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Published in:
Intensive and Critical Care Nursing

DOI:
10.1016/j.iccn.2022.103346

Publication date:
2023

Document version
Publisher's PDF, also known as Version of record

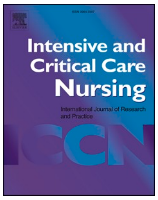
Citation for published version (APA):
Bohart, S., Lamprecht, C., Andreasen, A. S., Waldau, T., Møller, A. M., & Thomsen, T. (2023). Perspectives and wishes for patient and family centred care as expressed by adult intensive care survivors and family-members: A qualitative interview study. *Intensive and Critical Care Nursing*, *75*, [103346]. https://doi.org/10.1016/j.iccn.2022.103346

INTENS CRIT CARE NUR 75 (2023) 103346

Contents lists available at ScienceDirect

Intensive & Critical Care Nursing

journal homepage: www.sciencedirect.com/journal/intensive-and-critical-care-nursing



Research Article

Perspectives and wishes for patient and family centred care as expressed by adult intensive care survivors and family-members: A qualitative interview study

Søs Bohart [*], Cornelia Lamprecht, Anne Sofie Andreasen, Tina Waldau, Ann Merete Møller, Thordis Thomsen

Dep. of Anesthesiology and Herlev ACES, Herlev Anasthesia Critical and Emergency Care Science Unit, Copenhagen University Hospital, Herlev-Gentofte, Copenhagen, Denmark

ARTICLE INFO

Keywords:
Adult
Intensive Care Units
Family Nursing
Patient-Centered Care
Qualitative research

ABSTRACT

Objectives: To explore perspectives and wishes for patient and family centred care among adult patients and family-members with recent experience of admission to an adult intensive care unit.
Research design: An explorative descriptive study using an inductive thematic analysis. Semi-structured interviews with adults (≥18 years) who had experienced admission ≥48 hours to an adult intensive care unit as a patient or family-member within the previous three months. Interview data were analysed used the six phases of thematic analysis, described by Braun and Clarke. Semi-structured interviews with adults (≥18 years) who had experienced admission ≥48 hours to an adult intensive care unit as a patient or family-member within the previous three months. Interview data were analysed used the six phases of thematic analysis, described by Braun and Clarke.
Setting: Participants were recruited from six general (mixed surgical and medical) units in the Capital Region of Denmark.
Findings: From fifteen interviews a total of 23 participants (8 patients and 15 family-members) described their perspectives and wishes for patient- and family-centred care. Three main themes were identified: 1) Ongoing dialogue is fundamental. Both scheduled and spontaneous information-sharing is important. 2) Humanizing. High-quality treatment was especially evident for participants when staff maintain a humanized attitude. 3) Equipping family to navigate. We found a range of specific suggestions of attention that may help patients and family-members to navigate during admission.
Conclusions: We found that patients' and family-members' perspectives and wishes for PFCC centred around ongoing dialogue with staff and the importance of humanizing the ICU environment. Patients and family members needed to share and have their knowledge, concerns and perspectives brought forth and acknowledged by staff. Participants emphasized the pivotal role staff have in equipping patients and family-members to cope in the unit and supporting specifically family-members in fulfilling their role as advocates and supporters of the patient.

Implication for clinical practice

- Ongoing information-sharing between intensive care staff and family-members is fundamental, both spontaneous and scheduled, for bestowing patients and especially family members with a sense of overview and control.
- Showing interest in the everyday life and values of patients and family members in addition to the critical illness translates into high-quality care from the perspective of participants.
- Staff need to equip patients and family members to navigate and fulfill their individual roles during an admission.

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* Corresponding author at: Herlev and Gentofte Hospital, Borgmester Ib Juuls Vej 1, 2730 Herlev, Denmark.
E-mail address: soes.bohart@regionh.dk (S. Bohart).

https://doi.org/10.1016/j.iccn.2022.103346
Received 20 April 2022; Received in revised form 7 September 2022; Accepted 31 October 2022

Background

Patient and Family Centred Care (PFCC) is grounded in a mutually beneficial partnership between health care providers, patients, and families (IPFCC 2019). PFCC aims to include patients as respected partners in their own care (IPFCC 2019; Davidson et al. 2017). Importantly, PFCC emphasizes that families play a vital role in ensuring the health and wellbeing of the patient (IPFCC 2019). For critically ill patients requiring admission to an intensive care unit (ICU), PFCC seems hugely relevant. While in the ICU, many patients are periodically unable to actively engage in conversation and partake in treatment decisions due to delirium, the critical illness or sedation. Therefore, family often act as patient advocates. ICU admission furthermore implies a range of environmental and treatment related stressors for both patients and family and, not surprisingly, anxiety, depression, and posttraumatic stress disorder (PTSD) are prevalent in the aftermath of ICU admission in both patients and family-members (Held and Moss 2019; van Beusekom et al. 2016).

The Institute for Patient- and Family-Centered Care (IPFCC) describes four interrelated core concepts that are essential for PFCC; dignity and respect, information sharing, participation of patients and family in care, and collaboration (IPFCC 2019). IPFCC and other international organisations commend PFCC as crucial for enhancing the quality of care and, moreover, hypothesise that both patients and family-members in adult ICUs may profit psychologically from systematic PFCC (IPFCC 2019; Mitchell et al. 2016). At this point, studies have mainly investigated the general experience of ICU admission from either the patient or family perspective, including experienced needs, and wishes for participating in care (Imanipour et al. 2019; Danielis et al. 2020; Kynoch, Cabilan, and McArdle 2016; Wong et al. 2019). Reviews and qualitative studies of family members' experiences indicate that a high level of information and interpersonal communication are universal needs (Ågård et al. 2019; Imanipour et al. 2019; Wong et al. 2019; Verhaeghe et al. 2005). Furthermore, that healthcare professionals need to systematically support and consider the patients' family as a central collaborating partner so both patient and family expectations are addressed (Imanipour et al. 2019; Wong et al. 2019). However, how this should optimally be done remains uncertain. Similarly, a recent qualitative analysis of free-text comments from 1077 family members' evaluation of ICU care identified information, clinical skills, the ICU environment, and the circumstances surrounding discharge from the ICU to be important areas with room for improvement (Ågård et al. 2019).

Current quantitative evidence of the effect of PFCC in adult ICUs on delirium and psychological outcomes in patients and family members is uncertain (Bohart et al. 2021; Goldfarb et al. 2017). Perhaps this is because the evidence largely comes from trials of isolated components of PFCC, mainly different approaches to information-sharing, rather than multi-component interventions encompassing the complexity of needs experienced by patients and family members, i.e. all four concepts comprising IPFCC presented above (Bohart et al. 2021). So, the challenge remains, how best to realize PFCC in daily clinical practice. In this regard, knowledge of patients' and families' perspectives on and wishes for PFCC is fundamental.

Aim

We aimed to explore perspectives and wishes for PFCC among adult patients and family-members with recent experience of admission to an adult ICU.

Methods

We conducted an explorative descriptive study using inductive thematic analysis. The study adheres to the Consolidated Criteria for Reporting Qualitative research checklist (Tong, Sainsbury, and Craig 2007).

Participant recruitment

We used purposive sampling to identify participants. Designated clinicians in the participating ICUs were asked to identify potential informants and seek their approval to be contacted by the research team based on the following criteria:

- having experienced admission ≥48 hours to an adult ICU as a patient or family member within the previous three months.
- ≥ 18 years of age.
- family members who were primary caregivers to the patient and who had visited the patient on a regular basis during the ICU admission.

A family-member could be a spouse, adult child, sibling, partner, or friend (blood-related or not) (Davidson et al. 2017). The recruitment period lasted for 13 months, from October 2020 to November 2021.

Setting

Participants were recruited from six general ICUs in the Capital Region of Denmark. The interviews were conducted in a location chosen by participants. Due to the COVID-19 pandemic, some interviews were conducted face-to-face with appropriate distancing and the interviewer wearing a face mask, or by telephone.

Data collection

We conducted dyad interviews with patients and a family-member where this was possible. Dyad interviews hold the potential for participants to deepen and broaden the content and identify overlaps and contrasts in their experiences (Eisikovits and Koren 2010; Morgan et al. 2013). Interviewing family-members together, even early in a critical illness experience, has proven a feasible approach that contributes to knowledge of the family as a whole (Eggenberger and Nelms 2007). Dyad interviews add valuable nuances by considering the family to be more than the sum of its individual members (Eggenberger and Nelms 2007). If it was not possible to interview both the patient and a family-member together, we interviewed the possible party (patient or family-member). We developed an interview guide based on the aim of the study, inspiration from the concepts of PFCC (IPFCC 2019), and literature on prevention and treatment of delirium and the psychological consequences of an ICU stay (See Table 1) (Held and Moss 2019; van Beusekom et al. 2016). We evaluated the interview guide after the first two interviews. This was to revisit and refine the main interview questions in view of the first interviews. Furthermore, the interview guide

Table 1
Interview guide.

Research questions:
1. Please, tell me how the ICU staff (could have) accommodated and supported you in the best possible way during the stay at intensive care unit?
2. Do you have any specific ideas or experience with valuable interventions that were/could have been helpful for you during ICU?
3. What kind of needs did you (the patient) consider your family-member had during ICU?
4. What kind of needs did you (family-member) consider the patient had during ICU?
5. *In case the participants had any experience with delirium:* How can patient and family-members be helped to cope with delirium in the patient? Did you want to be involved in the detection and management of delirium?
6. *In case the participants had any experience with anxiety and depression:* How can patient and family-members be helped to cope with possible anxiety and depression? Did you want to be involved in the detection and management of anxiety and depression in patients and family-members?
7. What role would you (the patient/the family-member) like family-members to take on during the ICU admission?
8. How do you think that any possible patient- and family-centered care interventions you have experienced or wished to have been meet with did/would have made a difference to you post ICU?

was modified during the study according to participant responses in previous interviews.

All interviews were digitally recorded. Participants did not receive any training or familiarization with the concepts of PFCC prior to the interview as we did not want to influence participants' perspectives.

Participants were asked to complete a short, written questionnaire on basic demographic details, ICU primary diagnosis, and family-members' relation to the patient. All interviews were concluded with a short debriefing and participants were provided with a contact number to the interviewer in case any questions arose after the interviews. This occurred in two cases; for one participant, contact with the ICU was facilitated, and for another, contact to the hospital priest was established. The first author conducted all interviews. The first author has more than 12 years of experience as an ICU nurse and experience with interviewing family-members from a previous qualitative study.

Data analysis

Interviews were transcribed verbatim and imported into NVivo 12. We used the six phases of thematic analysis, described by Braun and Clarke to analyse data (Table 2) (Braun and Clarke 2006). Three authors (the first, second and last author) independently analysed data and subsequently met to discuss and agree on the final themes. We conducted interviews until we deemed that sufficient information power was achieved (Malterud, Siersma, and Guassora 2016).

Ethics

The study complied with the Declaration of Helsinki. Participants received written information about the study including the aim, criteria for participating and freedom to withdraw at any time. Confidentiality was ensured by not mentioning the participants' names or other identifying information in transcripts and analyses. Participants signed a consent form prior to being interviewed. The Danish Data Protection Agency approved the study (P-2020–822). According to Danish law, the study is exempt form formal approval, however we notified the Ethics Committee in the Capital Region, Denmark (file no 20061832).

Findings

Family and patient characteristics

We conducted fifteen interviews with a total of 23 participants (8 patients and 15 family-members), ten face-to-face and five by telephone. The interviews lasted from 25 to 77 minutes. Participant characteristics and recruitment sites are presented in Tables 3 and 4, respectively.

Themes

Analysis of the data identified three main themes (Table 5).

Theme 1: Ongoing dialogue is fundamental

This theme refers to the fundamental importance of information-sharing between ICU staff, family-members, and patients. Importantly, both scheduled and spontaneous information-sharing was important for maintaining a sense of overview throughout the ICU-admission, particularly for family-members.

Gaining a sense of the treatment plan. Participants were satisfied with day-to-day information and spontaneous updates about changes, positive and negative, in the patient's condition. However, a need for more frequent updates about the "overall treatment plan" was expressed. They acknowledged that the patient's critical condition demanded ongoing treatment amendments, making any clear-cut plan difficult to obtain.

> "*At least a plan of what was going to happen. I know it's difficult in the ICU, but still there must be a plan. I mean how long does he need to be on the ventilator? Why didn't they try to wean him from the ventilator?*". (Family-member, interview 3).

Pockets of spontaneous information and scheduled consultations equally important. Family-members mostly experienced getting information from ICU staff in "pockets of spontaneous information", for example when family-members telephoned the ICU-nurse, or during visits where family-members and ICU staff engaged in spontaneous, informal conversation.

Many family-members described how they by chance discovered they could request a formal consultation with the patient's allocated physician and nurse. Several family-members suggested that formal consultations should be systematically scheduled throughout the ICU admission regardless of the patient's condition. Although, the participants valued "pockets of spontaneous information" with updates, answers to "pop-up" questions, and "small talk", they emphasized the value of scheduled consultations.

> *"…itś hard to know what kind of questions to ask. Itś difficult to know how it is going. I think it's getting a little better, but I dońt know how much better or if they have any new ideas about what to do or new plans. Itś difficult for me to know. Sometimes I have been told the physicians wanted a formal meeting with me, and then we did that and that's been really good. And then there's been a while where I haven't asked for a formal meeting and they haven't said anything either. Then it's hard to know when to ask about anything new"* (Family-member, interview 8)

Participants emphasized the necessity of having the patient's allocated physician participate in scheduled consultations as they regarded them best qualified to explain the patient's condition and treatment. Furthermore, written information providing general information about the ICU was perceived as an important add-on source to the oral information.

Not knowing and being kept "on hold" is the worst. Waiting at home by the telephone for a planned phone-call from the ICU and experiencing that for some reason it was delayed, or trying in vain to get in contact with ICU and not being able to because ICU staff was busy, were tough situations for family-members. Not knowing resulted in anxiety and fear that something was wrong. Some family-members felt that ICU staff lacked understanding of the importance of these contacts and how anxious family-members became when appointments were not kept, or they felt put "on hold." As one family-member described, all they needed to hear was "he/she is fine". Then more detailed information could easily wait.

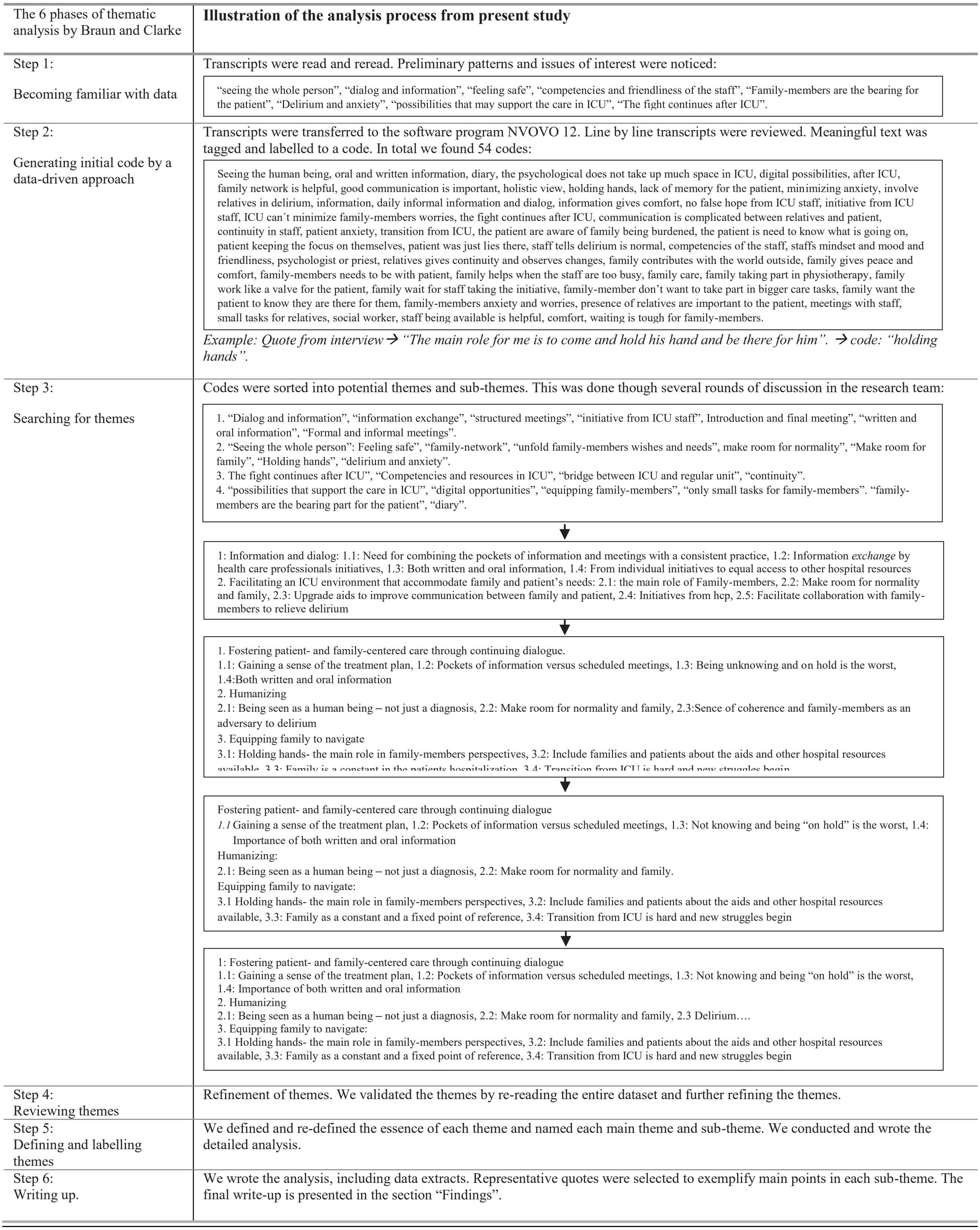
Theme 2: Humanising

This theme refers to patients' and families' appreciation of being recognized as "persons" with an everyday life more than "a critical illness" and the impact of humanizing the ICU environment for both patients and family-members.

Seeing the patient as a person – not just a diagnosis

It was important for both patients and family-members that ICU staff showed interest in the life, family, relations, and values of the patient. Family-members found it helpful when staff suggested that family-members bring pictures of the patient. Seeing the patient well-cared for, for example with newly washed hair, shaved, having a nurse put on nail varnish, taking the patient for a trip around the ICU in a wheelchair, or encouraging the patient to listen to podcasts or music of the patient's choosing are other examples of activities that family-members and patients regarded as supportive of recovery and personhood. Both family-members and patients viewed such initiatives as high-

Table 2
Illustration of the analysis using the six phases by Braun and Clarke.



The 6 phases of thematic analysis by Braun and Clarke	**Illustration of the analysis process from present study**
Step 1: Becoming familiar with data	Transcripts were read and reread. Preliminary patterns and issues of interest were noticed: "seeing the whole person", "dialog and information", "feeling safe", "competencies and friendliness of the staff", "Family-members are the bearing for the patient", "Delirium and anxiety", "possibilities that may support the care in ICU", "The fight continues after ICU".
Step 2: Generating initial code by a data-driven approach	Transcripts were transferred to the software program NVOVO 12. Line by line transcripts were reviewed. Meaningful text was tagged and labelled to a code. In total we found 54 codes: Seeing the human being, oral and written information, diary, the psychological does not take up much space in ICU, digital possibilities, after ICU, family network is helpful, good communication is important, holistic view, holding hands, lack of memory for the patient, minimizing anxiety, involve relatives in delirium, information, daily informal information and dialog, information gives comfort, no false hope from ICU staff, initiative from ICU staff, ICU can´t minimize family-members worries, the fight continues after ICU, communication is complicated between relatives and patient, continuity in staff, patient anxiety, transition from ICU, the patient are aware of family being burdened, the patient is need to know what is going on, patient keeping the focus on themselves, patient was just lies there, staff tells delirium is normal, competencies of the staff, staffs mindset and mood and friendliness, psychologist or priest, relatives gives continuity and observes changes, family contributes with the world outside, family gives peace and comfort, family-members needs to be with patient, family helps when the staff are too busy, family care, family taking part in physiotherapy, family work like a valve for the patient, family wait for staff taking the initiative, family-member don't want to take part in bigger care tasks, family want the patient to know they are there for them, family-members anxiety and worries, presence of relatives are important to the patient, meetings with staff, small tasks for relatives, social worker, staff being available is helpful, comfort, waiting is tough for family-members. *Example: Quote from interview→ "The main role for me is to come and hold his hand and be there for him". → code: "holding hands".*
Step 3: Searching for themes	Codes were sorted into potential themes and sub-themes. This was done though several rounds of discussion in the research team: 1. "Dialog and information", "information exchange", "structured meetings", "initiative from ICU staff", Introduction and final meeting", "written and oral information", "Formal and informal meetings". 2. "Seeing the whole person": Feeling safe", "family-network", "unfold family-members wishes and needs", make room for normality", "Make room for family", "Holding hands", "delirium and anxiety". 3. The fight continues after ICU", "Competencies and resources in ICU", "bridge between ICU and regular unit", "continuity". 4. "possibilities that support the care in ICU", "digital opportunities", "equipping family-members", "only small tasks for family-members". "family-members are the bearing part for the patient", "diary". ↓ 1: Information and dialog: 1.1: Need for combining the pockets of information and meetings with a consistent practice, 1.2: Information *exchange* by health care professionals initiatives, 1.3: Both written and oral information, 1.4: From individual initiatives to equal access to other hospital resources 2. Facilitating an ICU environment that accommodate family and patient's needs: 2.1: the main role of Family-members, 2.2: Make room for normality and family, 2.3: Upgrade aids to improve communication between family and patient, 2.4: Initiatives from hcp, 2.5: Facilitate collaboration with family-members to relieve delirium ↓ 1. Fostering patient- and family-centered care through continuing dialogue. 1.1: Gaining a sense of the treatment plan, 1.2: Pockets of information versus scheduled meetings, 1.3: Being unknowing and on hold is the worst, 1.4:Both written and oral information 2. Humanizing 2.1: Being seen as a human being – not just a diagnosis, 2.2: Make room for normality and family, 2.3:Sence of coherence and family-members as an adversary to delirium 3. Equipping family to navigate 3.1: Holding hands- the main role in family-members perspectives, 3.2: Include families and patients about the aids and other hospital resources available. 3.3: Family is a constant in the patients hospitalization. 3.4: Transition from ICU is hard and new struggles begin ↓ Fostering patient- and family-centered care through continuing dialogue *1.1* Gaining a sense of the treatment plan, 1.2: Pockets of information versus scheduled meetings, 1.3: Not knowing and being "on hold" is the worst, 1.4: Importance of both written and oral information Humanizing: 2.1: Being seen as a human being – not just a diagnosis, 2.2: Make room for normality and family. Equipping family to navigate: 3.1 Holding hands- the main role in family-members perspectives, 3.2: Include families and patients about the aids and other hospital resources available, 3.3: Family as a constant and a fixed point of reference, 3.4: Transition from ICU is hard and new struggles begin ↓ 1: Fostering patient- and family-centered care through continuing dialogue 1.1: Gaining a sense of the treatment plan, 1.2: Pockets of information versus scheduled meetings, 1.3: Not knowing and being "on hold" is the worst, 1.4: Importance of both written and oral information 2. Humanizing 2.1: Being seen as a human being – not just a diagnosis, 2.2: Make room for normality and family, 2.3 Delirium…. 3. Equipping family to navigate: 3.1 Holding hands- the main role in family-members perspectives, 3.2: Include families and patients about the aids and other hospital resources available, 3.3: Family as a constant and a fixed point of reference, 3.4: Transition from ICU is hard and new struggles begin
Step 4: Reviewing themes	Refinement of themes. We validated the themes by re-reading the entire dataset and further refining the themes.
Step 5: Defining and labelling themes	We defined and re-defined the essence of each theme and named each main theme and sub-theme. We conducted and wrote the detailed analysis.
Step 6: Writing up.	We wrote the analysis, including data extracts. Representative quotes were selected to exemplify main points in each sub-theme. The final write-up is presented in the section "Findings".

Table 3
Participants characteristics.

Participants	n
Patients (male)	8 (4)
Patient, mean age (range)	61 (48–68)
Family member (male)	15 (3)
Family, mean age (range)	53 (27–72)
Family members relationship to patient, n:	
Spouse/living together	11
Adult child	4
Duration of ICU admission, weeks (range)	6 (1–8.5)
Time from ICU discharge until interview, weeks (range)	2 (0–7)
The patient received mechanical ventilation during ICU admission, n (%)	15 (100)
Reason for ICU admission, n:	
COVID-19	7
Pneumonia	2
Sepsis	3
Cancer	1
Neurological condition	1
Vascular surgery	1

Table 4
Distribution of participants and recruitment site.

Interview	Participants	Time since ICU discharge to interview	Recruitment site
Interview 1	ICU-survivor and Family-member	1 week	A
Interview 2	Family-member	Patient still in ICU	B
Interview 3	ICU-survivor and Family-member	16 days	C
Interview 4	ICU-survivor and Family-member	12 days	A
Interview 5	ICU-survivor and Family-member	22 days	A
Interview 6	ICU-survivor and Family-member	19 days	D
Interview 7	ICU-survivor	7 weeks	B
Interview 8	Family-member	0 days (Patient was transferred to a regular unit the same day)	E
Interview 9	Family-member	1 week	F
Interview 10	Family-member and Family-member	3 days	B
Interview 11	Family-member	10 days	F
Interview 12	ICU-survivor and Family-member	24 days	E
Interview 13	ICU-survivor and Family-member	1½ week	A
Interview 14	Family-member	Patients still in the ICU	F
Interview 15	Family-member	Patients still in the ICU	B

Table 5
Overview of themes and sub-themes.

Themes	Sub-themes
(1) Ongoing dialogue is fundamental	(1.1) *Gaining a sense of the treatment plan* (1.2) *Pockets of spontaneous information and scheduled consultations equally important* (1.3*) Not knowing and being "on hold" is the worst*
(2) Humanizing	(2.1) *Seeing the patient as a person – not just a diagnosis* (2.2) *The importance of recognizing and making room for family*
(3) Equipping family to navigate	(3.1) *Family-members all-important role- holding hands and being a constant for the patients* (3.2) *Providing aids and facilitating contact to non-ICU resources* *(3.3) Preparing family for delirium* (3.5) *Engaging family members in the patient's transition from the ICU*

quality care. In contrast, as one patient recounted, it was de-humanizing just being placed in front of a TV to stare at it all day.

> *"Well, maybe just the thing about asking: Who is the patient as a person? Yes, that would have been nice, right? Because is he the kind of person who has played football all his life, a musician who has studied classical music at the Academy of Music or has he been homeless living on the street or something? So that you would be able to talk about those things when you are around the patient. I think that would be very good."…"You could have talked to the relatives. What kind of a person is it exactly we are dealing with?"* (Family-member, interview 10).

The importance of recognizing and making room for family. Some family-members reflected that more recognition of their situation would have helped them cope better. Family-members were anxious and concerned and considered that interest and support for their needs could be prioritized more by ICU staff.

> *"There is a tendency to not focus on the relatives either. Yes, they* (ICU-staff) *were nice and accommodating and encouraged me to ask any questions I felt like or call them if I had any worries. So, that is kind of an opening in relation to that. But they* (ICU staff) *were not really curious or decidedly proactive in relation to "what can we do to help YOU""*. (Family-member, interview 2)

Patientś described family-members as the sole representation of normality in the otherwise alienating ICU environment. Therefore, having family-members be able to be present and sensing that family-members were comfortable in the ICU was essential for patients as they represented a lifeline and hope for making it out of the ICU.

> *"I felt it* (visits from the wife) *kept me going. It was just, if I had to be here without any family-members or anyone, then I think my lifeline would have broken"*. (patient, interview 3)

Theme 3: Equipping family to navigate

This theme presents family-members' role as advocates and supporters of the patient. Furthermore, the pivotal role of clinicians in equipping them to fulfil this role.

Family-members' all-important role- holding hands and being a constant for the patients

Across all interviews, family-members described that their most important mission when visiting the patient was to "hold his/her hand" and focus on being present, protective, and caring towards the patient. Regardless if the patient was conscious or not, simply being allowed to be with the patient was comforting and important for family-members.

> *"The most important role for me was to come* (in the ICU) *and hold* (name of the patient) *hand and be there for* (name of the patient). *It may well be, that we couldńt communicate during the first week, but I could sit and hold his hand. I could sit next to him and caress his hair and he knew that I was there. Being present, that is the most important thing to me"*. (family-member, interview 3)

Many family-members did not wish to participate in practical caring tasks. They were intimidated by the gravity of the patient's condition and the technical apparatus connected to the patient. Some family-members had practical tasks outside the ICU related to the critical illness of the patient (for example economy, household, kids, communicating with the patient's workplace and family) and needed to focus their energy on being a constant and reassuring presence for the patient when they visited. One family-member had engaged in practical tasks such as lifting and feeding the patient when visiting, particularly when the ICU-staff was busy.

Some family-members took it upon themselves to keep a diary of the ICU admission, for example taking pictures and writing notes of daily events. They did this to support their own memory and to be able to process their experiences with the patient later on. Among those who did not write a diary, some wished that ICU staff had suggested they do this.

Providing practical aids and facilitating contact to non-ICU resources. Patients and family-members described the challenges of communicating while the patient was on mechanical ventilation. Provision of practical aids and guidance from ICU-staff to ease communication was lacking. Some experienced telecommunication as helpful when visiting was restricted due to the COVID pandemic and suggested that digital aids should be implemented as a regular practice.

Participants who were referred by ICU staff for counselling from non-ICU resources, e.g. a priest, psychologist, or social worker, found this helpful for their coping. The referrals were however random, dependent on the individual nurse's or doctor's awareness of the resources and their personal preferences. Participants therefore suggested that all patients and family-members systematically receive information about counselling resources during ICU admission.

> *"This is something you could be better at I think, at the units, to tell what resources you have available and what kind of help you can offer".* (Family-member, interview 6)

Preparing family for delirium. For some family-members delirium was frightening and some worried if the patient had suffered a stroke or brain damage of some sort. Typically, family-members said they became reassured when staff described delirium as "normal" for ICU patients. Other family-members wanted more information, guidance, and involvement in supporting the patient. One family-member reflected that the presence of family-members was especially important during delirium as they could quickly distinguish the patient's habitual behaviour from delirium. Some participants described family-members as having an important role in calming and comforting the patient.

> *"When* (wife) *came, for example, right, then it was difficult for me to get carried away in my own paranoia, I don't know, in… Well, even if I was very paranoid, then I could see you (the wife) were there, and I couldn't believe it* (the hallucination)*, because you were too real, and you were for real. So, it probably was the time and the physical presence. If you* (the wife) *had not been there, I would have stayed in the bubble for a longer time. Definitely".* (patient, interview 12)

Engaging family-members in the patient's transition from the ICU. Many participants experienced the transition from the ICU to the regular ward as sudden and wished to be more involved in planning the transition. Some participants suggested that when possible family-members should be physically present during the transition. Participants further suggested a mandatory discharge meeting in the ICU or the ward where concerns and questions could be discussed.

> *"At least, I should be involved in a way. That I could be present during the transition or present as close to the transition as possible."… "I had a lot of questions that I really wanted to ask or a possibility to put the questions to someone when we got there* (at the regular unit)*. I don't know what they had told him* (the patient) *of course, when he got there, but he was unable to repeat it."* (Family-member, interview 2)

Discussion

The findings of the present study clearly relate to the core concepts of PFCC; dignity and respect, information sharing, participation, and collaboration (IPFCC 2019).

Ongoing dialogue relates to the core concept of information-sharing and was fundamentally and unequivocally important for both patients and family. The importance of continuing dialogue is in line with several other studies and it appears essential to combine spontaneous information-sharing with frequent, scheduled consultations that may bring comfort and serve as a reliable point of reference in an otherwise chaotic situation (Ågård et al. 2019; Kydonaki, Kean, and Tocher 2020; Davidson et al. 2017; Auriemma et al. 2021). Based on our findings and previous findings, Davidson et al. recommend an interdisciplinary approach and interdisciplinary family conferences, to increase family satisfaction and reduce conflicts between clinicians and family-members (Davidson et al. 2017). Naef et al. (2021) also described it as essential to have an interdisciplinary approach to keep a sustained focus on PFCC in ICU practice. Otherwise, similar to our findings, they found that the level of information-sharing and care was random and dependent on the individual ICU-staff (Naef et al. 2021).

'Humanizing' essentially relates to all core concepts of PFCC, but perhaps most specifically to dignity and respect. We found that, for participants, high-quality treatment occurred when ICU-staff maintained a humanized attitude. Previous studies have touched upon the phenomenon of humanizing the ICU (Basile et al. 2021; Luiz, Caregnato, and Costa 2017). Studies indicate that family-members have a vital role in humanizing the ICU stay for patients and in some cases even reducing patients' anxiety (Heydari, Sharifi, and Moghaddam 2020). Some patients in ICU feel their inner strength and willpower are reinforced by having family present and experiencing connectedness (Alexandersen et al. 2021). Experiencing personalized attention and high-quality communication has been portrayed as the main components of humanized care (Luiz, Caregnato, and Costa 2017). Sensing detached or negative attitudes in staff, on the other hand, causes discomfort and demotivates families to participate in care (Blom, Gustavsson, and Sundler 2013; Al-Mutair et al. 2013). In non-ICU settings, Ecomaps (a visual map of a person's family, social and community relationships(Ray and Street 2005) have been successfully used to systematically gain insight into the patients' family dynamics, resources and vulnerability (de Souza and Kantorski 2009). The use of Ecomaps and genograms (diagram of family constellation) has been described in the literature as a potentially useful tool for family assessment (Wright&Leahey 2019). Use of Ecomaps could therefore relevantly be considered as a potential facilitator of PFCC in ICU settings.

'Equipping family to navigate' relates to the core concepts of participation and collaboration and touches on ways to make family-members best able to participate and be a collaborating partner in ICU. Previous studies have found that family-members want to participate in care (Wong, Redley, and Bucknall 2021). We found that holding hands was the main task for family-members while they had no need for practical obligations when visiting the patient. Kydonaki et al (2020) found that family-members were intimidated by the complexity of care in the ICU and, furthermore, argued that family members lacked the expertise to be actively involved in the physical care of the patient (Kydonaki, Kean, and Tocher 2020). As in other aspects of PFCC, individual needs and mutual expectations of both patients and families with regard to participating in care must be clarified and aligned to avoid any unnecessary burden on family-members and embarrassment or risk for patients (Mitchell et al. 2017).

Several issues made it difficult for participants to navigate, and patients and family-members appreciated being made aware of available helping resources e.g. psychologist, social worker, chaplain, as also previously reported (Davidson et al. 2017). These resources should be offered systematically to ensure equal access for all patients and families.

Delirium had a big impact on participants. Communication and provision of knowledge about delirium brings relief to family-members and helps them to make sense of the situation (Bohart, Merete Møller, and Forsyth Herling 2019; Leigh et al. 2019). Involvement of family-members in ICU delirium management may even protect family-members from post-ICU mental issues (Leigh et al. 2019). Family-members know the patient better than ICU-staff and therefore quickly discern changes in patients' cognitive and mental wellbeing (Leigh et al. 2019). Family-members' knowledge may therefore be beneficial to incorporate in the management of delirium (Kydonaki, Kean, and Tocher 2020).

Participants wished to be more involved in the transition from ICU. The challenge of transitioning and need for improved planning have previously been described (Ågård et al. 2019; Op 't Hoog et al. 2020). Actions to ease the transition for patients and family-members could include, if possible, family-members being present during the transition, information (also in writing), and a patient, family-staff meeting prior to transition (Ågård et al. 2019). Op´t Hoog et al. (2020) interestingly pointed out that lack of information and communication may be especially challenging in regular units (Op 't Hoog et al. 2020). Therefore, challenges related to the transition from the ICU cannot be solved by isolated solutions in ICU but may preferably include better collaboration with the regular units.

Strengths and limitations

Strengths of this study include the use of individual and dyad interviews that made it possible to elaborate different perspectives during the interviews. Transferability was strengthened due to recruitment of participants from six different hospitals. Credibility was strengthened by investigator triangulation during the analysis of data. The illustration of every step in the analysis process (Table 2) demonstrates that interpretations are grounded in the data.

Several limitations should be considered. It is a concern that some family-members and patients declined participation, often because of lack of energy due to critical illness of the patient.

We did not apply any validated instruments to formally test participants for delirium prior to interviews. This could be a relevant consideration in future studies. However, no participants presented with clinical signs of delirium. All participants were fully attentive during the interviews and provided coherent answers to the interview questions.

Perspectives and wishes of patients without family are not represented in this study. Their needs may differ substantially from those of patients with visiting family-members. Finally, we only interviewed patients and/or family-members one time and therefore do not know if their perspectives changed over time.

We collected data during the COVID-19 pandemic where visiting hours and ways of visiting were restricted for prolonged periods (e.g. 1-hour visits per patient per day, and visitors required to wear face mask). This may have affected the participants' experience and hence wishes for PFCC during ICU admission. Some perspectives and wishes might be accentuated, and others minimized due to the altered circumstances. Finally, the majority of participants were family-members, and some patients had little recollection of their ICU stay. Therefore, the perspectives and wishes presented predominantly represent the perspectives of family-members.

Conclusion

We found that patients' and family-members' perspectives and wishes for PFCC centred around ongoing dialogue with ICU-staff, the importance of humanizing the ICU environment, and a need for ICU-staff to equip family-members to be present and navigate in the ICU. Information-sharing between ICU staff, family-members, and patients was central. Both scheduled and spontaneous information-sharing was important to maintain a sense of overview throughout the ICU-admission, particularly for family-members. Patients and family members needed to share and have their knowledge, concerns and perspectives brought forth and acknowledged by ICU-staff. High-quality treatment was especially evident for participants when ICU-staff maintained a humanized attitude. We found a range of specific suggestions that may help patients and family-members to cope in the ICU and to support specifically family-members in fulfilling the need to act as advocates and supporters of the patient. ICU-staff have a pivotal role in equipping them to do this.

Ethical Statement

The study complied with the Declaration of Helsinki. Participants received written information about the study including the aim, criteria for participating and freedom to withdraw at any time. Confidentiality was ensured by not mentioning the participants' names or other identifying information in transcripts and analyses. Participants signed a consent form prior to being interviewed. The Danish Data Protection Agency approved the study (P-2020-822). According to Danish law, the study is exempt form formal approval, however we notified the Ethics Committee in the Capital Region, Denmark (file no 20061832).

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgement

We would like to thank all the patients and family-members for their participation and willingness to share their perspectives. Furthermore, we would like to thank collaborating nurses and ICUs; Brenda Lisbeth Vestergaard, Bispebjerg Hospital; Maria Andersen, Hillerød Hospital, Marie Oxenbøll Collet, Rigshospitalet; Mette Baumgarten, Hvidovre hospital; Lise Andersen, Heidi Knudsen, Helene Brix, Herlev; Britta Jepsen, Gentofte Hospital for recruiting participants for the study.

Funding Source

This work was supported by the Novo Nordisk Foundation [NNF200C0066106], The Department of Anaesthesiology and The Research Council at Herlev Hospital, University of Copenhagen, Denmark. Sources of funding and funders had no impact on the conduct of the research or study results.

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