Journal of Critical Care 49 (2019) 33–37

Contents lists available at ScienceDirect

Journal of Critical Care

journal homepage: www.journals.elsevier.com/journal-of-critical-care

Patient Centered Care

Identifying improvement opportunities for patient- and family-centered care in the ICU: Using qualitative methods to understand family perspectives

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ARTICLE INFO

Keywords:
Content analysis
euroFS-ICU
euroQ2
euroQODD
Family-centred care
Family satisfaction
ICU
Quality of care

ABSTRACT

Purpose: The purposes of the study were to provide richer context for families' quantitative assessments of the quality of ICU care, and to describe further quality areas of importance for family members.

Materials and methods: Free-text comments from 1077 family members of 920 patients focusing on family evaluation of ICU quality of care were analyzed using content analysis. Twenty-one Danish and Dutch ICUs participated from October 2014 to June 2015.

Results: Four themes emerged as important to families: information, clinician skills, ICU environment, and discharge from the ICU. Families highlighted the importance of receiving information that was accessible, understandable and honest. They indicated that quality care was ensured by having clinicians who were both technically and interpersonally competent. The ICU environment and the circumstances of the transfer out of the ICU were described as contributing to quality of care. The comments identified room for improvement within all themes.

Conclusions: The study highlights the importance of including both technical and emotional care for patients and families and the consequent need to focus on clinicians' mastery of interpersonal skills.

1. Introduction

When a critically ill patient is admitted to an Intensive care Unit (ICU), the entire family is affected. [1]. Being a family member of a critically ill patient often means being in a world of uncertainty with the risk of losing a loved one [2]. This can have both a physical and a mental impact on the family members during the ICU stay [3,4] and after ICU discharge [5]. The illness and recovery of ICU survivors or the loss of a loved one may impact fundamental aspects of everyday family life causing increased risks of anxiety, posttraumatic stress and depression for the family members [6-10]. Therefore, high quality ICU care must also include the needs of family members [11].

To assess family members' needs in the ICU, quantitative questionnaires have been used for decades to evaluate family satisfaction with issues identified as important by ICU professionals [12-14]. However, for the individual family member, there may be important issues that are not addressed by these questionnaires, suggesting that qualitative methods may be an important complementary research approach towards developing new knowledge on family satisfaction in the ICU [15].

Acknowledging differences in critical care across countries, in 2015, a Danish-Dutch research team developed the euroQ2 questionnaire [16], based on the North American "Family Satisfaction in the ICU" (FS-ICU) questionnaire looking at general family satisfaction [17] and the "Quality of Dying and Death" (QODD) questionnaire looking at quality of care in the ICU at the end-of-life [18].

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https://doi.org/10.1016/j.jcrc.2018.10.008
0883-9441/

In this paper, we present findings from the analysis of free-text comments from a euroQ2 questionnaire survey [19,20]. The purposes of the study were firstly to provide richer context for the quantitative assessments of care, and secondly to describe further areas of importance for families in regard to ICU quality of care.

2. Materials and methods

2.1. Settings

Participants were from 21 different ICUs (11 from Denmark and 10 from The Netherlands). The ICUs were identified through research and clinical network contacts and were selected to represent different parts of both countries, with diversity in characteristics including university and regional ICUs and ranging from level 1 to level 3 in critical care. The ICUs also represented different specialties (medical, surgical, mixed, and neurological). Depending on the critical care therapy level, the general nurse-patient ratio in the Danish ICUs is 1:1 to 1:1.4 and in The Netherlands 1:1 to 1:2.5. The ICUs in both countries are primarily arranged with one or two beds per room. In both countries, care is provided by physicians and nurses with specialised training in intensive care in an intensivist driven ICU. In Denmark, all ICUs have a flexible visitation policy allowing family to visit any time as long as visits do not interfere with patient care or patient integrity [21]. In the project period, ICU visitation in The Netherlands was typically fixed in three 60-min blocks between 10:30 AM and 7:30 PM.

2.2. Participants

2.2.1. Inclusion criteria

Family members of patients with ICU stays of 48 h or more that occurred between October 2014 to September 2015 were included in the study. Up to three family members per patient could participate. Family members were defined as the persons closest to the patient (as identified by the patient), including partners, siblings, children, parents and friends.

2.2.2. Exclusion criteria

Family members were excluded if they were under the age of 18, had cognitive impairment, or were not able to read or write Danish or Dutch, based on the country of the ICU.

2.2.3. Data collection

Family members who met the inclusion criteria were approached during the ICU stay and received information about the study. If they agreed to participate, they provided their name and home address and, three weeks after patient discharge from the ICU, received the questionnaire by mail [19].

2.2.4. Questionnaire

The euroQ2 consists of two sections. The first section is named the euroFS-ICU and includes questions about satisfaction with patient care, information and decision-making processes, and all participating family members complete this section. The second section is named the euroQODD and includes questions about quality of dying and quality of care in the last days of the patient's life [16]. Only family members of patients who die in the ICU complete this section. To allow participants to elaborate on their quantitative evaluations, participants are offered opportunities to write free-text comments providing context or additional details for their evaluations.

2.3. Data analyses

Data evaluated in this study were the verbatim transcripts of respondents' hand-written free-text comments in the sections of the euroQ2 questionnaire where comments could be added [16]. Analysis of the comments was managed using Microsoft Word allowing the researchers to code, sort and categorize the data. During analyses, the comments were retained in their original languages.

The anonymized comments from the questionnaires were analyzed inductively with qualitative content analysis methods [22] by Danish (ASÅ, HIJ) and Dutch (JH, MK) researchers. Content analysis is iterative, beginning with basic descriptive coding that labels the manifest content of each comment and moves to interpretive analysis and categorization of the latent content, i.e. identifying the underlying and intended meaning of the text. In order to achieve consensus on the coding, researchers in each country read their respective set of comments 2–3 times, coded for manifest content and, through discussions and repeated readings of the data, achieved consensus on the descriptive coding. This analytic process involving several rounds of discussions within and among the Danish and Dutch research groups allowed for a high level of researcher reflexivity. Later, and with the goal of categorizing the content, the two national teams presented an outline of their preliminary findings to each other. After several rounds of discussions within and between the two national teams, consensus on an overall structure of the findings encompassing the central elements of both the Danish and the Dutch findings was reached. During the early stages of the analysis process, quotes to illustrate the findings were selected by individual members of the research team. Later, the relevance of each quote was discussed within and between the national teams until consensus was reached. The findings from these analyses are presented below with illustrative quotes from both nationalities. In order to examine whether free-text comments mirrored the quantitative assessments provided in the participants' scores in the euroQ2, strictly negative comments were compared with the quantitative overall quality of care scores provided by the family members [19,20].

2.4. Ethical approval

In accordance with Danish law, the study did not need approval from the Regional Ethics Committees. The study was registered with The Danish Data Protection Agency (2008-58-0035). In The Netherlands, the Leeuwarden IRB (R-TPO) nr. nWMO 21a approved the study on behalf of all ICUs. All family members received oral and written information about the study and provided written consent.

3. Results

A total of 1077 family members participated, 573 from Denmark and 504 from The Netherlands. The family members represented 920 ICU patients [19]. The overall response rate of approached families was 72%, 75% in Denmark and 68% in The Netherlands. All participants had filled in the first section of the euroQ2, consisting of the euroFS-ICU, and 217 had additionally filled in the euroQODD section. The participants were primarily the ICU patients' partners (47%) or children (35%).

A total of 52% (n = 560) of the participants provided free-text comments in the euroFS-ICU section (61% in Denmark and 43% in The Netherlands). In the euroQODD section, 41% (n = 89) provided comments (38% in Denmark and 44% in The Netherlands). The comments described a wide range of patient- or relative-related issues and provided a rich description of experiences in the ICU.

3.1. Themes

Four themes emerged from the content analysis across both countries: information, clinician skills, ICU environment, and discharge from the ICU. Furthermore, four subthemes were identified (Table 1). The most frequent comments addressed information or clinical skills; comments that described the ICU environment or ICU discharge were less frequent.

Table 1
Themes and subthemes.

Theme	Subthemes
Information	Receiving and providing information Content and form of information
Clinician skills	Professional skills Interpersonal skills
ICU environment	
Discharge from the ICU	

3.1.1. Information

The role of information in families' experience with care was a critical theme in the comments, and was characterized by two aspects: 1) *receiving and providing information*, and 2) *content and form of information.*

Families noted the importance of *receiving information* at the right time while also having the opportunity to *provide information* to health care professionals about the patient's everyday life and preferences prior to hospital admission or about the family situation. Family members were grateful when staff foresaw and met the families' informational needs:

> "They took time for you despite the pressure of activities on the ICU. Physicians gave clear and complete information and the nurses were really interested in the patient and family. We felt well cared for." (Dutch respondent)

When doctors or nurses were not available or did not provide timely information, families felt they had to inquire themselves and reported this to be burdensome and difficult.

> "During visiting hours we mostly had to ask for information, this was a disagreeable situation. We only got information regarding our questions and nothing more. This was a burden to us." (Dutch respondent)

Some respondents noted they were not given opportunities to share their perceptions of care and therefore did not receive necessary information:

> "….different physicians provided information, but they did not know or did not ask what we knew."(Danish respondent)

The content and form of information was also described as important to families. High quality information was described by terms such as "honest", "clear", "understandable", "provided with empathy" and "not too little, not too much". In contrast, low quality information was characterized as "rushed", "sketchy", "unfeeling", "interrupted by phone calls" and "incomplete".

Finding the right balance between realism and optimism was a highly valued characteristic of high quality information. A few family members described how, at crucial moments during the ICU stay, they had not felt fully informed of the gravity of the situation. The daughter of a patient who died in the ICU said:

> "All through the ICU stay I asked whether my mother was going to die, because that was what she believed herself. I never got a direct response saying that it could happen. Again and again I was reassured that the tests showed the same or small improvements. Every time I asked, I got a hope that my mother would pull through. I kept telling my mother about this hope. Every time she cried and said it was over, I kept repeating that everything would be okay. I did not listen to her, I did not meet her in her fear. I so wish that I had known how serious it was, so I could have let her cry and be there for her. I was there, but I said all the wrong things". (Danish respondent)

Several family members commented that families should not receive information about the patient's situation in the patient's room and never across the bed. Also, if doctors or nurses were breaking bad news, the families would prefer to have other family members with them to receive this difficult news.

Lastly, continuity of care, and its impact on getting correct and timely information, was commented upon by a number of families. Although many families reported a high level of care continuity and made positive comments about its impact on care and information sharing others observed lower quality care and information associated with fragmented or uncoordinated care.

3.1.2. Clinician skills

Family members commented about clinician skills in two related, but distinct, sets of behaviours: a) *professional skills* and b) *interpersonal skills.*

Professional skills referred to the way in which clinicians provided care and treatment to the patient. Often, staff was described using words such as "competent", "well-educated", "in control", "high level of technical skills", "consistency of care", "capable" and "professionalism". To families, this provided feelings of security, safety and peace of mind. The families could relax a little, trust their loved ones in the hands of ICU staff and perhaps leave the hospital for a little while.

> "It was my impression that the treatment was excellent. Therefore, I was completely calm in regard to that and concentrated on caring for my mother-in-law". (Danish respondent)

In addition to professional skills, numerous comments described *interpersonal skills* making a huge difference for both patients and families during the ICU-stay.

> "When I have ticked "Excellent" it is because both my family and I felt that the staff not only took care of my wife. They also engaged themselves personally to a very high degree. For a family member it means a lot to experience this". (Danish respondent)

Interpersonal skills were further described by terms like "compassion", "respect", "emotional support", "empathy", "personalised care", "commitment", "interest", "patient and family receiving much attention", "taken seriously", "support", "dignified and respectful patient care", "caring", "trustworthy" and "dedicated".

> "We felt mother was treated with respect. As a family, we also received much attention and time. We felt welcome and this helped us a lot to cope with the situation". (Dutch respondent)

3.1.3. ICU environment

This theme included comments that addressed aspects of the physical environment of the ICU: noise and hygiene; possibilities for the families to be present at the bedside; waiting room facilities; facilities for clinician-family conferences; and access to food and drink.

Many family members commented on the level of noise, especially for patients sharing a room with other patients. Noises included those from treatments and alarms, but also from staff talking loudly to each other:

> "It was very hectic and busy in the ICU with much noise. Because of this, my friend had a headache many times, was restless and irritated. There was much noise due to people talking, alarms going, technical repairs. I thought that this was very strange because there are very sick people there, so rest would be preferable. This ICU reminds me of the ER department in American television programs". (Dutch respondent)

By contrast, others experienced the ICU as a quiet place, especially when the patient was in a single room, suggesting a quiet ICU environment was possible.

Being present at the bedside was another important issue for the families. Some families were spending their last days with their loved one and were regretful that a considerable amount of that time was spent waiting outside the patient's room:

> "We spent an incredible amount of time waiting outside, time we would have liked to have with dad. Just to be allowed to sit quietly at the bedside meant a lot for us, so more time with dad would have been better". (Danish respondent)

Other family members felt their presence at the bedside was not appreciated by staff.

Some families found the waiting rooms too small and uninviting, especially when the patient's condition was serious. Sharing the waiting room with worried or mourning families was difficult. Others were concerned that the waiting room was used for clinician-family conferences with other unrelated people present, or that clinician-family conferences took place in staff rooms that were unsuited for a conference.

Many families spent a lot of time in the ICU and especially for those, access to food and drink was important. At some ICUs, the families had been offered a variety of options and were very grateful for this whereas for others this had not been the case.

3.1.4. Discharge from the ICU

Several comments described challenges that occurred when the patient was discharged from the ICU to a ward. Even though most families realized that patients were transferred because their condition had improved, many family members felt it was too early and the altered levels of monitoring from the ICU to the parent ward frightened them:

> "Quite unexpectedly, our father was discharged to the ward. We found that very difficult after his long stay in the ICU. On the ward, there was no support for the family and less support for our father. The transition was immense". (Dutch respondent)

Another challenge in regard to discharge from the ICU was the information loss, which had a high impact on patient care in the ward.

3.2. Comparison with quantitative scores of quality of care

To explore whether family members' negative experiences with the quality of ICU care that they reported in their free-text comments were also captured in their quantitative assessments of care in the euroQ2, we examined the subset of surveys with strongly negative comments to describe these family members' quantitative assessment of overall quality of care (on a scale from 0 to 10) (16). Of a total of 7% of family members ($n = 77$) providing strongly negative comments, 87% ($n = 67$) scored 7–10.

4. Discussion

In our study of free-text comments from a large questionnaire study about family satisfaction with ICU care, we found four overall themes particularly important to families in the ICU: information, clinician skills, ICU environment, and discharge from the ICU. An earlier study from the United States using a similar study design found similar issues important to families in the ICU [23]. The fact that our findings from Denmark and The Netherlands are in line with this American study implies some universal family needs and experiences in the ICU. Other studies from Europe also suggest that areas with room for improvement in ICU care include emotional support for families, consistency of information, and coordination of care [24,25]. Additional needs identified include dealing with the uncertainty of the situation [2,3,26], support for efforts to be with the patient [27], a need for honest and consistent information [11,26,28], and a need for emotional support [25,26,29,30].

Questionnaires assessing family members' experience with ICU care allow evaluation of family members' assessments of issues that have been previously identified as important [12]. However, for the individual family member, other issues not addressed by the questionnaire may also be important, and the family member may want to elaborate on their quantitative assessment of the quality of ICU care. Therefore, free-text comments provided by respondents in a questionnaire can be valuable additions to the quantitative survey data, firstly as elaborations on assessments of the quality of care and secondly to guide the identification of further areas of importance for family members [31].

In our report of the quantitative questionnaire results from this study, the overall rating of quality of care was high [19,20]. While many of the qualitative comments from both countries were complimentary, many also identified aspects of care that needed improvement. Interestingly, we found that even among family members who provided high ratings of quality of care from the quantitative questionnaire data, some had very critical comments, suggesting the important role for incorporating both qualitative and quantitative sources of data to enable a more complete picture of patient and family experiences in the ICU [24,31]. Additionally, these findings stress the need to work continuously to secure high quality ICU care including both technical and emotional care for all patients and their families instead of viewing high survey-based ratings as sufficient "proof" of high quality care [31].

Danish and Dutch comments were generally quite similar. The shared themes that we identified may be those aspects of care in the ICU for seriously ill patients that are salient for families' experiences of care, influential in their perception of the delivery of quality care, and identified as critical to quality care regardless of country-specific practices, organizations and resources. Similar findings from an American study [23] support this view.

The findings show that although quantitative research and measurement is important (e.g. for bench marking), qualitative research can offer a novel and unique perspective that doesn't constrain family members to the issues in which the researcher is most interested [31]. The issues identified by family members in Denmark and The Netherlands might differ compared to other parts of the world, but the method for collecting qualitative information can be used everywhere. Furthermore, our findings demonstrate that even when family members provide scores of seven to ten out of ten on satisfaction questions, they may provide critical and actionable feedback to open-ended questions.

Many of the comments were related to information and showed the substantial impact that content and accessibility of information had on families. Our findings suggest that, to accommodate family informational needs, frequent family conferences may be important. Families express the need to have questions answered honestly and given information which is understandable and on time [1,32]. Using a structured approach in family-clinician communication (e.g., "VALUE" mnemonic) [1,33] could support high quality communication by facilitating true dialogue instead of just one-way passing of information from staff to families.

Our findings also demonstrate that clinicians' mastery of effective interpersonal skills was very important for both patients and families during the ICU-stay. This is in line with the suggestions by Ääri and colleagues who stress that clinician competence in critical care includes not only knowledge and technical skills but also attitudes and values that prioritize patient- and family-centred care [34]. The field of critical care has been described as a wide range of intertwining technical and humane skills [35], supporting our finding that families' acknowledge both professional and interpersonal clinician skills. Others have argued that distinguishing between technological and humane aspects of care is an invented difference, and that technology is also "an agent and object of touch" [36]. In our study from ICU practice, family members distinguished between professional skills and interpersonal skills as two related, but distinct, sets of behaviours. To further develop high quality care for families in the ICU our findings suggest that both aspects of critical care should be included as important professional issues in the ICU staff educational curriculum.

Most of the comments about discharge out of the ICU were critical of this experience. When conducting family conferences, ICU discharge plans could be discussed at an early stage allowing the family to address possible worries and providing time to adapt. Also, a user-centred discharge information brochure might be helpful [37].

Strengths of the study include the substantial number of participants from two countries and from different ICUs and regions within the countries providing a diverse participant population. Two independent analysts in each country used the same systematic analytical approach and found recurring patterns in the material from Denmark and The Netherlands adding to the credibility and transferability of our findings. Limitations include that the study was conducted on the basis of free-text comments and not by personal interviews and therefore with no opportunity to verify the meaning of the comments. Frequencies of comments were not presented as it may induce potential selection bias among family members who provided free text responses as well as the fact that other family members who did not provide comments in a specific domain may also agree (or disagree) with this domain.

Although the findings were similar to findings from a US study, the generalizability of the findings may be limited due to Denmark and The Netherlands, both being North European countries. Lastly, we didn't translate the comments into a shared third language (English) although that would have allowed a joint analysis. We made this decision because of our concerns that, by translating to a common language, we would lose linguistic details that were essential to a rich and nuanced understanding of the qualitative data.

5. Conclusion

The study highlights the importance of including both technical and emotional care for patients and families and the consequent need to focus on clinicians' mastery of interpersonal skills. Furthermore, the study suggests the important role for incorporating both qualitative and quantitative sources of data to enable a more complete picture of patient and family experiences in the ICU.

Acknowledgements

The authors thank all participating families and ICUs.

Funding source

The study was supported by The Region of Southern Denmark, The Novo Nordic Foundation, Denmark (11415), The Augustinus Foundation, Denmark (14-2421), and The Frisian ICU Research Fund, The Netherlands. The funding bodies had no influence on the study or the paper.

Conflict of interest

The authors declare that they have no competing interests.

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