is $S = (\sum [L - R_i + 1]) / L / N$, where L is the length

Words mentioned most often and earlier obtain highest salience scores.

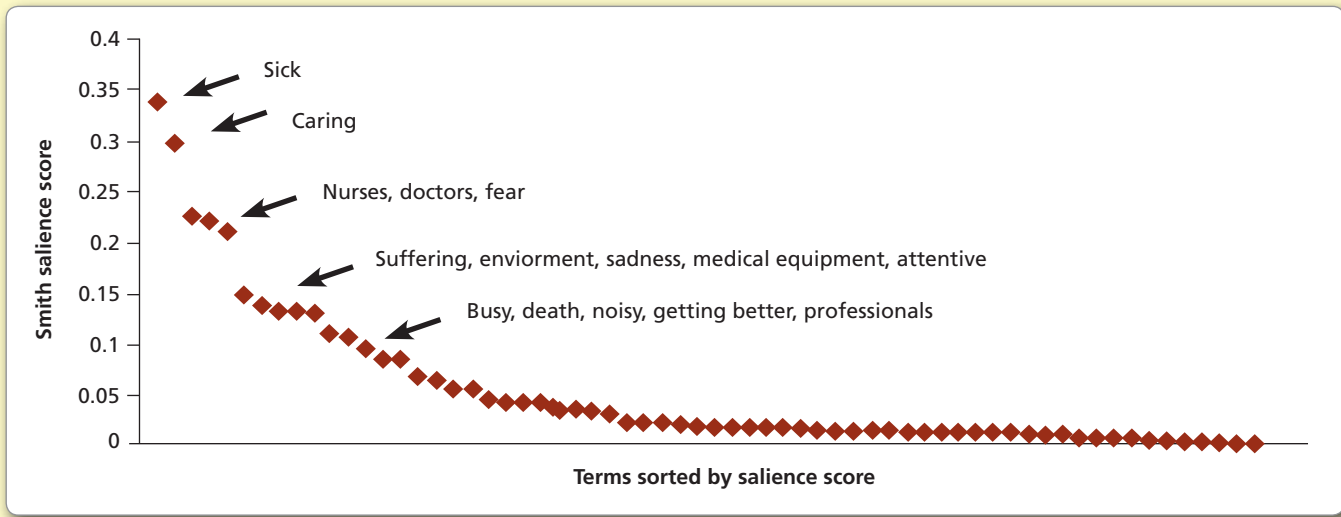


Figure 1 Scree plot for salience scores for terms elicited by freelisting for the phrase intensive care unit from all participants (n = 45). Numbers with a higher salience score (y-axis) are considered to be more salient, typical responses to the question.

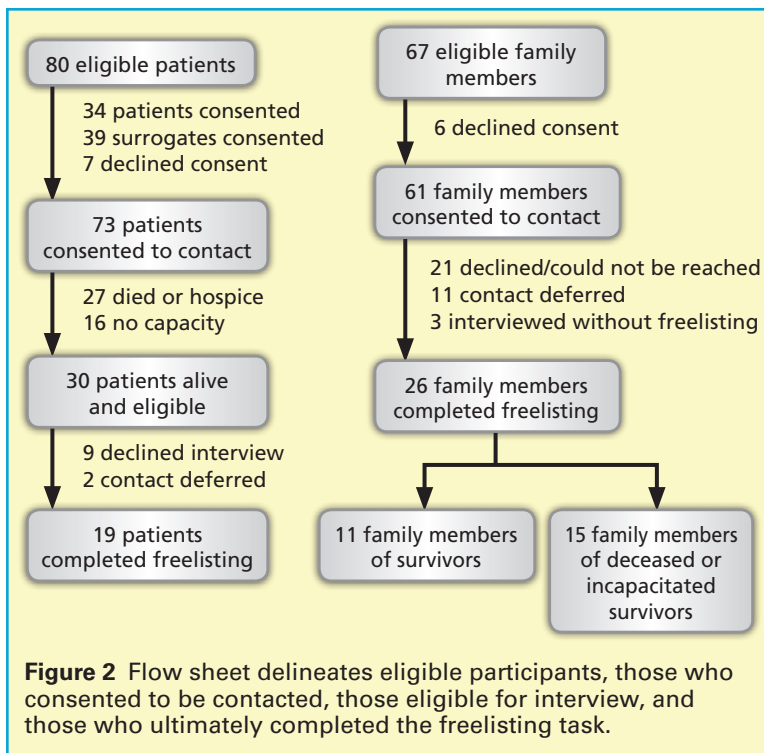


Figure 2 Flow sheet delineates eligible participants, those who consented to be contacted, those eligible for interview, and those who ultimately completed the freelisting task.

of each list, R_j is the rank of item J in the list, and N is the number of lists in the sample.³⁰ Words mentioned most frequently and earlier in most lists have the highest salience scores, thus indicating greater importance.

As illustrated in Figure 1, salience scores were sorted from high to low and plotted as a scree curve by using the salience scores as values on the y -axis. The curves were then inspected to identify a natural breaking point in the scores, which is identified

as the point at which a flattening of the slope of the curve occurs.^{21,32} Terms were considered to have a high degree of salience if they fell above a natural breaking point in the scree curve or were mentioned by at least 20% of the participants.³¹ Salience scores were generated for all words for all participants and separately for 3 subgroups: patients, family members of patients who survived the hospital stay, and family members of patients who died during or shortly after the hospital stay.

Results

Sample Characteristics

Figure 2 is a flow sheet describing recruitment and retention of participants. A total of 73 of 80 patients (91%) and 61 of 67 family members (91%) approached in the ICU consented to be contacted after hospital discharge. The initial population of patients who consented was similar to that of patients seen in the University of Pennsylvania medical ICU during the corresponding year with respect to age, sex, and race (Table 1). Mortality was slightly lower than seen in the ICU overall. The patients who consented initially and those who completed the study did not differ in age, race, ICU length of stay, or hospital length of stay (all $P > .05$). The final interview sample included a greater proportion of women than the value in the ICU registry data (68% vs 44%; $P = .03$), largely attributable to higher mortality and a greater likelihood of becoming incapacitated after the ICU stay among the men in the study.

Freelisting tasks were completed during interviews with 19 patients and 26 family members. Of the 26 family members, most were the spouse (62%) or a sibling (31%) of the ICU patient. A total of 57% were family members of a patient who died

Table 1

Demographic characteristics of patients admitted to intensive care unit (ICU) from September 2011 to September 2012 who stayed at least 4 days, participants who initially consented to be contacted, and participants who completed freelisting

Characteristic ^a	ICU overall	Consented to be contacted	Completed freelisting
Patients	n = 563	n = 73	n = 19
Age, mean (SD), y	58.9 (15.9)	57.5 (13.0)	55.3 (11.8)
Nonwhite, %	45.5	32.9	47.4
Female sex, %	43.7	45.2	68.4 ^{b,c}
Days in ICU	7.6 (5.2-12.3)	10.0 (6.0-16.0)	11.0 (7.0-13.0)
Days in hospital	18.3 (16.5-22.7)	22.0 (14.0-33.0)	23.0 (15.0-29.0)
Discharge location, %			
Died/hospice	39.4	24.7	—
Home	28.8	35.6	68.4
Skilled nursing facility	13.5	17.8	21.1
Long-term acute care hospital	10.5	13.7	0.0
Acute rehabilitation center	5.9	8.2	10.5
Family members	—	n = 61	n = 26
Age, mean (SD), y	—	56.2 (10.5)	55.1 (10.6)
Nonwhite, %	—	29.5	11.4 ^c
Female sex, %	—	57.4	53.8
Relationship to patient			
Spouse	—	60.7	61.5
Sibling	—	19.7	30.8
Child	—	14.8	7.7
Parent	—	4.9	0
Patient outcome, %			
Survived with capacity	—	39.3	42.3
Survived without capacity	—	21.3	11.5
Died	—	39.3	46.2

^a Data are presented as median (interquartile range) unless otherwise specified in this column.

^b $P < .05$ for comparison with ICU registry, determined by using univariate statistical analysis.

^c $P < .05$ for comparison with those who consented to be contacted, determined by using univariate statistical analysis.

or remained incapacitated after the ICU stay; the remaining 43% were family members of patients who survived and were no longer incapacitated by the time of the interview. Most family members were white (89%), and 54% were female. Corresponding data on demographic characteristics of patients' family members in the ICU were not collected.

Most interviews were conducted 1 month after discharge from the hospital or death. Mean time elapsed was 34.5 days (SD, 21.3) for patients and 32.9 days (SD, 20.4) for surrogates. Interviews were conducted in private and in person whenever possible; 5 of 45 interviews (11%) were conducted via telephone because of the respondents' distance from the study site. Interview locations included participants' homes, long-term acute care hospitals, rehabilitation hospitals, and research space at the study site.

Freelisting Responses

The freelisting exercise required approximately 5 minutes per participant. Respondents' lists ranged

from 1 to 19 items. Table 2 lists salient words with corresponding salience scores elicited by freelisting for the phrase *intensive care unit*. The most salient terms were *sick* and *caring*. The caring category included words such as *caring*, *compassion*, and *thoughtful*. Participants also often used words that described medical staff (*doctors*, *nurses*, *professionals*), their own emotional states (*fear*, *sadness*), suffering, and physical qualities of the ICU (*environment*, *medical equipment*). The environment category included terms such as *cold*, *hot*, *dark*, and *bright*.

Overall, patients and patients' family members used similar words to describe the ICU (Figure 3A). Salient words uniquely identified by patients included *noisy* and *personal care*. The personal care category included terms such as *bathing*. Both patients and family members mentioned the words or phrases *getting better*, *attentive*, and *consciousness*, but these terms were salient solely for patients. The only salient word uniquely identified by family members was *busy*. The word *sadness* was mentioned by both

Table 2
Salient words elicited from freelists for the phrase intensive care unit by all participants (n = 45)

Salient word	Smith S
Sick	0.335
Caring	0.296
Nurses	0.224
Doctors	0.218
Fear	0.208
Suffering	0.146
Medical equipment	0.136
Environment	0.132
Attentive	0.131
Sadness	0.129
Death	0.109
Busy	0.105
Noisy	0.093
Getting better	0.084
Professionals	0.083

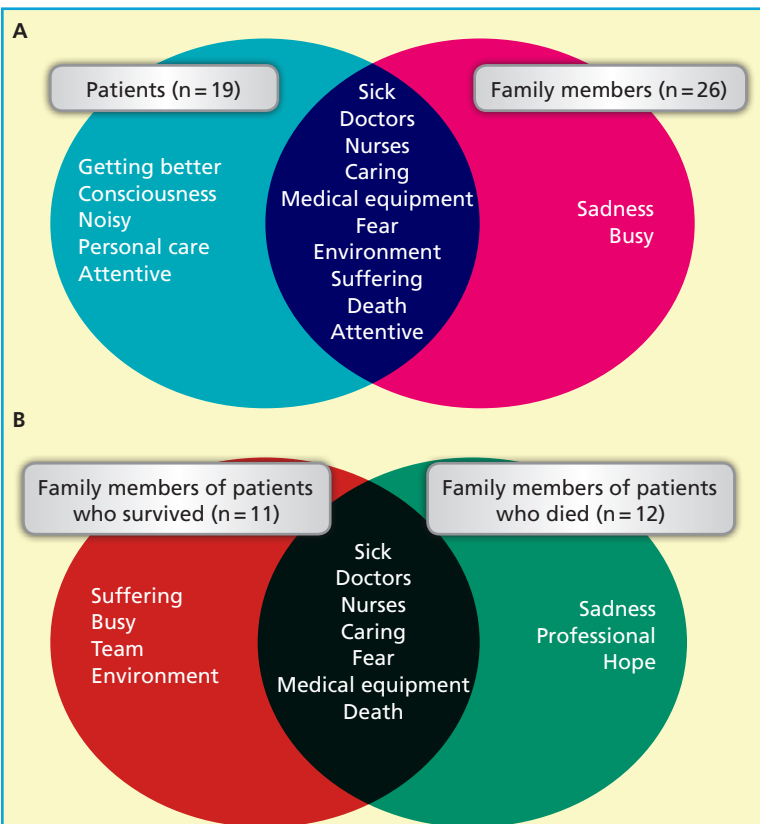


Figure 3 A, Venn diagram of unique and shared salient words elicited by freelisting for the phrase intensive care unit by patients and patients' family members. B, Venn diagram of unique and shared salient words elicited by freelisting for the phrase intensive care unit by family members of patients who survived and family members of patients who died. Family members of patients who survived the hospital stay but became severely incapacitated were excluded from this analysis.

patients and family members but was salient solely for family members.

Family members of patients who lived and were not incapacitated and family members of patients who died differed in several regards. The former listed the words *suffering*, *busy*, *environment*, and *team*. The latter listed *sadness*, *professional*, and *hope* (Figure 3B). The grouping for suffering included terms such as *suffering*, *pain*, and *hurt*. The words *busy* and *team* were uniquely mentioned by surrogates of patients who lived and were not incapacitated. The word *hope* was unique among family members of patients who died.

Discussion

In this study, we identified words and terms that patients and their family members use to define the ICU. Freelisting is an entirely open-ended approach, thereby enabling participants to share the terms most strongly associated with the phrase *intensive care unit*. Such associations related to the ICU itself, the experience of being in the ICU, and implications of admission to the ICU. The most salient themes for participants were sick, caring, medical staff, emotional states (fear, sadness), suffering, and physical qualities of the ICU (environment, medical equipment, noisy). Because salient terms reflect factors important in shaping perceptions and experiences related to the ICU, these findings identify themes most likely to be associated with the satisfaction of patients and patients' family members with the ICU experience and care.³³⁻³⁷ These themes can be used as a starting point for future studies to further refine the meaning of the themes to patients and patients' family members and ways to measure the themes.

Previous research³³ has documented that families of critically ill patients receiving end-of-life care in the ICU report level of care and "courtesy, compassion, and respect shown to [patients]" as strong predictors of satisfaction. In our study, the most salient term was *caring*, reported by 47% of all participants, and often early in their lists. Listing of the term *caring* by many participants and the salience of this term among all subgroups analyzed suggest that compassionate care is of primary importance to patients and patients' families, regardless of patients' clinical outcomes. The importance of *caring* is further supported by the results of Riley et al,³⁸ who noted that compassion and concern were important themes identified by patients' family members, nurses, and physicians during focus-group discussions about patient-centered ICUs. The overall similarity in responses from patients and from family members is not surprising. Stricker et al³⁹ noted similar levels of satisfaction in ICU patients and patients' family members.

Our results are consistent with those of other studies^{34,35} suggesting the importance of the ICU environment in satisfaction with care; ICU environment is an element of the ICU experience included in the Family Satisfaction in the Intensive Care Unit survey¹⁰ but not in the Critical Care Family Needs Inventory.¹¹ The participants in our study commonly identified terms associated with physical qualities of the ICU, such as the physical environment (*cold, dark*), medical equipment (*tubes, needles*), and noise level. In comparisons between responses of patients and responses of family members, the terms *environment* and *medical equipment* were salient for both groups, whereas the term *noisy* was salient solely for patients. The salience of the term *noisy* for patients is of particular interest because recent research^{36,37} has shown that the sound level in ICUs varies considerably and can affect patients' psychological well-being. Of note, neither the Family Satisfaction in the Intensive Care Unit survey nor the Critical Care Family Needs Inventory inquires about ICU noise. Future adaptors of the Family Satisfaction in the Intensive Care Unit survey who target patients' experiences should consider incorporating noise level as an element in the survey.

Notably, the term *death* was associated with the ICU for 26% of the participants in our study. Indeed, the word *death* was salient for both family members of patients who survived and of patients who died during the ICU stay. These results suggest that grieving and perceived associations between the ICU and death are not limited to families who experience death of a loved one. Such findings may help explain the results of Azoulay et al,⁴⁰ who found that family members of survivors and nonsurvivors both experienced symptoms of posttraumatic stress. In contrast, the term *hope* was uniquely salient to family members of patients who died, perhaps because patients who lived were less commonly so close to death that the need to experience hope was engendered.⁴¹

Among patients' family members, the term *suffering* was salient solely for those with loved ones who lived. The term also was salient for patients. Although pain and suffering are undoubtedly potential concerns for everyone in an ICU, this finding suggests that their impact is greatest on those who survive and are therefore able to continue experiencing the effects of the ICU event. This suggestion is supported by recent evidence that pain is prevalent in ICU survivors up to 4 months after discharge from the hospital.⁴² An alternative explanation for why the term *suffering* was not salient for family members of patients who died may be that these surrogates had chosen to withhold or withdraw life support in anticipation of suffering, or in an effort

to extinguish suffering. Such decisions precede more than 95% of deaths in our ICU.

Of note, several concepts that emerged as salient reflect themes queried in the Hospital Consumer Assessment of Healthcare Providers and Systems.⁴³ This assessment was developed by the Centers for Medicare and Medicaid Services to measure and publicly report patient-centered quality outcomes. Surveyed domains include communication with physicians and nurses, cleanliness and noisiness of the hospital environment, pain control, and discharge practices. Although much debate exists about the extent to which patient satisfaction scores truly measure delivery of patient-centered care or are linked to desired clinical outcomes,⁴⁴⁻⁴⁶ our findings provide evidence that these themes are indeed important to ICU patients and their families.

Our study has several limitations. First, the participants were recruited from a single center in a major US academic medical center, and our findings may not be generalizable to other settings. Second, because all of the participants spoke English, our findings may not account for different views among patients and patients' family members from different cultural backgrounds. Third, our final interview sample included a majority of female patients. Although this majority occurred because the male patients in the study had higher mortality and morbidity after the ICU stay than the female patients did, this limitation may bias results if views differ by sex. Finally, we were unable to recruit many family members of patients who survived the ICU stay but had severe cognitive and physical impairment. Thus, future studies should determine whether this group of family members might draw unique associations.

By identifying salient words used by patients and patients' family members to describe the ICU, our results provide a foundation for understanding aspects of critical care most important to patients and their families. With this understanding, we can begin to forge a framework for PFCC outcomes for critical care. Future exploration should further define these salient terms, ask participants to rank the relative importance of the terms, and compare salient terms from patients and patients' family members with salient terms of ICU physicians and nurses. Identifying similarities and differences between these groups could suggest areas for better alignment of the priorities of patients and their family members. Continued development of the framework for understanding the outcomes of PFCC in critical care may come from studies on the relative importance patients and patients' family members place on such outcomes as reductions in fear, improvements in a sense of caring, emphasis on compassionate care, and salutary modifications to

the ICU environment and particularly how these outcomes might be valued relative to more conventional ICU outcome measures such as mortality, nosocomial infections, and ventilator-free days.

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