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Family participation during physical activity in the intensive care unit: A longitudinal qualitative study

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ABSTRACT

Purpose: Family-centered care has been implemented in the ICU to meet relatives' needs concerning information, support, participation and shared decision making. This study explores the needs, beliefs, feelings and behaviors of relatives of patients admitted to the ICU regarding participation during physical activity.
Methods: Longitudinal qualitative study design following a grounded theory approach. Relatives were interviewed at 4, 8 and 12 days after the patient's ICU-admission. Data were analyzed using constant comparison.
Results: Twenty-five interviews were conducted in ten relatives. Relatives believed that physical activity in the ICU improves recovery. Participating in physical activity decreased their feelings of powerlessness and uselessness. Relatives mentioned that they would be stimulated to participate if they were invited, guided and informed by healthcare providers. The perceived reticence of healthcare providers, patient's health-changing capacity and the inability to communicate led to a more passive attitude towards participation.
Conclusions: The conceptual model shows how family participation during physical activity changes from a passive role, with negative beliefs and feelings of uselessness and powerlessness, to a more proactive participatory role. Relatives felt more useful and like they were part of the team. Providing relatives with additional information might be a viable strategy to help and stimulate participation.

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1. Introduction

The environment in the ICU is not only stressful for patients, but also for their relatives [1,2]. Findings from several studies suggest that symptoms of anxiety, depression and post-traumatic stress symptoms may persist for three months or longer [3,4]. These symptoms are known as Post-Intensive Care Syndrome-Family (PICS-F) and have a negative impact on quality of life [4,5].

Family-centered care (FCC) is an approach to healthcare that is respectful of and responsive to individual families' needs and values [6]. Family education programs have demonstrated beneficial effects for family members in the ICU by reducing anxiety, depression, post-traumatic stress, and generalized stress, while improving family satisfaction with care [7]. One component of FCC is family participation in patient care activities [8-10]. This participation might help to decrease PICS-F and feelings of powerlessness [11], while the presence of relatives is known to increase patients' feelings of safety [12]. Most relatives prefer being present during the daily bedside rounds and partaking in tasks such as massaging, oral care and bathing (of) their loved ones in the ICU [13,14].

In a scoping review, Davidson et al. (2017) highlighted the importance of additional research to identify effective interventions to improve participation during physical activity by relatives in the ICU [6]. Current patient physical activity levels in the ICU are low, for a variety of reasons, including the severity of illness, the presence of an endotracheal tube, delirium, the availability of equipment and human resources and/or a lack of knowledge in healthcare providers [15,16]. All of these factors might contribute to patients being unable to return to premorbid physical functioning [3,17]. Physical therapists play an important role in encouraging physical activity, although involving relatives in physical activity may not be usual practice [18-20]. The engagement of relatives might increase

Abbreviations: COREQ, Consolidated Criteria for Reporting Qualitative research; EPD, Electronic Patient Database; FCC, Family-centered care; FSS-ICU, Functional Status Score for the Intensive Care Unit; HCP, Healthcare providers; ICU, Intensive Care Unit; MRC, Medical Research Council; PICS-F, Post Intensive Care Syndrome-Family.

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the frequency of physical activities and could be a positive contribution to patient recovery. To date, only one study has investigated relatives' beliefs and needs to be actively involved in stimulating physical activity within the ICU. Most relatives were open to helping the ICU-staff to change the patients' positions in bed or transfer them to the chair [21].

Our qualitative study focuses on new topics like: 1) how do relatives feel about participating during physical activities, 2) what are relatives' needs, beliefs, feelings and behaviors immediately after ICU admission, and 3) over time, at what level do relatives participate? Therefore, this study aims to explore the needs, beliefs, feelings and behavior of relatives of adult patients in the ICU while participating in physical activity.

2. Materials and methods

2.1. Study design

A longitudinal qualitative study with an inductive, interpretative approach was conducted according to the grounded theory method by Corbin et al. [22-24]. Three semi-structured interviews were scheduled with each relative on days 4, 8 and 12 after the patient was admitted to the ICU [25,26]. This study follows an inductive approach to develop a conceptual model. The study protocol was approved by the ethics committee of the Radboudumc (CMO: 2017–3635).

2.2. Setting

The study was conducted at the ICU of Radboud university medical center (Radboudumc) in Nijmegen, the Netherlands, between January and June 2018. The ICU consists of five units with eight single rooms in each. There is a 24-h open visiting policy and separate family rooms. The ICU at the Radboudumc adopted FCC as part of the clinical care, and family participation was implemented into multidisciplinary practice in 2017. At these units, early mobilization is usual practice, while hydrotherapy is used to activate and rehabilitate critically ill ventilated patients [27,28].

2.3. Quality procedures

Two authors (KF and VvdW) work at the neurological ICU. To prevent observer bias, we excluded this unit. To improve trustworthiness, a third independent expert (NK) performed a peer review to check the open codes. Differences in codes were resolved by discussing them. Member validation was carried out by verifying a summary of the first and second transcribed interviews prior to the second and third interview [29]. The Consolidated Criteria for Reporting Qualitative research (COREQ) checklist was used for reporting [30].

2.4. Participants and recruitment

Participants were sampled conveniently (through availability). Inclusion criteria were: relative of a patient admitted to the ICU for at least 48 h, age > 18 years, related by blood or a close relationship with the patient, have visited at least once and able to speak Dutch. They were approached by telephone or in person and received additional information by e-mail or letter. Informed consent was signed prior to the first interview. Sampling and data collection were continued until no new conceptual insights were generated and theoretical saturation was reached [12,31].

2.5. Data collection

Semi-structured interviews were held face-to-face in a family room or by telephone. The interviews were performed by VvdW. She was not related to any of the patients or their relatives.

The interviewer had no prior interviewing experience. Bracketing and reflexivity skills were developed through four pre-study practice interviews [29]. Observational memos were made to catch relevant impressions and thoughts during the interviews. An interview guide including open questions based on literature and best practice was used to ensure that relevant topics were covered during the interview (see Appendix 1) [21,32].

The baseline characteristics of relatives were obtained prior to the first interview. Baseline characteristics of patients were collected from the Electronic Patient Database (EPD), including the number of physical therapy treatments and Functional Status Score for the Intensive Care Unit (FSS-ICU) during ICU admission. The FSS-ICU is a measure of physical function for ICU patients [33]. It describes the level of patient independency in activities of daily living.

2.6. Data analysis

Data analysis was conducted in accordance with the grounded theory methodology by Glaser and Strauss (see Table 1) [23,29]. All interviews were audio-recorded and transcribed verbatim (VvdW). Transcripts were entered in the qualitative software ATLAS.ti (Scientific Software Development GmbH. Version 7, 2012). To identify meaningful codes, line-by-line examination was carried out independently by two researchers (KF and VvdW). The results of the first interview identified codes for the subsequent interviews [34]. Axial coding was performed to identify the relationships between codes to formulate themes. In a reflective meeting, themes were discussed with KF, VvdW, NK, AO and TH until consensus was reached. Key themes were integrated into a conceptual model with the consensus of all authors [24]. The use of memos supported the analytical interpretation regarding relatives' expression.

The method used for data analysis is informed by the constant comparative method [22,35]. Each separate case (all longitudinal data of one participant) was analyzed, followed by an analysis across all cases and finally a synthesis of the findings [25,26]. Baseline characteristics were analyzed descriptively.

Table 1
Analytical process.

Data analysis
• **Transcribed verbatim:** all of the interviews to gain insight into the overall impression of the separate cases and the change in every case over time (VvdW).
• **Reading transcriptions:** to gain insight into the overall impression of the separate cases and the change in every case over time (KF). Six interviews (24%) were controlled to correct typing errors (KF).
• **Summarizing** all interviews to compare the time-changing beliefs, needs, feelings and behavior of the participants (VvdW).
• **Open coding:** two members independently identified text segments that contained meaningful codes for each of the 25 interviews (KF and VvdW).
• **Axial coding:** the two members compared the codes and discussed them to reach agreement. Matching codes were combined. A hierarchy of categories was formulated to show various relationships between themes which can be discussed during selective coding (KF and VvdW).
• **Longitudinal comparison** within cases and between categories. Quotations and codes were ordered chronologically to detect whether there was a time-dependent change in the family's beliefs, needs, feelings and behaviors regarding physical activity promotion (KF and VvdW).
• **Investigator triangulation:** to increase reliability and detect inappropriate subjectivity, an independent expert performed a peer review to check the open codes (NK). Themes were identified and discussed until consensus in interpretation was reached (KF, VvdW, NK, AO and TH) and the final conceptual model was created (KF, VvdW, NK, RN and TH).
• **Selective coding:** a theoretical framework within final themes were developed that give a deeper understanding of the changes over time and differences in the beliefs, needs and behaviors of relatives (KF, VvdW, NK, AO and TH).
Observational memos to enhance the transparency of the analytical process and to reflect on the process of the interviews by catching relevant impressions and thoughts (VvdW). The memos were written out in the transcriptions and linked to the codes to explain interpretations and conclusions.
Based on Strauss & Corbin 2007

3. Results

3.1. Participants

All approached participants were willing to participate. Ten relatives of ten patients represented a heterogeneous sample in terms of relationship to the patient, age, gender and educational level (see Table 2). The relationship to the patient was classified as parent, child (in law), sibling or spouse. Nearly all relatives visited the patient daily for one or more hours. The mean age of critically ill patients was 57.5 years (SD = 20.4) and the mean (SD) length of ICU stay in days was 18 (11) (see Table 2). Seven patients were completely immobile following ICU admission and needed help in all physical activities (FSS-ICU ≤2). Two patients were able to transfer out of bed with minimal assistance (FSS-ICU 19 and 23), and one patient was ambulating and able to walk while ventilated (FSS-ICU 30).

3.2. Interviews

A total of 25 interviews were conducted with a duration varying from 5 to 25 min. On average, the first, second and third interviews were conducted 4 days ($n = 10$), 9 days ($n = 9$) and 14 days ($n = 6$) after ICU admission (see Table 2). All interviews were conducted while the patient was still in the ICU. Data were incomplete for some cases as two patients died and two patients transferred to the low-care nursing department after the second interview (see Table 2). Theoretical saturation was reached after interviewing the eighth participant. To confirm data saturation, two additional interviews were conducted that generated no new conceptual insights.

Nine out of ten relatives were willing to participate, except for participant 4. In her role as sister, she wanted *'to be there'* for her brother, but not participate during physical activities. The other nine relatives participated in the following activities: massage of extremities, changing bed positions, transfer from supine to sit; supporting head and torso in upright position; sitting next to the patient at the edge of the bed; guiding the intravenous lines; assisting in breathing exercises and coughing; and giving verbal stimulation. Relatives believed physical activity had a positive effect on the recovery of the patient.

Four key themes were identified as a final theoretical framework. They described whether relatives wanted to participate during physical activities and what they needed for participation:

3.3. Relatives' expectations towards healthcare providers

There was a lack of knowledge among all relatives about the type of physical activity provided in the ICU. This led to a need for information, explanations and guidance to learn how to participate in the activities. Relatives needed a clear invitation to participate. Sometimes they found it difficult to participate, because there were no fixed times scheduled.

Two relatives mentioned a discrepancy in healthcare providers' attitude towards encouraging participation. Some healthcare providers were more reluctant to invite relatives and told them *'no, it's bad timing'*. One participant said:

> *"Yes uhm…to be honest, I participate less.., as I no longer feel free to participate. Because the healthcare providers' views differ too much"* (participant 7, interview 3).

Others were more open and willing to invite relatives to participate. Relatives often felt redundant, because there were already two healthcare providers helping the patient.

3.4. Benefits of participation for relatives

The need to *'being a part of the treatment'* instead of *'standing on the side'* was expressed by almost all relatives. The possibility to participate during physical activities made relatives *'feel useful'*. One relative even felt guilty if he chose not to participate. Another expressed it in the following way:

> *"To say in soccer terms: Otherwise it's a game of others and you are standing at the side, only watching. At least now you can make yourself useful...even if you are the ball boy. Now you at least have some influence on the game."* (participant 1, interview 2).

Some relatives believed that participating improves emotional coping. Others only experienced making a contribution to the functional recovery of the patient. A father said:

> *"He was surrendered by the white coats and by touching him, it feels like he becomes more connected to us, his loved ones."*
>
> [(participant 1, interview 3)]

The feeling of powerlessness is expressed by several relatives:

> *"I've been sitting here for two days now and I see a lot of people doing things, but I have had no influence. Now I have the feeling that I can do something, even if it is a little bit."* (participant 1, interview 1).

3.5. Impact of patient status

Relatives felt insecure about the patient's health-changing capacity, which made them hold back because they found it hard to estimate this. Patients' inability to express wishes and needs led to difficulties in communication and made relatives reluctant to ask permission to participate. They often tried to take into account and minimize the patients' embarrassments. A daughter said:

> *"I don't know if she wants me to help her. She is not quite awake yet and she is intubated."* (participant 8, interview 1).

One mother said:

> *"I don't know what's the right or the wrong thing to do for him…Well, now I think it's difficult to, for example, change the position of the pillow. Because I'm not sure if he can handle it."* (participant 7, interview 1).

3.6. Impact of fear and the relationship to the patient

A lot of relatives felt a strong fear *'of doing something wrong'*, while participating in physical activities fear that they '*might harm'* the patient or breaking some intravenous lines or tubes. The bronchial toilet was a frightening moment for relatives. Furthermore, they were afraid to stand in the way of the healthcare providers. A few relatives felt that healthcare providers had expert knowledge, so they decided to *"leave it to the specialist"*. Although one relative said:

> *"Patients have a better understanding when surrounded by people they are familiar with."*

One relative decided not to participate because of her own limited capacity. Participant 4 made a conscious choice to stand back and look over the shoulder of healthcare providers during physical activities. She said:

> *"You know, when I am visiting my brother, I would be completely down if I'm sitting there and have to do something…I would rather be happy to make some jokes when I'm sitting next to his bed…yeah, pass the time together."* (participant 4, interview 1).

Relatives 'relationship to the patient was a determining factor in that relatives wanted to be included during physical activities. Parents and spouses were closely involved and easily started to participate. However, a son, a sister and a daughter-in-law felt more distance between themselves and the patient. One sister said:

Table 2
Baseline characteristics.

Relatives						Patients					Interviews		
No. participant	Sex (M/F)	Age (years)	Relationship to patient	Highest education level	How many times did you visit your relative (hours/week) at first interview	Sex (M/F)	Age (years)	Reason for ICU admission	Length of ICU stay (days)	FSS-ICU score[a] at ICU admission	T0 First interview (days after ICU admission)	T1 Second interview (days after ICU admission)	T2 Third interview (days after ICU admission)
1	M	53	Father	HBO/4-years degree	Continuously	M	19	OOHCA after caffeine intoxication	24	0	3	8	13
2	M	66	Spouse	MBO/2-years degree	28 h/week on daily basis (every day 4 h)	F	65	Bilateral pneumonia (had two kidney transplantations and pacemaker because of atrium fibrillation)	11	0	2	6	11
3	F	41	Sister	Academic graduation	7 h/week (every day 1 h)	F	39	Respiratory failure by pneumonia (already known with mitochondrial myopathy)	30	30	6	10	17
4	F	60	Sister	MBO/2-years degree	7 h/week (every day 1 h)	M	69	Exacerbation COPD by pneumonia	18	23	5	10	14
5	F	54	Mother	MBO/2-years degree	Continuously	M	22	High energetic injury after a motor cross accident	3	19	2	6	X Nursing department
6	M	52	Son	Academic graduation	6 h/week (three days a week, 2 h per visit)	M	78	Respiratory failure by pneumonia	17	0	3	9	15
7	F	64	Mother	HBO/4-years degree	Continuously	M	41	Suicide attempt by intoxication an unknown drug	35	2	4	9	16
8	M	69	Spouse	MBO/2-years degree	28 h/week on daily basis (every day 4 h)	F	63	Cholangitis by pancreatic cancer	8	0	2	X Died	X
9	F	37	Daughter	MBO/2-years degree	28 h/week on daily basis (every day 4 h)	M	67	Respiratory failure by pneumonia	16	0	9	16	X Died
10	F	41	Daughter in law	MBO/2-years degree	Continuously	F	52	OOHCA by ventricular fibrillation and ventricular tachycardia	5	0	3	12	X Nursing department

No. number, M male, F female, ICU Intensive Care Unit, FSS-ICU Functional Status Score for the ICU, OOHCA Out Of Hospital Cardiac Arrest, COPD Chronic Obstructive Pulmonary Disease.
[a] This score has a range of 0–35 with higher score, indicating better functional status.

"Of course, I love my brother, but I think it is different... yeah, that I, as his sister, have to do that with him. It's my brother, not my spouse." (participant 4, interview 2).

3.7. Level of participation over time

The change in needs, beliefs, feelings and behavior over time is an ongoing process. Relatives experienced that it took time to get used to the situation in an ICU. During the first interviews, most relatives had a wait-and-see attitude because of fears and a lack of knowledge. A participant said:

"For healthcare providers it's a piece of cake, but I had to find out in which order things are done and how to act in the ICU environment." (participant 2, interview 2).

While analyzing the data and comparing the data over time, we found that relatives' behaviors and needs to participate during physical activities changes over time into a more proactive participating behavior. Actual participation in physical activity decreased feelings of powerlessness and uselessness. Participants confirmed this:

"I can imagine there are people who are in the ICU for 1-2 days. But if you are admitted for a long time, like my wife… she has been there for 11 days ... and then ... yes, surely you can help." (participant 2, interview 3).

Finally, the impact of the four key themes and their inter-relationship was visualized in a conceptual model (see Fig. 1).

4. Discussion

This study shows relatives' needs for information, explanation and guidance from healthcare providers when participating in physical activities to reduce fear and gain insight to in the patient's health-changing capacity. According to relatives, participation could be facilitated if relatives were presented fixed time schedules, and all healthcare providers would display an unambiguous positive attitude regarding family participation. Barriers to participate include the believing that healthcare providers are more skilled in providing physical activity, and the impossibility to communicate with and ask permission from the patient to participate. Relatives' behavior and needs in participating during physical activities changes over time from a wait-and-see attitude in the first days after ICU admission, to a more proactive participatory behavior.

Other research specifically focused on family participation in daily care activities instead of physical activities at the ICU [14,32]. According to both relatives and healthcare providers, participation of relatives during transfers and respiratory training are the most unpleasant active care tasks [14]. Findings in this study are a positive attitude of relatives towards participating in physical activities such as changing the position in bed or keeping the trunk or head upright. Earlier research described that being able to move during ICU admission appeared to help patients regain control and belief in their recovery and therefore involving family in physical activities could be an extra motivator [28]. Our study also sanctions the need for explanation that relatives have about safe participation during physical activities [36]. Mistraletti et al. try to answer this need by using an information brochure and dedicated website [10]. However, as already suggested by those authors, our findings confirm that besides information there is a need for explanation by human interaction and guidance during participation [37].

4.1. Strengths and weaknesses of the study

Longitudinal data collection is a strong point in this study as it contributes to understanding the dynamic process relatives are going through and how they respond to the ICU environment. This provided

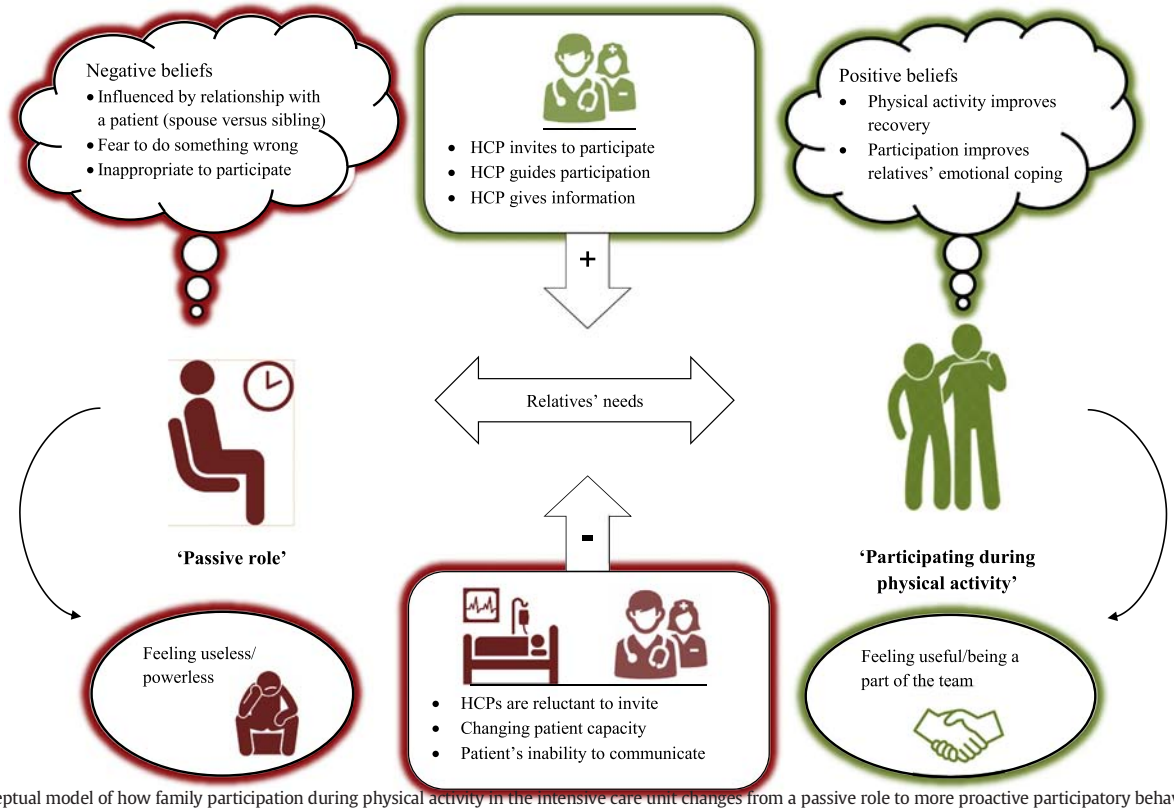

Fig. 1. Conceptual model of how family participation during physical activity in the intensive care unit changes from a passive role to more proactive participatory behavior. Abbreviations: HCP; healthcare provider.

insight into the needs that were most relevant when relatives were participating during physical activity. Another benefit of serial interviewing is the development of a relationship between researcher and participant. Reflecting on earlier findings enables more depth in the following interviews.

A first limitation of this study is that, at the start of their first interview, relatives were provided with information about early mobilization and physical activity in the ICU as a part of their usual care. This culture may have influenced the interview outcomes, because it provided them with information on the effect and benefits of physical activity. Moreover, as mentioned by the relatives themselves, providing additional information seems to be a viable intervention to help and motivate relatives to participate during physical activities of their loved ones.

A second limitation is that the interviewer (VvdW) had limited interview experience, but she has five years of working experience as a physical therapist, of which three years in ICU-care. The literature shows that professional experience makes interviewers more sensitive to patients' beliefs and experiences [38]. To improve the interview experience, we performed four pilot interviews [29], and VvdW followed education in qualitative research.

A third limitation is that this is a single center study in an academic setting in the Netherlands with a positive attitude towards early physical activity. The transferability of the outcomes to other settings might, therefore, be limited. Moreover, we included a low number of relatives with different relationships to the patients. Other ethnical or religious backgrounds or other cultural attitudes towards physical activity, family participation and/or FCC can influence the needs, beliefs, feelings and behaviors of relatives regarding participation during physical activity. In this study, we included a convenience sample, whereby we first checked the eligibility of the patients admitted to the ICU and afterwards approached their relatives after checking the inclusion criteria. This resulted in a non-homogeneous sample with a wide variation of relatives concerning sex, age, educational level and relationship to the patient. Moreover, there was considerable variability in the characteristics and health status of the patients. We noticed that the relationship between relative and patient influenced the level of participation. For a more in-depth interpretation of these data, we should have asked more detailed how well relatives knew their relative. However, in this study we reached data-saturation, so although, the variation in answers can be larger, it seems that the themes will be comparable. Regardless, future studies with a larger and more homogeneous population in different settings will still be necessary to fully understand all beliefs, needs, feelings and behaviors of relatives with loved ones admitted to the ICU.

4.2. Implications for clinical practice

This study could give healthcare providers tools to adapt their own attitude towards the needs of relatives during participation in physical activities. However, the differences in the individual approach implicate the need for a clear vision and agreement of the department about family participation and a uniform attitude and approach to relatives. The results of this study could contribute to the development of a program that will coach healthcare providers how to improve the participation by relatives in ICU-care. This program should provide general information on the way of working in the ICU for relatives of patients: an open invitation. Healthcare providers need to communicate with relatives whether or not physical activity can be fitted to the agenda of relatives. Shared decision-making could enhance the motivation of relatives. In addition, healthcare providers should receive training how to: 1) start personal communication and information to relatives, 2) invite relatives participate safely in physical activities, and 3) stimulate, instruct, and guide relatives during physical activities. We believe that there is no one-size-fits-all solution to include relatives, in part because of the changing needs of the relatives. Healthcare providers should take into account these (changing) needs of each individual relative. Above all: family participation is always voluntarily. It is allowed, if it is safe and it contributes to the needs and possibilities of relatives and patients.

5. Conclusions

Our interpretations of the interview data suggest that, at ICU admission, relatives can feel powerless, useless and frightened of harming the patient. Relatives reported that these feelings can decrease if they are invited, guided and informed to participate during therapeutic sessions and the promotion of physical activity. The grounded theory suggests that family participation during the ICU admission is an evolving process, starting from a 'passive role' towards 'proactive participation'; however, this theory needs to be confirmed in future research.

Ethics approval and consent to participate

Ethical approval was granted by the medical ethics committee of the Radboud University Medical Center, Nijmegen, the Netherlands (number 2017–3635). All relatives gave written informed consent before taking part in the study.

Consent for publication

All interviewed relatives signed informed consent for publication. The original signed consent forms are retained by the corresponding author.

Availability of data and material

The data that support the findings of this study are available from the corresponding author, KF, upon reasonable request.

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Authors' contributions

KF, VvdW, RN and TH designed the study. VvdW recruited the participants and the data. KF and TH supervised the data analysis. All authors participated in data analysis, interpreted the data, and provided critical input into the manuscript revision. All authors approved the final version of the paper and are entitled to authorship as listed authors.

Declaration of Competing Interest

The listed authors have no competing interests.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jcrc.2021.05.004.

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