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ORIGINAL

Giving a voice to patients at high risk of dying in the intensive care unit: a multiple source approach

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Abstract

Purpose: Data are scarce regarding the experience of critically ill patients at high risk of death. Identifying their concerns could allow clinicians to better meet their needs and align their end-of-life trajectory with their preferences and values. We aimed to identify concerns expressed by conscious patients at high risk of dying in the intensive care unit (ICU).

Methods: Multiple source multicentre study. Concerns expressed by patients were collected from five different sources (literature review, panel of 50 ICU experts, prospective study in 11 ICUs, in-depth interviews with 17 families and 15 patients). All qualitative data collected were analyzed using thematic content analysis.

Results: The five sources produced 1307 concerns that were divided into 7 domains and 41 sub-domains. After removing redundant items and duplicates, and combining and reformulating similar items, 28 concerns were extracted from the analysis of the data. To increase accuracy, they were merged and consolidated, and resulted in a final list of 15 concerns pertaining to seven domains: concerns about loved-ones; symptom management and care (including team competence, goals of care discussions); spiritual, religious, and existential preoccupations (including regrets, meaning, hope and trust); being oneself (including fear of isolation and of being a burden, absence of hope, and personhood); the need for comforting experiences and pleasure; dying and death (covering emotional and practical concerns); and after death preoccupations.

Conclusion: This list of 15 concerns may prove valuable for clinicians as a tool for improving communication and support to better meet the needs of patients at high risk of dying.

Keywords: Dying patients, Experience, Concerns, Qualitative study

Introduction

Over the last decades, major efforts have been made to provide better support for patients at the end of their lives. For instance, careful attention has been given to symptoms' management, addressing emotional needs as well as spiritual questions. The central role of family members has also been recognized [1], with their

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increased implication in discussions about goals of care. In the intensive care unit (ICU), support provided to patients and family members has considerably increased [2–6]. Quality of dying and death in the ICU has also been explored [7–10]. However, if these studies shed light on the family and ICU clinicians' experience, they give less emphasis to the needs and experiences of the patients themselves, even though they are at the heart of the process.

In the ICU, for patients at high risk of death and their relatives, one of the main elements of good care is communication—empathic, clear, and timely [11]. However, various studies [12, 13] have shown that it is precisely communication that can be insufficient in these end-of-life situations. Fortunately, these communication gaps with family members have been investigated and practices have improved. These improvements are important also for the patients who worry about their loved-ones [14–16]. However, communication with patients requires further attention. Care for patients at the end of life must not only include symptoms' management but must also preserve the patient's dignity, respect their perspective, as well as their autonomy by adapting the care plan to their expressed wishes, needs, and preoccupations [17–20]. Clinicians should thus feel committed to eliciting their concerns to better respond to them and to better meet their needs.

Breaking the "wall of silence" by allowing patients to question those around them, to express their emotions and concerns may benefit both the patient and the ICU team who can personalize the end-of-life process. It is true that many critically ill patients are unconscious or incapable of communicating with nurses, doctors, and family members. However, when conscious and if possible, some patients at high risk of dying may choose to receive less mechanical ventilation and sedation [21, 22]. For those who are conscious and capable of interacting, clinicians and researchers should not miss the opportunity to elicit their concerns. The aim of this study was therefore to develop a list of concerns important to critically ill conscious patients at high risk of death.

Methods

This study was approved by the Comité de Protection des Personnes Ile de France III, on January 21st 2020 (Dossier n° 2019-A02267-50; Réf CPP: 3760-NI; Réf CNRIPH: 20.01.08.58958). An invitation to participate in the study was sent to 14 ICUs actively involved in our Famiréa research network.

Study population

In this study, patients were considered to be at "high risk of death" when their ICU physician estimated their risk of dying at over 80% within 3 months (based on team discussion that included data such as Simplified Acute Physiology Score (SAPS) II score between 55 and 62). Patients were considered "conscious" if they were capable of expressing themselves and able to actively interact with clinicians and/or with researchers (i.e., patients with a normal vigilance status, a Glasgow Coma Scale (GCS) at 15, and capable of answering baseline questions).

Take-home message

Data are scarce regarding the experience of critically ill patients at high risk of death. This list of 15 concerns expressed by conscious patients at high risk of dying in the ICU provides clinicians with a tool for improving communication and support to better meet the needs of patients in end-of-life situations

Sources of data

We used a multiple source approach [23] targeting data from five different sources: a literature review (source 1); ICU physicians and nurses working in the field of end-of-life (source 2); a 6-month study in the participating ICUs in which physicians and nurses recorded all questions and preoccupations expressed by patients at high risk of dying (source 3); in-depth qualitative interviews with families of patients at high risk of dying (source 4); and in-depth qualitative interviews with patients at high risk of dying (source 5).

Source 1. Concerns were identified in the literature by performing a search for articles published with an abstract, in English, between January 2000 and October 2020 using PubMed, Sciencedirect and Cairn, with the following Mesh terms: [« Patients End of Life»] AND [« questions» OR « concerns» OR « experience»] AND [« Intensive Care Unit» or « Palliative Care»]. We included research articles (quantitative, qualitative, or mixed) as well as literature reviews focused on the patient's perspective/experience of end of life in the ICU or in palliative care. We excluded articles focused on euthanasia, assisted suicide, or therapeutic obstinacy with specific legal frameworks as well as articles dealing with end of life in the traditional cultures with little or no access to the intensive-care unit or focusing on end of life in the context of a specific rare chronic disease. Relevant articles found during the review were added to the analysis.

Source 2. In February 2020, 50 ICU physician and nurse experts (i.e., who published at least one article focused on end of life care in the ICU) were each invited to complete a table to list the questions and concerns ever expressed by their patients at high risk of dying. Participants were allowed to generate as many concerns as they wished.

Source 3. Between October 2020 and March 2021, we conducted a prospective study on concerns expressed by patients at high risk of dying. In each participating ICU, two panels were displayed to record in a real-time manner any questions/preoccupations expressed by patients at high risk of death, including a blue panel for physicians and a white panel for nurses and other allied professionals. These panels were displayed in areas inaccessible to patients and families. The recorded questions were transcribed verbatim by two of us (VS and NKB).

Source 4. Between February 2020 and May 2022 (the study was temporarily interrupted due to the coronavirus disease 2019 (COVID-19) pandemic between the end of March 2020 and the beginning of May 2021), in two ICUs, in-depth structured interviews with family members of patients at high risk of dying were performed and audiotaped by three researchers (VD, ALP, and EB). During interviews, families were asked to report what they believed to be their loved-one's concerns (Supplementary Table 1). Interviews were audiotaped, transcribed, and anonymized, and the concerns were extracted.

Source 5. Between February 2020 and May 2022 (study was temporarily interrupted due to COVID-19 pandemic between the end of March 2020 and beginning of May 2021), in five ICUs, in-depth structured interviews with conscious patients at high risk of dying were performed and audiotaped by four researchers (ALP, CG, CG, and AR). The interviews focused on the patient's concerns (Supplementary Table 2). Questions were phrased sensitively and respected recommendations for interviews with people in palliative care settings [24, 25]. Interviews were audiotaped, transcribed, and anonymized, and the concerns were extracted.

Selection of concerns

All concerns were recorded exhaustively, and data were exported into a unique file. Two researchers, NKB (sociologist) and ALP (psychologist), read through the whole set and excluded concerns or items that were out of scope. They then independently reviewed the set of concerns from source 2 and identified key domains that occurred throughout the set. They used thematic content analysis that allows to identify significant data out of a data corpus gathered from different sources [26]. A tentative codebook was then developed through an iterative process that started with the systematic comparison of the investigators' respective codes and ended when they achieved consensus [27]. Data from source 2 were recoded using this refined codebook. After consolidation, the codebook was then used for independent analysis of data from sources 1 and 3 by the two researchers. Once again, a systematic comparison of their respective codes was organized, discrepancies were resolved by discussion, and new codes were added if necessary. Data from sources 4 and 5 were split between the two researchers, coded, and then systematically discussed. Once coding was finalized, thematic domains and sub-domains were generated and defined, and were reviewed and consolidated during a multidisciplinary team meeting (NKB; ALP; EA; FP; CG; VS; AR). We used descriptive statistics to describe and summarize the distribution of each domain in each source.

In each domain, researchers then identified and listed all duplicates and redundant concerns. These were defined as concerns and questions that could be formulated in exactly the same way, or with different synonymous words, so that the meaning of the concern was the same. For example, "What will happen to my children after I die?" and "I'm concerned about my children once I'm gone" were considered duplicates. These duplicates where then summarized into a single generic question, representative of the overall meaning of the concern. In the case of the previous example, the generic concern would be "I'm preoccupied about my loved-ones after I die".

For each sub-domain, the two researchers (NKB and ALP) then proposed a single concern representative of the issues identified and grouped similar concerns and questions together. This final list of concerns was validated by the whole team (NKB; ALP; EA; FP; CG; VS; AR).

Role of the funding source

The funder of the study had no role in study design, data collection, data analysis, data interpretation, writing of the report, or decision to submit the manuscript.

Results

Eleven ICUs (characteristics reported in Supplementary Table 3) participated in the 6-month study (source 3, ICU panels), two ICUs participated in source 4 (family interviews), and five participated in source 5 of the study (patient interviews).

Data collection

We collected 1307 concerns as shown in Fig. 1. Twelve items were deleted because of irrelevance (for example, in source 2, the following statement was excluded "Stress attitudes and non-verbal questions") leaving 1295 items that were divided into 7 domains and 41 sub-domains.

The literature review included 45 relevant articles (out of 3037) and allowed us to identify 135 concerns. The 50 physicians and nurses reported 280 concerns (162 from physicians, 118 from nurses). In the 6-month study, physicians and nurses recorded a total of 289 concerns, respectively 199 and 90. Seventeen family members and fifteen patients participated in qualitative interviews. Characteristics of participants are presented in

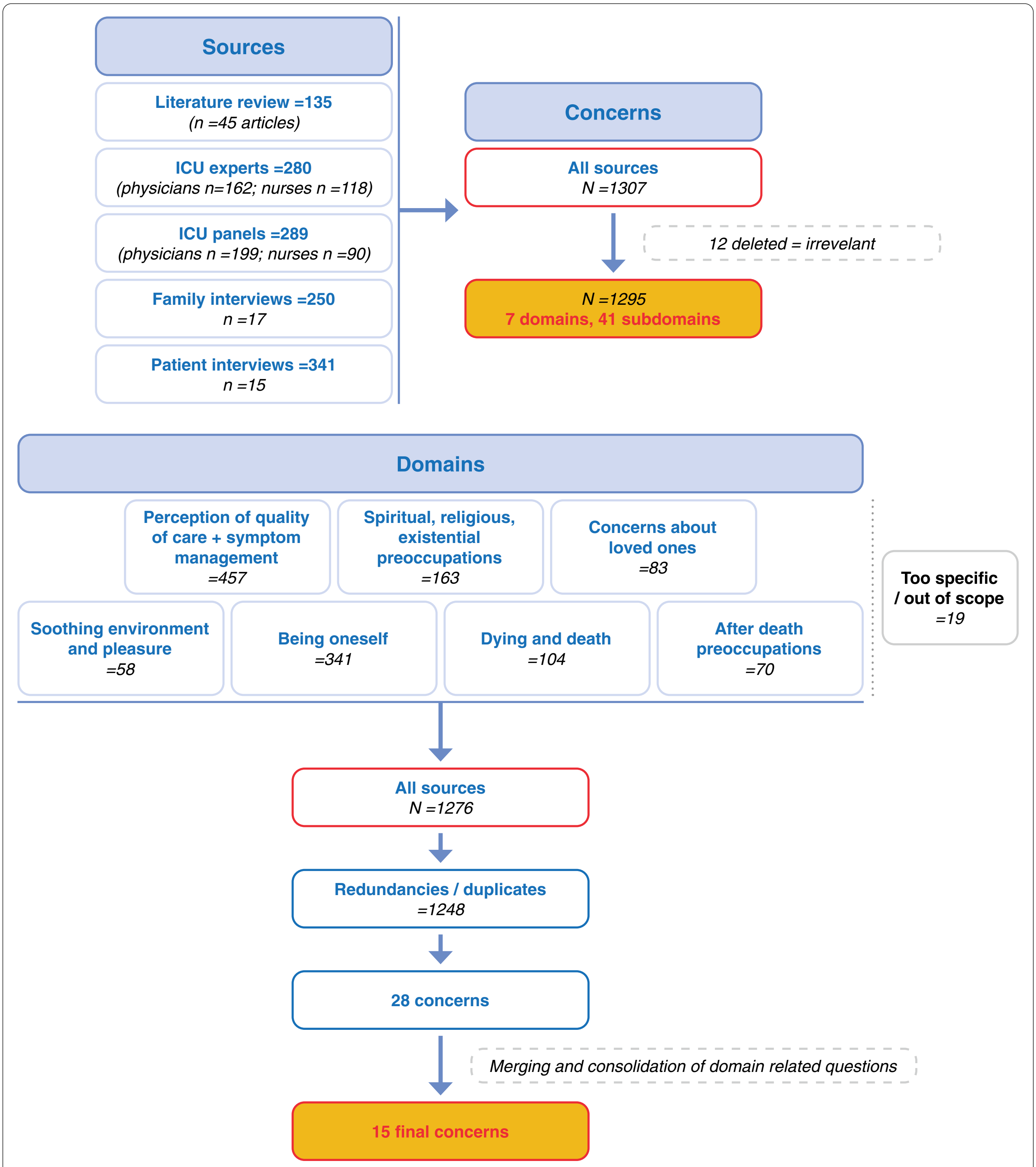


Fig. 1 Study flowchart

Supplementary Tables 4–5. Interviews lasted between 9 and 53 min (median 38 min) for family members and between 2 and 46 min for patients (median 29 min). Two hundred and fifty concerns were obtained from the in-depth interviews with family members and 341 from the in-depth interviews with patients themselves. At this stage, 19 items were deleted, because too specific or out of scope, leaving 1276 items.

Classification

The 1276 items were classified according to the seven domains of analysis (Table 1). From the most represented to the least represented: *Perception of quality of care and symptom management* ($n=457$; 36%); *Being oneself* ($n=341$; 27%); *Spiritual, religious, existential preoccupations* ($n=163$; 13%); *Dying and death* ($n=104$; 8%); *Concerns about loved-ones* ($n=83$; 7%); *After death preoccupations* ($n=70$; 5%); *Soothing environment and pleasure* ($n=58$; 5%) (Fig. 2). According to the sources, some domains were more prevalent than others: *Being oneself* was more prevalent in source 1 (literature review); *Perception of quality of care and symptom management* more prevalent in source 2 (more specifically from physician experts), and 4. *Spiritual, religious, existential preoccupations* was particularly prevalent in source 5.

Qualitative analysis

Among the 1276 concerns, 1248 were independently identified by two researchers (ALP and NKB) as duplicates/redundant, leaving a total of 28 concerns that covered all seven domains. Some domains required several questions to be fully covered, such as *Perception of quality of care and symptom management* (8 questions), *Spiritual, religious, existential preoccupations* (6 questions), and *Being oneself* (5 questions), whereas others required less, such as *Concerns about loved-ones*.

As described in Table 2, to reduce the number of concerns while being attentive to domain accuracy, we merged and consolidated domain related concerns that resulted in the final list of 15 concerns, consensually validated by the multidisciplinary steering committee of the study (Table 3). All seven initial domains remained represented. *Concerns about loved-ones* domain was reduced to one question. *Perception of quality of care and symptom management* was reduced to three questions that cover trust in the team, discussing goals of care and symptom management. *Spiritual, religious, existential preoccupations* domain was reduced to three questions that cover regrets, meaning, and hope and trust. *Being oneself* was the domain with the most questions (4) that cover fear of isolation, fear of being a burden, absence of hope, and personhood. *Soothing environment and pleasure* remained one question that covers the need for comforting experiences. *Dying and death* was reduced to two questions that cover emotional and practical preoccupations. Last, *After death preoccupations* was reduced to one question.

Discussion

This study is the first to establish a list of concerns important to patients at high risk of dying in the ICU. The multiple source approach and multicentre design as well as the involvement of nurses, physicians, and family members in addition to patient interviews helped us to identify many concerns. This list brings important information to clinicians, as interacting with patients at risk of dying is often experienced as emotionally difficult by physicians and nurses who feel helpless in the absence of a curative project [28, 29]. As hospital mortality rates are high for ICU patients [30], these conversations are not uncommon. Moreover, as ICU resources are increasingly used in the sickest patients, including frail, elderly, and sometimes dying patients [31], it can be expected that ICU clinicians will progressively face more and more end-of-life situations. Finally, there is a continuum in communication needs, meaning that this list could also apply to other patients with longer term mortality.

Qualitative research with patients at high risk of dying in the ICU is scarce: first, because in this environment, many of these patients are sedated/unconscious and cannot participate in study protocols; and second, because these interviews can only be done by trained researchers, able to navigate these delicate discussions without adding burden to the patients themselves.

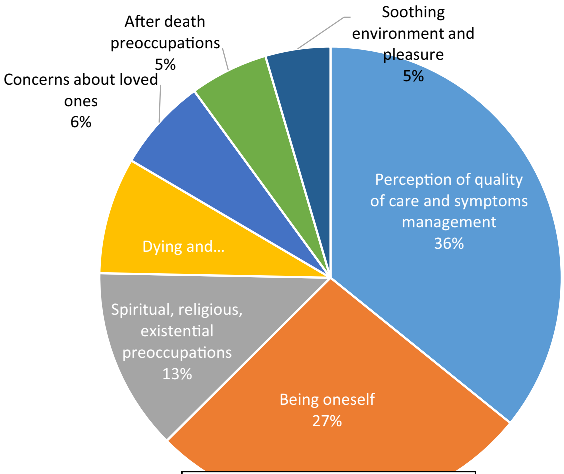
In end-of-life situations, *Being oneself* is a major domain that covers different concerns. Isolation, that refers to the factual state of being separated from others and away from home is a reality for many ICU patients and can also be accompanied by a feeling of loneliness, which can be mentally distressing. Loneliness [32] was a frequent emotion in our set of dying patients and included social, emotional, and existential loneliness [33]. It can be related to a lack of connectedness with loved-ones and/or clinicians and can be generated also by the inability to find meaning in their situation [33]. This concern “I'm afraid of feeling isolated, I need to feel connected to others” refers to patients' need to feel supported in their experience and to potentially openly discuss their situation and reinforce relationships [17, 34]. Related to this is the need, as for families [35], to express important things and pass on information to loved-ones before death, including the possibility of saying good-bye [17, 20, 36].

Patients also worry about their loved-ones and are concerned that their illness and ICU stay will generate burden [37]. Incurable illness changes the social status of patients who may feel that they can no longer fulfill their social and familial roles [38]. However, continuity is an important aspect of the patient's trajectory during end of life. Thus, the worry that loved-ones will suffer should be addressed early during the ICU stay, and all the more so, because self-perceived burden has been shown to be associated with increased motivation for death-hastening practices [39, 40]. In parallel, the feeling of abandonment is strong in dying patients and covers fear of abandonment from the ICU clinicians [11] and from relatives, and

Table 1 Initial domains and sub-domains

Domains	Subdomains
1. Concerns about loved-ones	
	1. Communicating about illness
	2. Intergenerational transmission
2. Perception of quality of care, including symptom management	
	3. Pain and symptom management
	4. Diagnosis and treatment (goals of care)
	5. Prognosis
	6. Leaving the ICU/hospital
3. Spiritual, religious, and existential preoccupations	
	7. Regret
	8. Despair
	9. Meaningless experience, injustice
	10. Unacceptance
	11. Hope
	12. Trust
	13. Meaningful experience
	14. Acceptance and completion
	15. Connectedness
4. Being oneself (physical and psychological integrity)	
	16. General anxiety
	17. Dependence
	18. Incompetence
	19. Feeling useless
	20. Being a burden
	21. Weariness
	22. Advanced directives
	23. Feeling isolated
	24. Dignity
	25. Independence
	26. Competence
	27. Feeling useful
	28. Social recognition
	29. Personhood
5. Soothing environment and pleasure	
	30. Soothing environment and pleasure
6. Dying and death	
	31. Feeling death coming
	32. Anxiety and Fear of death
	33. Death wish
	34. Fear of abandonment
	35. The dying process
	36. Place of death
7. After death preoccupations	
	37. Concerns about loved-ones after the death
	38. Concerns about pets
	39. Financial concerns
	40. Funeral arrangements
	41. Inheritance, estate

Seven domains



Concerns about loved ones **Domain represents**
1% of Literature review preoccupations
3% of Experts' preoccupations
6% of Panels' preoccupations
16% of Family interviews preoccupations
5% of Patient interviews preoccupations

Soothing environment and pleasure **Domain represents**
30% of Literature review preoccupations
1% of Experts' preoccupations
5% of Panels' preoccupations
4% of Family interviews preoccupations
5 % of Patient interviews preoccupations

Dying and death **Domain represents**
4% of Literature review preoccupations
14% of Experts' preoccupations
13% of Panels' preoccupations
4% of Family interviews preoccupations
4% of Patient interviews preoccupations

After death preoccupations **Domain represents**
2% of Literature review preoccupations
9% of Experts' preoccupations
7% of Panels' preoccupations
3% of Family interviews preoccupations
4 % of Patient interviews preoccupations

Spiritual, religious, ... **Domain represents**
10% of Literature review preoccupations
8% of Experts' preoccupations
7% of Panels' preoccupations
10% of Family interviews preoccupations
23% of Patient interviews preoccupations

Being oneself **Domain represents**
38% of Literature review preoccupations
23% of Experts' preoccupations
27% of Panels' preoccupations
21% of Family interviews preoccupations
24% of Patient interviews preoccupations

Perception quality care and ... **Domain represents**
15% of Literature review preoccupations
42% of Experts' preoccupations
35% Panels' preoccupations
42% of Family interviews preoccupations
35% of Patient interviews preoccupations

Fig. 2 The circle represents the distribution of the 7 domains across all sources. The tables show the distribution of domains by source

the fear that loved-ones will feel abandoned by the dying patient him–herself, specifically after their death -concerns that emerged in other domains.

These previous concerns are also connected to the patient's feeling of dignity and being respected as a person, thus creating a bridge between *Being oneself* and the importance of *quality of care and symptom management*, another major domain. Indeed, discussing goals of care with the team as well as management of physical and psychological symptoms, and having ones' choices taken into account are pillars of the patient's experience [17–19] as found in all sources of our project. Being free from pain is one of the most frequent preoccupations [41]. Improving communication in end of life (EOL) situations is crucial, using personalized strategies that empower the patients and give them space for expression of emotions and wishes as well as doubts and regrets [41].

Eliciting the patient's own "existential and spiritual perspectives" is a component of palliative care. Our results show that these perspectives can diametrically differ from one patient to the other (feeling of injustice vs. feeling death has meaning). It is thus the clinicians' responsibility to not have closed expectations and to leave space for conversations about what the patient at high risk of dying really needs from the team as well space to search for their own answers to their questions [42].

Finally, the *Dying and death* domain shows that some patients need to have reference points for the journey they are on ("How will I die?") to be able to anticipate the end-of-life process. Conversations addressing these concerns are needed to reassure the patients and give them opportunities to express their preferences, such as dying at home. The multidisciplinary team, as well as relatives, can play important roles in this respect. This is true also for *After death preoccupations* that can be addressed early during ICU stay. Interestingly, although it was the least strong domain, the need for *Comfort and pleasure* was present and needs addressing, especially in the highly technical ICU environment. A focus on both dying and living well [43] could help enhance patients' sense of security.

The qualitative approach of the study revealed that, for many participating patients, these interviews were experienced as a safe opportunity to express themselves and to share difficult emotions, as well as to not feel abandoned, confirming that the need for connectedness is strong. We, therefore, suggest that clinicians should not hesitate to initiate these discussions, starting with an open-ended question (such as "Are there any concerns you would like to express, any preoccupations you would like to share?") and then using the list of concerns to guide the conversation.

Table 2 **28 questions (before final merging and consolidation) and final 15 questions**

Domain	Initial 28 questions	Merged with other question(s) or stands alone	Final 15 question
Concerns about loved-ones $n=83$	1. How can I talk to my loved-ones about my illness without hurting them? $n=16$	Merged with question 2	1. I worry that my loved-ones will suffer because of my illness $n=83$
	2. I worry that my loved-ones will suffer because of my illness $n=67$	Merged with question 1	1. I worry that my loved-ones will suffer because of my illness $n=83$
Perception of quality of care and symptom management $n=457$	3. Can you explain the diagnosis? Are you certain? $n=44$	Merged with question 8	2. Can I trust this team and their competence? $n=55$
	4. What is my prognosis? Am I going to die? $n=90$	Merged with questions 5 and 9	3. What can I expect from my health care professionals: can we discuss my goals of care? $n=243$
	5. I'm concerned that I'm not getting adequate information about my illness and treatment: can we discuss my goals of care? $n=109$	Merged with questions 4 and 9	3. What can I expect from my health care professionals: can we discuss my goals of care? $n=243$
	6. I'm preoccupied by my pain/my symptoms, including during dying and death $n=95$	Merged with question 7	4. I'm preoccupied by my physical and psychological symptoms, including during dying and death $n=159$
	7. I feel so much anxiety/stress $n=64$	Merged with question 6	4. I'm preoccupied by my physical and psychological symptoms, including during dying and death $n=159$
	8. Is this team competent? $n=11$	Merged with question 3	2. Can I trust this team and their competence? $n=55$
	9. When/Can I leave the ICU/the hospital and/or go home? $n=44$	Merged with questions 4 and 5	3. What can I expect from my health care professionals: can we discuss my goals of care? $n=243$
Spiritual, religious and existential preoccupations $n=163$	10. When I think about my life, I have regrets $n=18$	Merged with question 11	5. When I think about my life, I have regrets and feel this is unfair $n=47$
	11. Why me? I feel this is unfair $n=29$	Merged with question 10	5. When I think about my life, I have regrets and feel this is unfair $n=47$
	12. I feel this has meaning, I have lived a good life $n=45$	Stands alone	6. I feel this has meaning, I have lived a good life $n=45$
	13. I need to have hope $n=40$	Merged with questions 14 and 15	7. I need to have spiritual/religious faith and/or support, as well as hope and trust $n=71$
	14. I need to have spiritual/religious faith and/or support $n=3$	Merged with questions 13 and 15	7. I need to have spiritual/religious faith and/or support, as well as hope and trust $n=71$
	15. I need to have trust $n=28$	Merged with questions 13 and 14	7. I need to have spiritual/religious faith and/or support, as well as hope and trust $n=71$
Being oneself $n=341$	16. I have things to tell my loved-ones before I die $n=40$	Merged with question 17	8. I'm afraid of feeling isolated, I need to feel connected to others $n=104$
	17. I'm afraid of feeling isolated, I need to feel connected to others $n=64$	Merged with question 16	8. I'm afraid of feeling isolated, I need to feel connected to others $n=104$
	18. I do not want to become incompetent, dependent on others and feel a burden $n=72$	Stands alone	9. I do not want to become incompetent, dependent on others and feel a burden $n=72$

Table 2 (continued)

Domain	Initial 28 questions	Merged with other question(s) or stands alone	Final 15 question
	19. I'm tired of all this, I have no hope, leave me alone $n = 85$	Stands alone	10. I'm tired of all this, I have no hope, leave me alone $n = 85$
	20. I am a person, I care about my dignity, I want to remain competent and for my choices to be respected $n = 80$	Stands alone	11. I am a person, I care about my dignity, I want to remain competent and for my choices to be respected $n = 80$
Soothing environment and pleasure $n = 58$	21. I need to be in a soothing environment and experience pleasure $n = 58$	Stands alone	12. I need to be in a soothing environment and experience pleasure $n = 58$
Dying and death $n = 104$	22. I can feel death coming $n = 28$	Merged with questions 23 and 24	13. I'm preoccupied about death coming and related emotions $n = 79$
	23. I'm afraid of dying $n = 31$	Merged with questions 22 and 24	13. I'm preoccupied about death coming and related emotions $n = 79$
	24. I want to die $n = 20$	Merged with questions 22 and 23	13. I'm preoccupied about death coming and related emotions $n = 79$
	25. How will I die? What will happen? Where will I die? $n = 25$	Stands alone	14. How will I die? What will happen? Where will I die? $n = 25$
After death preoccupations $n = 70$	26. I'm worried about my loved-ones/What will happen to my loved-ones? $n = 37$	Merged with questions 27 and 28	15. I'm preoccupied about my loved-ones after I die $n = 70$
	27. Who will look after my pet? $n = 10$	Merged with questions 26 and 28	15. I'm preoccupied about my loved-ones after I die $n = 70$
	28. I need to get things sorted out before I die $n = 23$	Merged with questions 26 and 27	15. I'm preoccupied about my loved-ones after I die $n = 70$

Table 3 List of 15 final questions and preoccupations

1. I worry that my loved-ones will suffer because of my illness
2. Can I trust this team and their competence?
3. What can I expect from my health care professionals: can we discuss my goals of care?
4. I'm preoccupied by my physical and psychological symptoms, including during dying and death
5. When I think about my life, I have regrets and feel this is unfair
6. I feel this has meaning, I have lived a good life
7. I need to have spiritual/religious faith and/or support, as well as hope and trust
8. I'm afraid of feeling isolated, I need to feel connected to others
9. I do not want to become incompetent, dependent on others and feel a burden
10. I'm tired of all this, I have no hope, leave me alone
11. I am a person, I care about my dignity, I want to remain competent and for my choices to be respected
12. I need to be in a soothing environment and experience pleasure
13. I'm preoccupied about death coming and related emotions
14. How will I die? What will happen? Where will I die?
15. I'm preoccupied about my loved-ones after I die

This study has several limitations. First, the number of qualitative interviews could imply that some questions were missed. However, recruitment of new participants was interrupted when data saturation was reached, i.e., when no new themes emerged from the interviews. Moreover, the final list was generated using multiple sources of concerns processed through qualitative analysis. Of note, qualitative interviews were done both pre- and post-epidemic peaks, but no differences were found between the two time periods. Second, the study was performed in France and concerns may arise about the generalizability of the list. However, the study was performed in 11 ICUs and involved all clinicians, in addition to relatives and patients, as well as international literature related to the subject. Third, this study might be exposed to cognitive bias as our data do confirm the existing domains of concern identified in clinical practice. However, the two main investigators (NKB and ALP) are humanities and social science researchers, and all findings were crosschecked to limit subjectivity. Fourth, we did not conduct formal member checking as this would have been challenging in the context. However, at the end of each interview (with patients and families), the researcher summarized the main concerns expressed by the participants to check for accuracy and resonance. Finally, a dedicated trial using a communication strategy based on this list of concerns is needed to confirm that it improves quality of dying and death.

Conclusion

Conversations with patients about end of life, dying and death may be the most challenging of all communication scenarios. Communication strategies that target patients' preoccupations and questions should be seen as a priority. In clinical practice, this list of 15 concerns could provide guidance for clinicians in their communication with patients at high risk of dying. It could also be used in research projects aiming to improve the quality of life at the end of life, as well as the quality of dying and death.

Supplementary Information

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Author contributions

NKB, ALP, and EA wrote the study protocol. NKB and ALP did the qualitative analysis. All co-authors approved the study protocol. NKB and ALP wrote the first draft of the report with input from EA and FP. EB, VD, CG, CG, AR, VS, AR, AC, DF, LCL, OG, SM, AM, and OL provided substantial contribution to the acquisition of data. All authors had full access to all the data in the study and had final responsibility for the decision to submit for publication.

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Data availability
Data will be made available on request to the principal investigator, based on a legitimate request (research).

Declarations

Conflicts of interest
NKB reports having received a fee for a lecture from GE Healthcare. EA reports receiving fees for lectures from Gilead, Pfizer, Baxter, GE Healthcare, and Alexion. His research group has been supported by Ablynx, Fisher & Payckle, Jazz Pharma, and MSD, outside the submitted work. AC reports receiving fees for lectures from Bard, outside the submitted work. DF reports receiving fees for lectures from Alexion, outside the submitted work. ALP, EB, VD, CG, CG, AR, VS, AR, LCL, OG, SM, AM, OL, and FP have no conflicts of interest to declare.

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