



Research Article



Exploring patients' and relatives' needs and perceptions regarding family participation in essential care in the intensive care unit: A qualitative study

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ABSTRACT

Objectives: To examine the needs, perceptions and influencing factors according to former adult intensive care unit patients and relatives with regard to family participation in essential care in the unit.

Research design: A qualitative interpretive descriptive study using inductive thematic analysis.

Setting: Twelve pairs of former Dutch patients and their relatives were interviewed within two months after the patient's discharge from the unit between December 2017 and April 2018.

Findings: Four themes emerged: *the family's history*, *the patient's condition*, *supporting the patient and supporting the relative*. *The family's history*, in particular the relationship with the patient and former experience with care, determined the level of participation in essential care. The level of participation was also influenced by *the patient's condition*, more specifically level of consciousness, stability of the patient's situation and length of the patient's stay. The third theme, *supporting the patient*, related to presence/being able to 'be there' for the patient and a mostly positive attitude towards family participation. The last theme was *supporting the relative*, with three subthemes associated with relatives' needs and perceptions: (dis)comfort with participation in essential care, need for invitation and support, and concern about the possible strain experienced by relatives.

Conclusion: *Supporting the patient* and *supporting the relative* are reflecting the needs and perceptions of patients and relatives regarding family participation in essential care. Both *the family's history* and *the patient's condition* influence the relative's level of participation. Intensive care unit nurses and other healthcare providers could take these themes into account when encouraging family participation in essential care.

Implications for clinical practice: Patients' and relatives' needs and perceptions of family participation in essential care in the intensive care unit vary. Family participation in essential care is influenced by *the family's history* and *the patient's condition*. Healthcare providers could take these findings into account when implementing family participation in essential care.

Introduction

A stay in the intensive care unit (ICU) is not only stressful for the patient, but the relatives as well (Jeziarska, 2014). The impact for relatives may result in feelings of anxiety, and helplessness (Davidson et al., 2012; Hupcey, 1999). Critical illness and ICU treatment cause long-term

consequences in half of the patients after their stay in the ICU, including physical, mental and cognitive impairments, addressed as postintensive care syndrome (PICS) (Geense et al., 2021; Harvey and Davidson, 2016; Needham et al., 2012). Among relatives symptoms such as anxiety, depression and posttraumatic stress were reported in 13–56% in the first months after the patient's ICU discharge (Davidson et al., 2012). These

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symptoms are described as postintensive care syndrome-family (PICS-F) (Bialek and Sadowski, 2021; Davidson et al., 2012; Matt et al., 2017).

Currently, a transition towards patient and family-centered care (PFCC) is taking place (Bohart et al., 2023; Goldfarb et al., 2017; Mitchell et al., 2016). PFCC is an 'approach to the planning, delivery, and evaluation of healthcare, grounded in mutually beneficial partnerships among healthcare providers (HCPs), patients, and families' (Institute for Patient- and Family-Centered Care, 2015). PFCC includes family involvement and family participation; family involvement can be seen as a continuum, ranging from passive ('presence') to active forms ('contribution to care') (Olding et al., 2016). In our article 'contribution to care' is referred to as family participation in essential patient care activities.

Research shows that family participation in essential care may diminish feelings of powerlessness during the patient's stay in ICU among relatives and was also associated with a significant reduction in satisfaction, mental health symptoms as anxiety, depression and post-traumatic stress disorder (PTSD) (Amass et al., 2020, Davidson et al., 2012; Skoog et al., 2016; Yoo and Shim, 2021). Furthermore the patient's feeling of safety or comfort may be increased (McAdam et al., 2008; Bohart et al., 2023). Family participation could also prepare relatives for a role as informal caregiver after the ICU patients' discharge (Wyskiel et al., 2015).

In our integrative review about needs, perceptions, preferences and capacities of patients, relatives and ICU HCPs regarding family participation in essential care, we identified five themes representing needs and perceptions of patients and relatives. Relatives participate in essential care because they want to help the patient and feel useful. They generally have a positive attitude towards family participation. Furthermore some relatives experience stress regarding patient safety; however most perceived positive effects. Family participation also enabled relatives to feel in control. We also concluded that knowledge of the patients' and relatives needs, perceptions and preferences regarding family participation in essential care is rather limited (Dijkstra et al., 2022) corroborated by a scoping review (Olding et al., 2016). To expand the knowledge about needs and perceptions of former ICU patients and relatives regarding family participation, and possible influencing factors, we performed a qualitative study conducting interviews.

Objectives

The primary aim of this study was to examine the needs and perceptions of both former ICU patients and relatives with family participation in essential care in the ICU. The secondary aim was to identify factors that may influence family participation.

Methods

Design

We performed a qualitative interpretive descriptive study, following Thorne's methodology (Thorne, 2016), using inductive thematic analysis. Interpretive description is a qualitative method that is used to gain an understanding of a phenomenon of interest for health and well-being, its characteristics and nature, and aims to develop relevant knowledge that can be easily applied in practice (Thorne, 2016). In this methodology it is assumed that there are multiple constructed realities being subjective, complex, and contextual (Thorne, 2016). This research approach matches with the complex interactions between biological and psychosocial phenomena that influence patients' and relatives' experiences (Thorne, 2016) and is frequently used in nursing science (Dammann et al., 2022; Twamley et al., 2022; Sunner et al., 2021). Thorne's interpretive description methodology was deemed suitable to explore, describe and analyse former ICU patients' and relatives' needs and perceptions regarding family participation in essential care in the ICU. Interviews were used to gain insight into the former ICU patients' and

relatives' subjective realities. Field notes were made after each interview to document relevant main issues, and were used in the inductive thematic analysis. The themes were derived in an iterative process with a team that consisted of an ICU nurse, a physical therapist, a lecturer and three professors, all have extensive experience in intensive (nursing) care and/ or qualitative research. In our opinion this qualitative design is most appropriate to identify former ICU patients' and relatives' needs, perceptions and possible influencing factors regarding family participation in essential care, to gain a better understanding of this specific practice, as part of PFCC, in a complex context.

The study adheres to the Consolidated Criteria for Reporting Qualitative research checklist (Tong et al., 2007).

Setting

The study was conducted in the Netherlands with patients and relatives from three ICUs including one university, one teaching and one general hospital. One ICU had single rooms and an open visiting policy, the other two had both single rooms and multi-bed rooms and more restricted visiting policies (limited visiting hours in the afternoon and evening). The university hospital has an average number of 2251 admissions, the teaching hospital 1028 admissions and the general hospital 725 admissions each year (Stichting NICE, 2023). The Dutch healthcare system for regular (short-term) medical treatments is funded by obligatory health insurance.

Ethics

The study was approved by the Research Ethics Committee (CMO 2017-3635) and subsequently by the Hospital Ethics Committees of the participating ICUs, and complied with the Declaration of Helsinki. Potential participants were provided with both verbal and written information about the study. After expressing willingness to participate, written informed consent was obtained from all participants. At the start of the interview, the researcher explained that consent could be withdrawn at any time. Data were stored anonymously on a network disk, secured by the HAN University of Applied Sciences, specifically for research purposes. This disk is only accessible to authorized persons. HAN University of Applied Sciences has drawn up rules in this regard and has its own Ethics Committee.

Participants

Selection criteria for former ICU patients and their relatives included age >18 years, discharge from the ICU between two and eight weeks earlier, discharged home and not in a palliative care trajectory and speaking the Dutch language.

In each participating hospital, an ICU nurse received a written instruction for contacting the relative of the patient (first contact person in the patients' record) by phone, to inform them about the study, two to four weeks after the patient's discharge from the ICU. The ICU nurse inquired whether the relative and the former ICU patient wanted to share their needs and perceptions regarding family participation. If so, the ICU nurse asked whether contact details could be shared with the researcher (BD). After agreement to participate relatives and former ICU patients were visited and interviewed simultaneously by the researcher at their homes, or another location following to the former ICU patients' and relatives' wishes.

Data collection

Interviews were carried out between December 2017 and April 2018 by the primary researcher (BD). She is an ICU nurse with a master's degree in nursing science, and has experience in conducting interviews with patients and relatives. Where possible, interviews were carried out with both the former ICU patient and the relative, to ensure that both

perspectives and possible similarities and differences were discussed (Morgan et al., 2013). The semi-structured interview was conducted with use of an interview guide. The interview guide was based on literature, previous research among relatives of ICU patients (Noome et al., 2016), expert opinion and experience with family participation in essential care activities of the research team members (see Table 1).

All interviews were audio recorded and transcribed verbatim by the researchers (BD, KFB, MvdV). After the first interview, the audio recording was assessed by two fellow researchers (KFB, MvdV), and no adjustments in topic list nor conduct of the interview were deemed necessary. Field notes were made by the primary researcher (BD) after the interviews, to document identified key points. Data collection ended when no new findings were identified, as discussed and agreed upon by the two researchers (BD, KFB), and data saturation was reached.

Data analysis

All interview transcripts were imported in ATLAS.ti, version 9, software for qualitative data analysis. Three interview transcripts were analysed independently by two researchers (BD, KFB), comparing findings and discussing differences, until consensus was reached. Inductive thematic analysis was performed, following Braun and Clarke (2006). The two researchers (BD, KFB) independently read the entire transcripts from three interviews and then re-read the transcripts and assigned codes. After reviewing and discussing these codes, one researcher (BD) assigned codes to the remaining nine transcripts. Then all codes were reviewed and discussed by the two researchers, followed by deriving themes from these codes. These themes were discussed by all researchers until consensus was reached. The derived (sub)themes and relevant quotes were translated into English by the primary researcher (BD) and approved by all researchers.

Trustworthiness

To establish trustworthiness, we applied the following criteria: credibility, transferability, dependability, and confirmability (Lincoln and Guba, 1991). Credibility was established through prolonged engagement with sufficient time for data collection to gain an in-depth understanding regarding family participation in essential ICU care (Korstjens and Moser, 2018).

The primary researcher (BD), an experienced ICU nurse and researcher, tried to elicit experiences to describe the needs and perceptions from the perspective of former ICU patients and their relatives (Korstjens and Moser, 2018). Appropriate interpretation was established

Table 1
Interview guide relative's and former ICU patient's experience with family participation in essential care activities.

Opening question: what are your experiences with family participation in essential care in the ICU?
What was the patient's situation and condition in the ICU?
What do you remember of the nursing care?
Did you (relative) have the possibility to participate in essential care activities? Possible care activities are...
Do you (patient) have memories of your relative participating in essential care activities?
How did you (patient) feel about your relative helping you?
Would you (patient) have liked your relative to help you?
Do you (relative) agree?
How did you (relative) feel about helping the patient?
Would you (relative) have liked to help the patient?
Do you (patient) agree?
Did the ICU nurses invite you (relative) to participate?
Did you (relative) take the initiative to participate yourself?
Did you (relative) receive information and support from the ICU nurse?
Did other ICU healthcare providers, e.g. physical therapists, invite you (relative) to participate?
Could you (relative) visit the patient at your convenience? Visiting hours?

with use of interview techniques and repeated checking and summarizing the patients' and relatives responses (Op 't Hoog et al., 2020). To enhance credibility, we used triangulation with the selection of former ICU patients and relatives from different hospitals with differing backgrounds, the use of field notes, the deployment of a diverse research team and independent data analysis with two researchers (Sim and Sharp, 1998).

Transferability was established with a detailed 'thick description' of the study participants, setting and the research process (Lincoln and Guba, 1985).

To ensure dependability and confirmability, notes were taken throughout the research process to ensure possible replication (Korstjens and Moser, 2018).

Findings

Twelve pairs of former ICU patients and twelve relatives were interviewed. Demographics of study participants are presented in Table 2. Interviews lasted between 27 and 77 min.

ICU nurses of the three hospitals contacted 21 relatives by phone, 17 agreed to share contact details with the researcher (BD). Three relatives chose not to be interviewed, when contacted by the researcher, because they considered an interview too stressful at that time. After planning of the interviews, two of the former ICU patients were not able to participate, one of them was still hospitalized and delirious, the other had an acquired brain injury and was not able to communicate verbally (see Table 2).

Overall four general themes, *the family's history*, *the patient's condition*, *supporting the patient* and *supporting the relative*, and ten subthemes were identified from the interviews (see Table 3).

Theme 1: The family's history

The *family's history* theme was characterised by two subthemes: 'relationship between patient and relative' and 'former experience'. These subthemes were described by the patient's and the relative's perceptions of their situation before ICU admission influencing the level of participation in essential care activities.

a) *Relationship between patient and relative*

The relationship between patient and relative e.g. partner, parent, child (adult) or other and the intensity and quality of the relation had a major impact on family participation. In the interviews various

Table 2
Demographics of study participants.

Patient no.	Sex	Age	Reason for admission	LOS	Relative	Hospital
1	Male	59	Thoracic surgery	2	Wife	University
2	Female	77	Thoracic surgery	2	Husband	University
3	Male	66	Cardiothoracic surgery	14	Wife	University
4	Female	68	Cardiothoracic surgery	6	Son	University
5	Female	72	Cardiothoracic surgery	3	Husband	University
6	Male	73	Cardiothoracic surgery	3	Wife	University
7	Female	64	Respiratory distress	21	Son	Teaching
8	Female	67	Respiratory distress	21	Ex-husband	Teaching
9	Male	45	Abdominal surgery	9	Wife	Teaching
10	Male	81	Abdominal surgery	16	Wife	General
11	Female	25	Respiratory distress	7	Partner	General
12	Female	60	Abdominal surgery	5	Husband	General

Table 3
Themes and subthemes.

Theme	Subtheme
1 The family's history	a Relationship between patient and relative b Former experience
2 The patient's condition	a Level of consciousness b Stability of the patient's situation c Length of the patient's stay
3 Supporting the patient	a Presence/being able to 'be there' for the patient b Positive attitude towards family participation
4 Supporting the relative	a (Dis)comfort with participation in essential care activities b Need for invitation and support c Concern about the possible strain experienced by relatives

relationships emerged, for example spouses who had been married for more than 30 years and a young woman who had only recently moved in with her boyfriend, with longer relationships appearing to relate to being more comfortable participating. Most spouses felt the need to participate. Individual and family manners and habits also played a role, as expressed by several relatives, reflecting the family's domestic or usual intimacy sphere, illustrated by the following quote:

'We're used to help, we are used to doing so [since she has a history of health problems, requiring assistance]' (relative 12, husband).

The interview with two patients and their sons offered a different perspective on family manners and habits. Both sons tried to support their mother the best they could, though they preferred not to participate in (some) physical care activities.

Furthermore, relatives often knew what the patients' wishes and needs were, as the following quote illustrates:

'He always wanted a damp cloth on his head, occasionally wetting it again, or turning it' (relative 10, wife).

b) Former experience

Former experience, for example as an informal caregiver at home or HCP or after a previous stay in the hospital or the ICU was also an important determinant. The ICU environment could be quite overwhelming for patients and relatives, especially with a first admission. The following relative, a HCP, would have liked to participate in care, when possible:

'Yes, I work as a healthcare provider, I would have helped him then, or, assisted as much as I could' (relative 1, wife).

Theme 2: The patient's condition

The *patient's condition* theme was characterised by three subthemes: *'level of consciousness'*, *'stability of the patient's situation'* and *'length of the patient's stay'*. These subthemes were described by the patient's and the relative's perceptions of their situation during ICU stay determining the level of participation in essential care activities.

a) Level of consciousness

Several relatives mentioned that it was often difficult to ascertain the patients' wishes and needs related to the patient's level of consciousness, eg. sedated, comatose, delirious or alert and calm. Many patients were sedated or had altered consciousness and were unable to express

their wishes and needs and not all relatives knew what the patient's wishes and needs were.

This was illustrated by a former ICU patient who told that her mother, a HCP, did not want to participate in care activities for her daughter, since she was sedated and not able to express her wishes, making her mother uncomfortable with participating.

'I also spoke to my mother [about this interview], and she told me, she is a HCP herself, and she cared for her father at the end and she said, I just really don't want to do that with you without your permission. You were so will-less, you couldn't say anything, you couldn't indicate anything, then I'm really not going to.....' (patient 12, partner).

b) Stability of the patient's situation

The increasing stability of the patient's situation in the ICU was mentioned by several relatives as an important stimulus to participate in care activities. The patient's situation usually improved and relatives began to feel more at ease with the situation. This was illustrated by a relative who noticed that the number of catheters decreased, making participation easier, as earlier in the patient's stay in ICU he considered it quite difficult at times with all the lines that had to stay in place.

c) Length of the patient's stay

As the length of stay in the ICU increased, often associated with increasing stability, relatives felt more at ease with the situation resulting in increasing opportunities to participate, reflected in the following quote:

'In the beginning we did not help that much, ..., we watched first, what the ICU nurse did, and later on, we tried to participate more' (relative 12, husband).

Theme 3: Supporting the patient

The *supporting the patient* theme was characterised by two subthemes: *'presence/being able to 'be there' for the patient'* and *'positive attitude towards family participation'*. These subthemes reflected the patient's and especially the relative's needs and perceptions regarding family participation in essential care activities, aiming to help the patient. Theme 3 and theme 4 are interdependent, however, theme 3 focuses on the relatives' own needs to help the patient.

a) Presence/being able to 'be there' for the patient

For many relatives the opportunity to be with the patient was greatly appreciated, facilitated by open visiting policies in some cases, allowing them to support the patient where and whenever possible. This relative visited his wife early one morning, pleased with the ample opportunities, saying:

'Yes, I just wanted to be with you then, to support you' (relative 5, husband).

b) Positive attitude towards family participation

Most patients would have appreciated having a relative participating in essential care activities, when asked about this and provided with examples of various possible care activities by the interviewer. The following quote illustrates this:

'Yes, the best is, of course, if your own wife helps you' (patient 9, husband).

Most relatives would have liked to participate or actually did participate in essential care activities, also implying a positive attitude,

as this quote shows:

'I would have gladly helped, if they had asked me to' (relative 8, ex-husband).

Some relatives were glad 'to do something' for the patient and really appreciated this, having a more active coping style, others preferred leaving the provision of care to HCPs, having a more passive coping style.

An example of the former was a husband, who really wanted to assist when the ICU nurse wanted to help his wife to sit on the edge of the bed. During this interview he mentioned several times how much he had appreciated being able to do something for his wife, and his wife said that she had appreciated his help, as the following quote shows:

'She's ill, you want to help, you want to do something for her' (relative 2, husband).

Some other relatives preferred ICU nurses providing care, illustrated by the following quotes:

'Leave it to them [ICU nurses], I cannot do anything, I prefer they do it just right' (relative 4, son).

'No, I felt no need to help, he was well taken care of, I just had to be there for him' (relative 6, wife).

Several patients and relatives perceived participation in care as positive, illustrated by the following quotes:

'Oh yes, certainly, I really liked it, my husband helping me' (patient 5, wife).

'But helping, well in my case, I just got a really good feeling about it' (relative 2, husband).

Theme 4: Supporting the relative

The *supporting the relative* theme was characterised by three sub-themes: '*(dis)comfort with participation in essential care activities*', '*need for invitation and support*' and '*concern about the possible strain experienced by relatives*'. These subthemes reflected the relative's needs and perceptions and the patient's perceptions regarding family participation in essential care activities, that ICU HCPs could take into account when applying family participation. Theme 3 and theme 4 are interdependent, however, theme 4 focuses on the relatives' need for support from ICU HCPs when participating in essential care activities.

a) *(Dis)comfort with participation in essential care activities*

Several relatives mentioned that they did not know what they could do for the patient. Other relatives did not want to impose themselves and believed the ICU nurses were doing a good job, and they tried to be good guests. Some relatives considered it helpful when ICU nurses offered suggestions for possible care activities, for example reading to the patient, assisting the ICU nurse with repositioning the patient or helping the patient to do breathing exercises.

Some relatives were afraid to or felt insecure about the possibility of harming the patient. The possible dislocation of a catheter or alarms from the monitor or mechanical ventilator caused distress, making care activities that involved touching the patient stressful. The following quote demonstrates this:

'You don't know what the habit is, what is expected of you, because if someone asks you to do this or that for him, of course you do it. But you are also afraid that you will do something wrong, sure, well it is easy to talk now, but then they are full of catheters and bells and whistles' (relative 10, wife).

Some relatives expressed feeling comfortable with physical care activities, such as applying body lotion or bathing, whereas others felt uncomfortable participating in such activities. The following quote came from a relative, invited by the physical therapist to watch when

she performed limb exercises. When she removed the bed sheet from the patient's legs, he felt uncomfortable with the possibility of seeing her only wearing her hospital gown, and told them he was leaving the room for coffee and would come back when they were ready.

'I was there once, when the physical therapist came in, and she invited me to watch when she performed limb exercises, but, no, then I thought no, she [the patient] wasn't wearing any underwear' (relative 4, son).

b) *Need for invitation and support*

Some relatives didn't recall being invited by ICU nurses or physical therapists to participate in essential care activities and would have liked to participate if they had been invited. This relates to most relatives expressing a need for support when participating in care, as the following quote illustrates:

'Well yes, I'm not a nurse, I lack knowledge, so everything I do, I want to be supported by an ICU nurse' (relative 2, husband).

'[HCPs] have to be well aware that not all people are the same, and that this requires good communication skills of HCPs' (patient 10, husband).

c) *Concern about the possible strain experienced by relatives.*

Some former ICU patients were concerned about the possible emotional and physical strain experienced by relatives and wondered whether care activities should only be performed by the ICU nurses. One former ICU patient thought that ICU admission was stressful enough for his wife, he considered himself being taken care of, but was well aware that his wife had to take care of herself.

The wife of another ICU patient had a friend whose husband had been hospitalized and saw that it had been difficult for her friend to keep going, and this wife paid well attention to her own situation and tried to stay fit. The previous concerns are related to the following quote, coming from a former ICU patient, whose son had visited her every day:

'No, I would not have minded if [my son had participated], but I would consider it a bit of a strain for my son' (patient 4, mother).

Discussion

The aim of this study was to deepen the knowledge on needs and perceptions of former ICU patients and their relatives with regard to family participation in essential care activities in the ICU, and to identify influencing factors. Four main themes emerged that have, to our knowledge, not been described in previous studies.

'Habits within the family', related to the subtheme *relationship between patient and relative*, were not mentioned in previous studies, though this seems to influence patients' and relatives' needs and perceptions regarding family participation. Kydonaki et al. (2020) found the 'need for "doing family"' as a theme, a principle for enacting PFCC, with a focus on maintaining integrity and normality of the family during the ICU stay, showing common ground with our first theme *the family's history*. However, our theme focused on the time before ICU admission and the patients' and relatives' history, and patients and relatives trying to continue family habits in the ICU where possible. Another similarity was described in a study by Wong et al. (2019), the theme 'advocating for them' illustrated relatives' role to protect the patient, comparable to our 'knowledge of the patient', however perhaps a less burdensome responsibility for relatives. The subtheme *former experience* might act as an influencing factor, as well. Previous studies considered former ICU experience or a longer ICU stay facilitating (Azoulay et al., 2003; Garroute-Orgeas et al., 2010; Hupcey, 1999; Kean and Mitchell, 2014),

however, none of these studies took relatives' experience as informal caregiver or HCP into account. In our study this experience seemed to facilitate participation for relatives and is relevant for ICU HCPs when applying family participation in essential care.

The patient's *level of consciousness*, a subtheme of the second theme, often resulting in difficulties regarding communication with patients, hindered relatives and HCPs to check the patient's wishes and needs regarding family participation. Many relatives are capable of acting as the patient's spokesperson, though not all relatives know what the patient's needs are under specific circumstances (Dijkstra et al., 2022), as we have established in this study too. Though relatives were usually capable of filling in gaps for former ICU patients who were not able to recall much from their ICU stay or were suffering from reduced cognitive function, this may have influenced the information they shared in the interviews. An effort to gain insight in the patient's perspective has been made in some studies (Bohart et al., 2023; Garrouste-Orgeas et al., 2010; Hupcey, 1999; Kydonaki et al., 2020), and our current study has contributed to this, future research may add further knowledge on the patient's perspective. This perspective is relevant for the development of interventions and guidelines aiming to reduce negative effects of an ICU stay for patients and their relatives.

The subtheme *positive attitude towards family participation*, was confirmed by several patients, who would have appreciated their relative participating in care activities, illustrating more insight in the patients' wishes and needs. The interviews also showed that most relatives would have liked to partipate or actually participated. This is in contrast with the results from Kydonaki et al. (2020) and Bohart et al. (2023), who found that many relatives believed their contribution to the emotional and psychological support of the patient being more important or preferable than to physical activities. On the other hand, Wong et al. (2019) reported the theme 'contributing to their recovery', including relatives' participation in care activities, endorsing our third theme, *supporting the patient*. Research on relatives actually participating in essential care activities remains scarce though (Dijkstra et al., 2022; Olding et al., 2016). These findings show that needs, perceptions and preferences regarding family participation in essential care activities differ and should be taken into account by ICU HCPs. These findings may also serve as building blocks in the development of an intervention aiming at the application of family participation in essential care activities.

The subtheme *need for invitation and support* from ICU HCPs, from the last theme *supporting the relative*, was described in several studies (Blom et al., 2013; Davidson et al., 2010; Eldredge, 2004; Hammond, 1995; Hupcey, 1999; Liput et al., 2016; Mitchell et al., 2009). In our study most relatives did not recall being invited, but would have liked to participate in care activities, demonstrating the importance of ICU HCPs' awareness of the relatives' *need for invitation and support*. This subtheme has been listed in our integrative review (Dijkstra et al., 2022) and should be addressed prior to the implementation of family participation in essential care activities with clear information and instructions for relatives and an emphasis on participation being free of obligation. Though the *need for invitation and support* is described in various studies since 1995, it still was not common practice during the conduct of this study, and requires attention in the education of ICU HCPs.

Another subtheme, *concerns about the possible strain that relatives may experience*, expressed by some patients, when participating in care activities, have been expressed by ICU HCPs in previous studies as well (Azoulay et al., 2003; Kydonaki et al., 2020; McConnell and Moroney, 2015; Mitchell et al., 2017; Wyskiel et al., 2015). Some studies indicated though, that family participation actually might alleviate stress among relatives (Azoulay et al., 2003; Hetland et al., 2017). These concerns should be taken into account by ICU HCPs, bearing in mind that other patients and relatives in our study did not express such concerns, reflecting the variation in needs and perceptions. This is also suggested in the systematic review on interventions regarding family involvement by Xyrichis et al., (2021): development of future interventions should be

with closer input from relatives, while allowing different kinds and levels of family involvement.

Patients' and relatives' needs and perceptions regarding family participation in essential care activities in the ICU vary, influenced by various personal, professional and organisational factors. This variation makes implementation of a standardized way to apply family participation in essential care activities challenging for ICU HCPs. However, the findings of our study provide additional knowledge for an intervention aiming at the application of family participation in essential care activities.

Strengths and limitations

Strengths of this study were the interviews with former ICU patients and relatives simultaneously. Research among (former) ICU patients remains scarce, and our study adds relevant knowledge to other recent studies. In addition, most relatives were able to add information for former ICU patients, who sometimes had difficulty remembering what they had experienced in the ICU. Although our study was only performed in one country, in contrast to other studies we recruited patients from three different hospitals. This offered us a broader perspective on family participation. For example, these hospitals had different visiting hours, influencing possibilities for relatives to participate in essential care activities.

Some limitations should be considered. We were not able to recruit participants from different cultural backgrounds, who might have offered a different perspective on family participation. Olding et al. (2016) have suggested more attention for this aspect as well. We did not include relatives from patients who were in a palliative care trajectory, they might have offered a different perspective on family participation too.

Interviews with former ICU patients and relatives separately could have provided different information. Both could have experienced other difficulties or barriers they did not want or dare to reveal in the presence of the other, this may have limited the findings of our study.

Our study was carried out before the COVID-19 pandemic. Visitation policies in the early phase of the COVID-19 pandemic resulted in the reduced presence or absence of relatives in the ICU, having a great impact on ICU HCPs, patients and their relatives (Forsberg et al., 2023; Jungstrand et al., 2023; McPeake et al., 2023; Wendlandt et al., 2022). Open visitation policies in ICUs currently appear to have halted in progress (Milner, 2023), despite guidelines recommending unrestricted visitation (Davidson et al., 2017) and evidence-informed consensus statements to guide visitation policies in the ICU during a pandemic maintaining PFCC (Fiest et al., 2022). To what extent the COVID-19 pandemic has influenced the attitude and perceptions of all involved regarding family participation in essential care is difficult to ascertain and requires further research.

Conclusion

Patients' and relatives' needs and perceptions with regard to family participation in essential care in the ICU vary. Relatives generally have a positive attitude towards family participation, reflected in the theme *supporting the patient*. *Supporting the relative* includes relatives' (dis) comfort with participation in essential care activities, the need for invitation and support and concerns about the possible strain they may experience. These themes relate to several personal, professional and organisational barriers and facilitators. *The family's history*, affects the level of participation. Furthermore *the patient's condition* influences the relatives participation in essential care. These findings could support ICU nurses and other ICU healthcare providers when encouraging family participation in essential care, provide further knowledge for the development of an intervention aiming at the application of family participation in essential care activities and the consequent required training and education.

CRedit authorship contribution statement

Boukje M. Dijkstra: Conceptualization, Methodology, Validation, Formal analysis, Writing – original draft. **Karin M. Felten-Barentsz:** Formal analysis, Writing – review & editing. **Margriet J.M. van der Valk:** Formal analysis, Writing – review & editing. **Johannes G. van der Hoeven:** Formal analysis, Writing – review & editing. **Lisette Schoonhoven:** Formal analysis, Writing – review & editing. **Lilian C.M. Vloet:** Conceptualization, Methodology, Validation, Formal analysis, Writing – review & editing, Funding acquisition.

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.

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Ethics approval and consent to participate.

The study was approved by the Research Ethics Committee (CMO 2017-3635) and subsequently by the Hospital Ethics Committees of the participating ICUs.

Written informed consent was obtained from all participants.

Consent for publication

Written informed consent was obtained from all participants.

Availability of data and materials

The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

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