Important questions asked by family members of intensive care unit patients

Vincent Peigne; Marine Chaize; Bruno Falissard; Nancy Kentish-Barnes; Katerina Rusinova; Bruno Mégarbane; Nicolas Bele; Alain Cariou; Fabienne Fieux; Maite Garrouste-Orgeas; Hugues Georges; Merce Jourdain; Achille Kouatchet; Alexandre Lautrette; Stéphane Legriel; Bernard Régnier; Anne Renault; Marina Thirion; Jean-François Timsit; Dany Toledano; Sylvie Chevret; Frédéric Pochard; Benoît Schlemmer; Elie Azoulay

Objectives: Relatives often lack important information about intensive care unit patients. High-quality information is crucial to help relatives overcome the often considerable situational stress and to acquire the ability to participate in the decision-making process, most notably regarding the appropriate level of care. We aimed to develop a list of questions important for relatives of patients in the intensive care unit.

Design, Setting, and Participants: This was a multicenter study. Questions asked by relatives of intensive care unit patients were collected from five different sources (literature, panel of 28 intensive care unit nurses and physicians, 1-wk survey of nurses and 1-wk survey of physicians in 14 intensive care units, and in-depth interviews with 14 families). After a qualitative analysis (framework approach and thematic analysis), questions were rated by 22 relatives and 14 intensive care unit physicians, and the ratings were analyzed using principal component analysis and hierarchical clustering.

Results: The five sources produced 2,135 questions. Removal of duplicates and redundancies left 443 questions, which were distributed among nine predefined domains using a framework approach ("diagnosis," "treatment," "prognosis," "comfort," "interaction," "communication," "family," "end of life," and "postintensive care unit management"). Thematic analysis in each domain led to the identification of 46 themes, which were reworded as 46 different questions. Ratings by relatives and physicians showed that 21 of these questions were particularly important for relatives of intensive care unit patients.

Conclusion: This study increases knowledge about the informational needs of relatives of intensive care unit patients. This list of questions may prove valuable for both relatives and intensive care unit physicians as a tool for improving communication in the intensive care unit.

KEY WORDS: ●●●

Over the past decades, tremendous effort has been expended to support people with a loved one admitted to the intensive care unit (ICU). The result is family-centered care (1), which rests on the principle that family members are no longer mere visitors to the ICU (2, 3).

A key component of family-centered care is the provision of clear and understandable information by the nurses and doctors (4–6). Communicating with the relatives of ICU patients is among the main tasks of ICU staff (7). Epidemiologic and interventional studies have shown that strategies for improving communication result not only in better information from families but also in better fulfillment of families' needs (8, 9), both overall and more specifically at the end of life (10). However, although these studies have highlighted the reality of informational needs, overall, and he style with which information should be provided, they did not guide the nature and the content of the information.

Factors that improve family satisfaction include open access to the ICU, timely information, availability of ICU staff for informal discussions, and active listening by ICU clinicians (2, 11). The shared decision-making model is a communication strategy that empowers family members (12, 13) and helps them to overcome symptoms of anxiety, depression, and stress (14, 15). These manifestations of emotional burden should not lead to the exclusion of family members from the decision-making process (16, 17). Rather, high-quality communication with careful attention to providing consistent data may help families to understand the situation of the patient, to de-

velop reasonable expectations about the outcome, and to participate in decisions about the appropriate level of care (18–22).

Qualitative and quantitative studies indicate poor comprehension of the patient's situation among family members early after ICU admission (23–25). However, comprehension is crucial (26–28). Asking questions is an important tool for family members seeking to understand the patient's situation. However, finding the right questions to ask may be difficult, particularly when having to cope with substantial emotional strain. Helping families ask questions relevant to their needs therefore may hold promise for improving family-centered care. Thus, providing families with a list of potentially useful questions might improve family comprehension. Furthermore, such a list might help clinicians to understand the informational needs of families (29–32).

The objective of this study was to collate a list of questions felt to be important for family members of ICU patients. To accomplish this goal, we used both qualitative and quantitative methods to develop a list of important questions using information from the literature, physicians, nurses, and family members of ICU patients.

PATIENTS AND METHODS

This study was approved by the Institutional Review Board of the Pitié-Salpêtrière Teaching Hospital. An invitation to participate in the study was sent to 15 ICUs belonging to our study group, of which 14 participated in all the steps of the study.

Sources of Data

We first developed a list of questions potentially important to families by referring to five sources of data (Fig. 1): the medical literature (source 1); 28 ICU nurses and physicians in the 14 participating ICUs (source 2); a 1-wk study in the 14 participating ICUs, in which ICU nurses (source 3) and physicians (source 4) recorded all questions asked by relatives; and in-depth interviews of family members (source 5). Questions were identified in the literature by performing a MEDLINE search with the following key words: "family needs," "family questions," "communication," "information," "ICU," and "critical care." Relevant articles were defined as articles reporting questions asked by family members of ICU patients or describing ICU family satisfaction scores. When several articles described the same satisfaction score, we analyzed only the
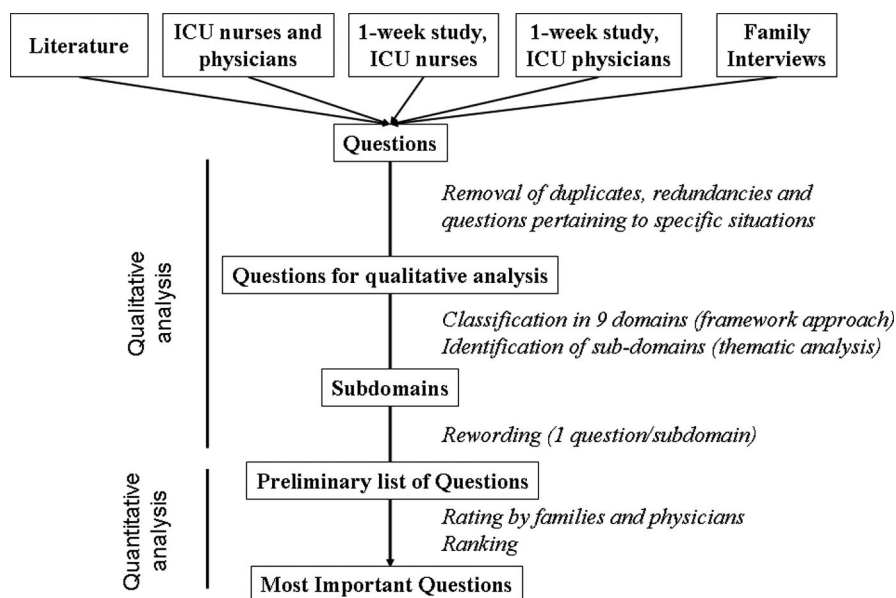

Figure 1. Major steps used to develop the list of important questions. *ICU*, intensive care unit.

more recent one. Only articles in English were reviewed, and questions that were described as important to relatives of ICU patients were collected (source 1). In September 2007, 28 ICU nurses and physicians at the 14 participating ICUs were invited to participate in a written survey. They were asked to indicate which questions they felt were important to families. Participants were allowed to generate as many questions as they wanted (source 2). In January 2008, a 1-wk real-time study on questions important to families was conducted in the 14 participating ICUs (five medical ICUs, two surgical ICUs, and seven medical and surgical ICUs, from eight teaching hospitals and five general hospitals; total number of beds, 206). Blank white posters were placed in each ICU and were used by the nurses to write every question they heard relatives ask during their shifts (source 3); similarly, blue posters were used by physicians to record questions asked by relatives (source 4). All the nurses and physicians of the 14 ICUs were invited to participate, including the 28 who answered the written surveys of source 2. The recorded questions were transcribed verbatim by one of us (V.P.). Finally, in March 2008, in-depth interviews of 14 family members were performed and audiotaped by a psychologist (M.C.) and a physician (K.R.). Each family member was interviewed on the day the patient died or was discharged from the ICU. The psychologist first determined which questions the family member had actually asked the ICU staff. Then, the interviewers referred to different facets of the ICU stay (admission, diagnosis, treatment, interaction with staff, and so on) and listed the questions the family member had asked or would have liked to ask about each facet. The interviews were transcribed and the questions extracted (source 5). These five data sources produced the crude list of questions.

Selection of Questions

Three of us subjected the crude list of questions to a qualitative analysis to identify questions that could be eliminated from the list without losing any information. Thus, intra-source and inter-source duplicates and redundancies were deleted. Duplicates were defined as identically worded questions and redundancies were defined as questions having identical meanings. Context-specific questions that were not relevant to all ICU patients were deleted.

The remaining questions were handled using a framework approach (33–35) with nine literature-based pre-established domains: diagnosis, treatment, prognosis, comfort, interaction, communication, family, end of life, and post-ICU management (36). The choice of the domains was approved by consensus between 14 physicians. A thematic analysis was conducted to identify subdomains (37). Three investigators (E.A., M.C., V.P.) read several times all the questions of each domain to identify the different subjects reflected by these questions. The definitive list of subdomains was established by consensus between the three investigators. Each subdomain was reworded as a single question by a psychologist (M.C.) and a sociologist (N.K.B.). They read several times all the questions of each subdomain and formulated a question that seemed to reflect most of these questions. The definitive list of questions was established by consensus between the psychologist and the sociologist and was validated by two other investigators (E.A. and V.P.). The list of these questions constituted the preliminary list of questions.

A quantitative analysis was performed to rank the questions in the preliminary list. We excluded most of the questions related to the

end of life because we estimated that this situation is specific and we aimed to identify questions important to most of ICU patients' relatives. Furthermore, a specific intervention already had been proven effective in this situation (10). This intervention is a proactive communication strategy that values and appreciates what the family members said, acknowledges the family members' emotions, listens to the relatives, asks questions that would allow understanding of who the patient was as a person, and elicits questions from the family members. In addition, at the end of the meeting, a bereavement leaflet was provided to the relatives.

The questions on the preliminary list were rated by 14 physicians (one per participating ICU) and 22 relatives of patients ventilated for >48 hrs based on the perceived importance of each question. The physicians were asked how important the questions were to family members. The family members were asked how important the questions were to them. Each question was rated from 1 (not important at all) to 5 (very important).

Statistics

The question ratings were analyzed using R software. Agreements among families, among clinicians, and between families and clinicians were evaluated using Cronbach's α coefficients. For each question, we computed the mean rating by families and the mean rating by physicians. A question was considered important to families if its mean rating by families was higher than the median of mean family ratings for all questions; similarly, a question was considered important to physicians if its mean rating by physicians was higher than the median of mean physician ratings for all questions.

To avoid redundancy and minimize questionnaire length, it is necessary to discard questions that grasp the same aspect of the measured construct. Because the number of questions is high, this reduction process had to be performed through the use of exploratory multidimensional approaches like principal component analysis and hierarchical clustering analysis. Principal component analysis was performed to obtain a graphic representation of correlations of ratings across questions and between families and physicians. When two points are close to each other, the underlying variables are positively correlated. When two points are diametrically opposed, the underlying variables are negatively correlated. Similarly, hierarchical clustering analysis represents graphically with a "dendrogram" (a tree-like diagram) the nearness of two variables. Because the variables were normalized here, nearness is mathematically equivalent to the strength of the Pearson correlation coefficient. In practice, hierarchical clustering analysis was performed to identify questions that received similar ratings from families and phy-

sicians. When two or more questions were similar by hierarchical clustering and had comparable contents, they were merged into a single question. Questions were considered important if they received high ratings from either families or clinicians (nurses and doctors) or both, and if they received homogeneous ratings within each group.

RESULTS

Data Collection

We collected 2,135 questions (Fig. 2). The literature review identified seven relevant publications (3, 11, 26, 38–41), from which 96 questions were collected. The 28 ICU nurses and physicians reported 499 questions. In the 1-wk study, the nurses reported 869 questions and the physicians 577 questions. Finally, 94 questions were obtained from the in-depth interviews of family members.

Qualitative Analysis

The qualitative analysis showed that 1,692 (79%) questions were duplicates or redundancies or were related to specific situations that did not apply to all ICU patients (Fig. 2). The framework analysis

distributed the remaining 443 (21%) questions among the nine pre-established domains as follows: diagnosis, 118 (26.6%) questions; treatment, 57 (12.9%) questions; prognosis, 52 (11.7%) questions; comfort, 26 (5.9%) questions; interaction, 23 (5.2%) questions; communication, 32 (7.2%) questions; family, 70 (15.8%) questions; end of life, 22 (5.0%) questions; and post-ICU management, 43 (9.7%) questions.

The thematic analysis identified 46 subdomains (Fig. 2 and Supplemental Table I [Supplemental Digital Content 1, http://links.lww.com/CCM/A234]), six in the diagnosis domain, and five in each of the other eight domains. These 46 subdomains yielded a preliminary list of 46 questions (Supplemental Table I [Supplemental Digital Content 1, http://links.lww.com/CCM/A234]).

Quantitative Analysis

Of the 46 questions, 42 were rated by the family members and physicians. The remaining four questions pertained to end-of-life care and were excluded from this step of the study.

All the questions but one had mean ratings >2.5 (Table 1). The median rating by
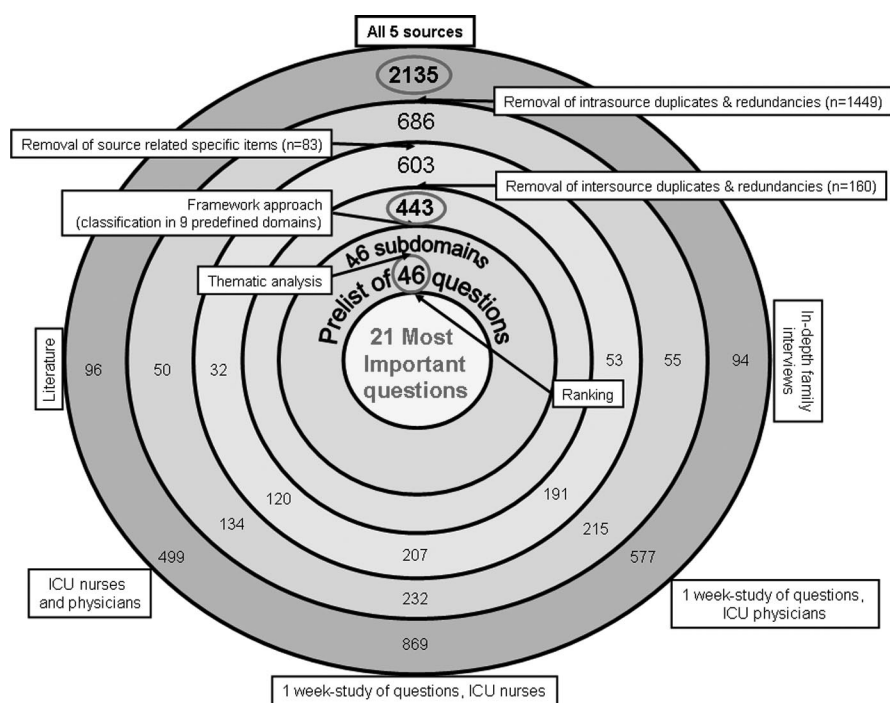
Figure 2. Flow chart of questions. The circles represent the different steps of the analysis and the figures represent the number of questions at each step. The *upper part* of the diagram (*bold figures*) shows all questions from the five sources; the *lower part* shows the number of questions at each step from each of the five sources (literature, opinions of 28 ICU nurses and physicians, 1-wk prospective collection of questions asked to intensive care unit [*ICU*] nurses and physicians in 14 French ICUs, and in-depth interviews of relatives of ICU patients by a psychologist).

relatives was 3.9 (interquartile range, 3.5–4.1), and the median rating by physicians was 3.8 (interquartile range, 3.5–4.1). Cronbach's α coefficient was 0.78 across families, 0.77 across physicians, and 0.81 between families and physicians, indicating good interobserver consistency.

Figure 3 shows the results of the principal component analysis and the mean ratings. Seventeen questions received high ratings by families and physicians, seven only received high ratings by families, and eight received high ratings only by physicians. Ratings of the remaining ten questions by families and physicians were below median rating. "Futility" and "relatives' distress" were the only questions that received high ratings by either the families or the physicians and were the only questions that did not have homogeneous notations. These two questions were eliminated.

Based on the hierarchical clustering results (Supplemental Figure I and Supplemental Figure II), the following questions were merged: "relapse" with "disease"; "transfer" with "recovery"; "appointment" with "being informed"; "talking," "touching," and "answering" with "hearing"; 'investigations" with "news"; "visiting" with "my participation"; "medication" with "what treatments"; "death" with "probability"; "vital parameters" with "appearance"; and "religion" with "relatives' distress."

Among the remaining 28 questions, 21 received high ratings by families or physicians or both and were considered the most important questions for families (Table 2). This list of important questions included questions from eight of the nine domains.

DISCUSSION

We established a list of 21 questions important to relatives of ICU patients. This list was obtained by identifying questions asked by family members and then evaluating how important these questions were to families and physicians.

Several arguments suggest that a prompt list of questions could be more clinically significant in the critical care setting than anywhere else in the hospital. First, because most ICU patients are unable to make their own choices, ICU clinicians interact mostly with the relatives. This situation occurs far less frequently in other hospital wards. Second, family members of ICU patients have to cope with their own distress and with prognostic uncertainties of their loved one's disease. Questions might be specific to this situation. Third,

Table 1. Ratings given by relatives and physicians to each of the 42 questions on the preliminary list

Domain	Subdomain	Relatives' Ratings (n = 22)	Physicians' Ratings (n = 14)	High Ratings
Diagnosis	Neurologic status	3.7 ± 1.2	3.9 ± 1.0	Physicians
Diagnosis	Fever	2.8 ± 1.4	3.4 ± 1.0	Never
Diagnosis	Disease	4.4 ± 1.1	4.2 ± 0.9	Relatives and physicians
Diagnosis	Appearance	3.7 ± 1.0	3.8 ± 1.2	Physicians
Diagnosis	Vital parameters	4.0 ± 1.0	2.9 ± 1.3	Relatives
Diagnosis	Investigations	4.6 ± 0.6	3.6 ± 0.9	Relatives
Treatment	Surgery	3.1 ± 1.6	2.5 ± 1.2	Never
Treatment	What treatments?	3.9 ± 1.0	3.9 ± 0.9	Relatives and physicians
Treatment	Weaning	4.1 ± 1.1	4.3 ± 1.0	Relatives and physicians
Treatment	Tubes and machines	3.5 ± 1.1	3.7 ± 0.9	Physicians
Treatment	Medication	3.2 ± 1.0	3.5 ± 0.9	Never
Prognosis	Recovery	4.5 ± 0.8	3.9 ± 0.9	Relatives and physicians
Prognosis	Death	3.6 ± 1.6	3.6 ± 1.3	Never
Prognosis	Probability	3.9 ± 1.1	3.6 ± 1.4	Relatives
Prognosis	How and when families will know	3.9 ± 1.1	4.1 ± 0.9	Relatives and physicians
Prognosis	Recent events	4.2 ± 0.9	3.8 ± 1.2	Relatives and physicians
Comfort	Psychological distress	4.2 ± 1.2	2.3 ± 1.1	Relatives
Comfort	Supplying comfort items	3.9 ± 1.2	3.6 ± 0.9	Relatives
Comfort	Physical pain	4.1 ± 1.0	4.6 ± 0.6	Relatives and physicians
Comfort	Food	3.3 ± 1.1	3.4 ± 1.2	Never
Comfort	Sleep	3.5 ± 1.1	3.0 ± 1.0	Never
Interaction	Talking	3.8 ± 1.5	4.5 ± 0.9	Relatives and physicians
Interaction	Answering	3.5 ± 1.5	4.0 ± 1.1	Physicians
Interaction	Touching	3.9 ± 1.1	4.4 ± 0.9	Relatives and physicians
Interaction	Hearing	3.7 ± 1.5	4.6 ± 0.5	Physicians
Interaction	My participation	4.0 ± 1.1	3.8 ± 1.0	Relatives and physicians
Communication	Appointment	4.1 ± 1.2	3.9 ± 1.0	Relatives and physicians
Communication	Being informed	4.6 ± 0.7	4.4 ± 0.5	Relatives and physicians
Communication	News	4.5 ± 0.7	3.7 ± 1.0	Relatives and physicians
Communication	Staff members	3.7 ± 1.3	3.4 ± 1.3	Never
Communication	Phone	4.3 ± 0.9	4.3 ± 0.8	Relatives and physicians
Family	Visiting	3.7 ± 1.2	4.1 ± 0.9	Physicians
Family	Contamination	3.7 ± 1.1	2.9 ± 0.9	Never
Family	Decision-making	3.9 ± 1.0	3.2 ± 1.3	Relatives
Family	Relatives' distress	3.0 ± 1.2	3.8 ± 1.3	Physicians
Family	Religion	2.7 ± 1.5	3.6 ± 1.2	Never
Post-ICU	Length of stay	3.9 ± 1.2	3.9 ± 1.0	Relatives and physicians
Post-ICU	Relapse	4.1 ± 0.9	3.9 ± 1.0	Relatives and physicians
Post-ICU	Sequelae	4.3 ± 1.2	4.5 ± 0.8	Relatives and physicians
Post-ICU	Transfer	4.3 ± 0.8	3.5 ± 1.0	Relatives
Post-ICU	Memory	3.4 ± 1.4	3.1 ± 1.0	Never
End-of-life	Futility	2.9 ± 1.4	3.8 ± 1.2	Physicians
		Cronbach's α: 0.78	Cronbach's α: 0.77	
			Cronbach's α: 0.81	

ICU, intensive care unit.

Data are mean ± SD. Physicians and families rated each question from 1 (not important at all) to 5 (very important). High ratings were defined as ratings above the median for all questions (3.9 for families and 3.8 for physicians).

Figure 3. Principal component analysis and ranking according to mean ratings. Questions that received higher ratings are further on the *left*. Questions with smaller differences in ratings by families and physicians are closer to the *x-axis*. *Red*, questions with high ratings by families and physicians. *Green*, questions with high ratings by families only. *Blue*, questions with high ratings by physicians only. *Black*, questions with no high ratings.

Table 2. List of the 21 most important questions asked by family members of patients in the intensive care unit

Domain	Subdomain	Question
Diagnosis	Neurologic status	Why is he/she not fully conscious?
Diagnosis	Disease	What is wrong with him/her?
Diagnosis	Appearance	I am upset by the way he/she looks. Can you tell me why he/she looks different?
Treatment	What treatments?	What treatments and other care is he/she receiving?
Treatment	Weaning	When will he/she be able to breathe on his/her own?
Treatment	Tubes and machines	What is the purpose of the tubes and machines attached to him/her?
Prognosis	Recovery	Will he/she get better?
Prognosis	Probability	What are the chances that he/she recovers?
Prognosis	How and when families will know	How and when will we know what is going to happen?
Prognosis	Recent events	Is he/she better today?
Comfort	Psychological distress	Is he/she in psychological distress?
Comfort	Supplying comfort items	Is there anything I can do to make him/her more comfortable? (music, newspaper, food)
Comfort	Physical pain	Is he/she in pain?
Interaction	Hearing	Can he/she hear me when I speak to him/her?
Interaction	My participation	What can I do for him/her? (help with care, feeding, washing)
Communication	Being informed	Can I be sure I will be told if something happens?
Communication	News	Will I be informed regularly of changes and, if so, how?
Communication	Phone	Can I call to find out how he/she is doing?
Family	Decision-making	In a decision-making situation, what is expected of me?
Post-ICU	Length of stay	How long will he/she stay in the ICU?
Post-ICU	Sequelae	Will he/she have any after-effects?

ICU, intensive care unit.

given the huge burden on the relatives, a list of questions could improve comprehension, decrease symptoms of anxiety, depression, and stress, and also improve the quality of the decision-making and reduce ICU conflicts.

The multicenter design and the involvement of nurses, physicians, and family members helped us to identify a large number of questions actually asked by families. Having questions from several different sources offers opportunities to identify important questions that family members would have reported, without being able to recall them at the time of the survey because of their acute stress and their symptoms of anxiety and depression (15). We therefore asked ICU nurses and physicians about questions they felt were important to family members, and we also reviewed the literature on this topic. Furthermore, the in-depth family member interviews were specifically designed to elucidate questions deemed important by families. More than 2,000 questions were thus collected. A qualitative analysis was then performed to shorten the list of questions without losing information (37).

Evaluating the importance of a question to family members is a challenging task. In our study, the questions were rated not only by family members but also by ICU physicians who had experience with a vast array of families, as well as knowledge of families' concerns after the ICU experience. The participation of physicians in the ranking of the questions allowed us to eliminate biases related to the impact of the emotional burden of the families, to the small number of ranking families, to the lack of information about cultural/ethnicity of these families. Such a strategy could create confusion by mixing families and physicians' preferences. We therefore analyzed ratings by families and physicians separately to avoid excluding questions well-noted by families and not by physicians. Although the family members and the physicians used a numerical scale to rate the questions, we did not seek to determine a cut-off above which questions were important. Instead, we relied on a combination of statistical approaches. Hierarchical clustering allowed us to merge questions reflecting similar concerns. Principal component analysis provided us with an overview of both the importance of the questions and the agreement between families and physicians regarding the importance of the questions. All these data helped us to

perform an objective analysis of question ratings and to identify the most important questions for family members of ICU patients.

Asking and answering questions have a major role in communication with ICU family members. Several studies showed how specific communication strategies could help clinicians to better meet the informational needs of families (8–10, 20). However, these strategies were designed to improve the delivery of information, and the studies did not investigate whether the content of the information was at odds with the expectations of the relatives. This deficiency was emphasized in a recent study of information leaflets (42). In this study, Soltner et al (42) found that relatives of ICU patients wanted more information than was provided in the leaflets or recommended in published guidelines. This information gap may contribute to explaining the low level of comprehension by family members of the patient's situation in the ICU (23, 24). The list of important questions established in our study may help to fill this gap by drawing attention to the topics about which ICU families want information. The list could be used by families to help them determine which questions they want to ask. Such a strategy has been validated in the palliative care setting (43). A recent literature review and meta-analysis identified 23 studies evaluating question checklists before consultations in oncology and cardiology clinics (44). The impact of these interventions on question-asking, participation, anxiety, knowledge, and satisfaction was limited. These settings are quite different from the ICU because our patients are often unable to communicate and intensivists interact mostly with family members. Another difference between intensive care medicine and oncology or cardiology clinics is the time scale: unfortunate and fatal events occur faster in the ICU.

The question list proposed in our study may also prove useful to physicians for preparing family conferences. Increasing awareness among physicians of the specific informational needs of families may diminish the number of missed opportunities during family conferences (45). The clinical significance of the list could be decreased anxiety, improved understanding, or increased number of questions asked by family members, and the list should be evaluated prospectively.

This study has several limitations. First, questions important to family members were not identified through a purely qualitative process with semi-structured interviews. Therefore, important questions could have been missed. However, the prompt list was extracted from multiple sources of questions processed through qualitative analysis. Second, the study was performed in France and concerns may arise about the generalizability of the list of questions to other countries. However, the study was performed in 14 ICUs and involved both nurses and physicians, in addition to relatives. Third, our major goal is to reduce burden on the relatives. However, the demonstration that this list of questions can effectively improve the ICU experience for family members still needs to be demonstrated.

In summary, we identified 21 questions that are important for relatives of ICU patients. This list might help families to determine which questions they want to ask at a time when they are undergoing considerable emotional strain and, therefore, may have difficulty assessing their informational needs. It may help ICU physicians to check the completeness of the information they provide to families. Studies of families with relatives in the ICU are needed to assess the effect of using the list on comprehension, participation in decision-making, and post-ICU emotional burden.

REFERENCES

1. The SUPPORT Principal Investigators: A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. *JAMA* 1995; 274:1591–1598
2. Lilly CM, Daly BJ: The healing power of listening in the ICU. *N Engl J Med* 2007; 356: 513–515
3. Wall RJ, Engelberg RA, Downey L, et al: Refinement, scoring, and validation of the Family Satisfaction in the Intensive Care Unit (FS-ICU) survey. *Crit Care Med* 2007; 35:271–279
4. Dodek PM, Heyland DK, Rocker GM, et al: Translating family satisfaction data into quality improvement. *Crit Care Med* 2004; 32:1922–1927
5. Truog RD, Campbell ML, Curtis JR, et al: Recommendations for end-of-life care in the intensive care unit: A consensus statement by the American College [corrected] of Critical Care Medicine. *Crit Care Med* 2008; 36: 953–963
6. Davidson JE, Powers K, Hedayat KM, et al: Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005. *Crit Care Med* 2007; 35:605–622
7. Azoulay E, Pochard F: Meeting the needs of intensive care unit patients' family members: Beyond satisfaction. *Crit Care Med* 2002; 30: 2171
8. Lilly CM, De Meo DL, Sonna LA, et al: An intensive communication intervention for the critically ill. *Am J Med* 2000; 109: 469–475
9. Lilly CM, Sonna LA, Haley KJ, et al: Intensive communication: Four-year follow-up from a clinical practice study. *Crit Care Med* 2003; 31:S394–S399
10. Lautrette A, Darmon M, Megarbane B, et al: A communication strategy and brochure for relatives of patients dying in the ICU. *N Engl J Med* 2007; 356:469–478
11. Azoulay E, Pochard F, Chevret S, et al: Meeting the needs of intensive care unit patient families: A multicenter study. *Am J Respir Crit Care Med* 2001; 163:135–139
12. Carlet J, Thijs LG, Antonelli M, et al: Challenges in end-of-life care in the ICU. Statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003. *Intensive Care Med* 2004; 30:770–784
13. White DB, Braddock CH 3rd, Bereknyei S, et al: Toward shared decision making at the end of life in intensive care units: Opportunities for improvement. *Arch Intern Med* 2007; 167:461–467
14. Azoulay E, Pochard F, Kentish-Barnes N, et al: Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *Am J Respir Crit Care Med* 2005; 171: 987–994
15. Pochard F, Azoulay E, Chevret S, et al: Symptoms of anxiety and depression in family members of intensive care unit patients: Ethical hypothesis regarding decision-making capacity. *Crit Care Med* 2001; 29:1893–1897
16. Azoulay E: The end-of-life family conference: Communication empowers. *Am J Respir Crit Care Med* 2005; 171:803–804
17. Arnold RM, Kellum J: Moral justifications for surrogate decision making in the intensive care unit: implications and limitations. *Crit Care Med* 2003; 31:S347–S353
18. Quill TE, Brody H: Physician recommendations and patient autonomy: finding a balance between physician power and patient choice. *Ann Intern Med* 1996; 125:763–769
19. Prendergast TJ, Puntillo KA: Withdrawal of life support: Intensive caring at the end of life. *JAMA* 2002; 288:2732–2740
20. Azoulay E, Pochard F, Chevret S, et al: Impact of a family information leaflet on effectiveness of information provided to family members of intensive care unit patients: A multicenter, prospective, randomized, controlled trial. *Am J Respir Crit Care Med* 2002; 165:438–442

21. Way J, Back AL, Curtis JR: Withdrawing life support and resolution of conflict with families. *BMJ* 2002; 325:1342–1345

22. Tulsky JA, Fischer GS, Rose MR, et al: Opening the black box: How do physicians communicate about advance directives? *Ann Intern Med* 1998; 129:441–449

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

24. Rodriguez RM, Navarrete E, Schwaber J, et al: A prospective study of primary surrogate decision makers' knowledge of intensive care. *Crit Care Med* 2008; 36:1633–1636

25. Rabow MW, Hauser JM, Adams J: Supporting family caregivers at the end of life: "They don't know what they don't know." *JAMA* 2004; 291:483–491

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

27. Covinsky KE, Goldman L, Cook EF, et al: The impact of serious illness on patients' families. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *Jama* 1994; 272:1839–1844

28. Cuthbertson SJ, Margetts MA, Streat SJ: Bereavement follow-up after critical illness. *Crit Care Med* 2000; 28:1196–1201

29. Cegala DJ, Post DM: The impact of patients' participation on physicians' patient-centered communication. *Patient Educ Couns* 2009; 77:202–208

30. Haynes AB, Weiser TG, Berry WR, et al: A surgical safety checklist to reduce morbidity and mortality in a global population. *N Engl J Med* 2009; 360:491–499

31. Lingard L, Regehr G, Orser B, et al: Evaluation of a preoperative checklist and team briefing among surgeons, nurses, and anesthesiologists to reduce failures in communication. *Arch Surg* 2008; 143:12–17; discussion 18

32. Wilkins VM, Quill TE, King DA: Assessing families in palliative care: A pilot study of the checklist of family relational abilities. *J Palliat Med* 2009; 12:517–519

33. Smith SK, Dixon A, Trevena L, et al: Exploring patient involvement in healthcare decision making across different education and functional health literacy groups. *Soc Sci Med* 2009; 69:1805–1812

34. Haines TP, Cornwell P, Fleming J, et al: Documentation of in-hospital falls on incident reports: Qualitative investigation of an imperfect process. *BMC Health Serv Res* 2008; 8:254

35. Dudoit S, Speed TP: A score test for the linkage analysis of qualitative and quantitative traits based on identity by descent data from sib-pairs. *Biostatistics* 2000; 1:1–26

36. Clarke EB, Curtis JR, Luce JM, et al: Quality indicators for end-of-life care in the intensive care unit. *Crit Care Med* 2003; 31:2255–2262

37. Pope C, Mays N: Qualitative research in healthcare. Oxford, UK, Wiley-Blackwell, 2006

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

39. McDonagh JR, Elliott TB, Engelberg RA, et al: Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with increased satisfaction. *Crit Care Med* 2004; 32:1484–1488

40. Burns JP, Mello MM, Studdert DM, et al: Results of a clinical trial on care improvement for the critically ill. *Crit Care Med* 2003; 31:2107–2117

41. Nelson JE, Kinjo K, Meier DE, et al: When critical illness becomes chronic: Informational needs of patients and families. *J Crit Care* 2005; 20:79–89

42. Soltner C, Lassalle V, Galienne-Bouygues S, et al: Written information that relatives of adult intensive care unit patients would like to receive–A comparison to published recommendations and opinion of staff members. *Crit Care Med* 2009; 37:2197–2202

43. Clayton JM, Butow PN, Tattersall MH, et al: Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. *J Clin Oncol* 2007; 25:715–723

44. Kinnersley P, Edwards A, Hood K, et al: Interventions before consultations for helping patients address their information needs. *Cochrane Database System Rev* 2007:CD004565

45. Curtis JR, Engelberg RA, Wenrich MD, et al: Missed opportunities during family conferences about end-of-life care in the intensive care unit. *Am J Respir Crit Care Med* 2005; 171:844–849