Giving a Voice to Patients at High Risk of Dying in the Intensive Care Unit – a multiple source approach

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Abstract (278)

Background: Data is scarce regarding the experience of critically ill patients' at high risk of death. Identifying their concerns, could not only allow clinicians to better meet dying patients' needs, but could also help align the patients' 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 at high risk of dying were collected from five different sources (literature review, panel of 50 ICU expert nurses and physicians, prospective study in 11 ICUs, and in-depth interviews with 17 families and 15 patients). All qualitative data collected was analysed using thematic content analysis.

Findings: The five sources produced 1307 concerns that were then divided into 7 domains, and 41 sub-domains. After removing redundant items and duplicates, and then combining and reformulating similar items, 28 concerns were extracted from the analysis of the data. To increase accuracy, they were then merged and consolidated, and resulted in a final list of 15 concerns pertaining to the following 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.

Interpretation: 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

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BACKGROUND (390)

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 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): 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 palliative 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 which is important 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 and sense of peace, 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 in order 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 ventilate their emotions and to express their 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, patients at high risk of dying tend to prefer receiving less mechanical ventilation and sedation. 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 (1065)

This study was approved by the Comité de Protection des Personnes Ile de France III, in January 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, of which 11 participated in step 3 of the study (source 3), and 2 participated in source 4 and 5 participated in source 5 of the study (qualitative interviews).

Study population

In this study, patients were considered to be at "high risk of death" when their ICU physician estimated at 80% and over their risk of dying within 3 months. Patients were considered "conscious" if they were capable of expressing themselves and able to actively interact with clinicians and/or with researchers.

Sources of data

We used a multiple source approach(21) 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 11 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 a specific legal framework as well as articles dealing with end of life in traditional cultures 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 physicians and nurses experts (i.e. who published at least one article focused on end of life care in the ICU) were invited to list individually 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. The study took place in 11 ICUs (ICU characteristics are reported in Supplemental table 1). In each ICU, a blank blue panel (for physicians) and a blank white panel (for nurses and other allied professionals) were displayed to record in a real-time manner any questions/preoccupations expressed by patients at high risk of death. 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 (study was temporarily interrupted due to COVID-19 pandemic), in 2 ICUs, in-depth interviews with family members of patients at high risk of dying were performed and audiotaped by three researchers (VD, ALP, et EB). During interviews, families were asked to report what they believed to be their loved-one's concerns. 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), in 5 ICUs, in-depth interviews with conscious patients at high risk of

dying were performed and audiotaped by four researchers (ALP, CG, CG, AR). The interviews focused on the patient's concerns. Questions were phrased sensitively and respected recommendations for interviews with people in palliative care settings (18, 19). Interviews were audiotaped, transcribed and anonymized, and the concerns were extracted.

Selection of concerns

All concerns were recorded exhaustively and data was 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(22). 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(23). Data from source 2 was 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 was 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 then 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 (518)

Data collection

We collected 1307 concerns as shown in Figure 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.

Literature review included 45 relevant articles (out of 3037) and permitted 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 reported 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 Supplemental Tables 2-3. Interviews lasted between 9 and 53 minutes (median 38 minutes) for family members and between 2 and 46 minutes for patients (median 29 minutes). 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 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%) (Figure 2). According to the sources, some domains were more prevalent than others: *Being oneself* was more prevalent in source 1 (literature review); *Perception 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, 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 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, in order 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 reduce to one question. *Perception 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 (931)

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 multicenter design as well as the involvement of nurses, physicians, and family members in addition to patient interviews helped us to identify a large number of 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(24,25).

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, is a reality for many ICU patients and can also be accompanied by a feeling of loneliness which can be mentally distressing. Loneliness(26) was a frequent emotion in our set of dying patients and included social, emotional and existential loneliness(27). 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(27). 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(17,28). Related to this is the need, as for families(29), to express important things and pass on information to loved ones before death, including the possibility of saying good-bye(17,20,30).

Patients also worry about their loved ones and are concerned that their illness and ICU stay

will generate burden(31). Incurable illness changes the social status of patients who may feel they can no longer fulfil their social and familial roles(32). 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(33,34). 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 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 "Care and symptom management", other 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(35). Improving communication in EOL situations is crucial, using personalised strategies that empower the patients and give them space for expression of emotions and wishes as well as doubts and regrets(35).

Last, the "Dying and death domain" shows that some patients need to have reference points for the journey they are on ("How will I die?") in order 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. The multidisciplinary team, as well as relatives, can play important roles in this respect. 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(36)

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 a means to not feel abandoned, confirming that the need for connectedness is strong.

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. 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 does confirm 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. Last, 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. This list of 15 concerns could be used both in clinical practice and research projects aiming to improve the quality of dying and death.

Contributors

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, C Goulenok, C Garret, A Renault, VS, A Renet, AC, DF, LCL, OG, SM, AM, 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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Declaration of interests

Nancy Kentish-Barnes reports having received a fee for a lecture from GE Healthcare. Elie Azoulay reports receiving fees for lectures from Gilead, Pfizer, Baxter, and Alexion. His research group has been supported by Ablynx, Fisher & Payckle, Jazz Pharma, and MSD, outside the submitted work. Alain Cariou reports receiving fees for lectures from Bard, outside the submitted work. Anne-Laure Poujol, Emilie Banse, Victoire Deltour, Cyril Goulenok, Charlotte Garret, Anne Renault, Virginie Souppart, Anne Renet, Diane Friedman, Ludivine Chalumeau-Lemoine, Olivier Guisset, Sybille Merceron, Antoine Monsel, Olivier Lesieur and Frédéric Pochard have no conflicts of interest to declare.

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