

RESEARCH ARTICLE

Relatives' experiences of the transition from intensive care to home for acutely admitted intensive care patients— A qualitative study

Aaltje Meiring-Noordstra MSc, RN¹ | Ingeborg C. van der Meulen PhD^{2,3} |
Marisa Onrust RN² | Thóra B. Hafsteinsdóttir PhD^{4,1} |
Marie Louise Luttk PhD^{5,2}

¹Nursing Science, Program in Clinical Health Sciences, University Medical Center Utrecht, Utrecht, The Netherlands

²Department of Critical Care, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

³Research Group Nursing Diagnostics, Hanze University of Applied Science Groningen, Groningen, The Netherlands

⁴Nursing Science Julius Center of Health Sciences and Primary Care, University Medical Center Utrecht, Utrecht, The Netherlands

⁵Family Care, University of Applied Sciences Hanzehogeschool, lectorate in Nursing Diagnostics, Groningen, The Netherlands

Correspondence

Aaltje Meiring-Noordstra, Nursing Science, Program in Clinical Health Sciences, University Medical Center Utrecht, Utrecht, The Netherlands.

Email: aaltjenoordstra@hotmail.com

Abstract

Background: Acute admission to an intensive care unit (ICU) can negatively affect quality of life for patients and their relatives. Relatives play an important caregiving role after the patient's admission. More knowledge and understanding of their needs are necessary as the patient transitions home.

Aim: This study aims to explore relatives' experiences of acutely admitted ICU patients' transition from the ICU to a general ward and then home.

Study design: A qualitative study with a phenomenological approach was conducted. Interviews were in-depth and featured open-ended questions. The interviews took place after the patients transitioned from ICU to home and were conducted online by videoconference. Data were analysed using Colaizzi's seven-step method.

Results: Twelve relatives of acutely admitted ICU patients were interviewed. Five main themes emerged: (1) mixed feelings, (2) sense of not being involved, (3) limited information provision, (4) lack of acknowledgement as a caregiver, and (5) an uncertain future perspective. Relatives experience major uncertainties during transitions and prefer to be actively involved in care and care decisions.

Conclusions: This study indicates that relatives of ICU patients experience a lack of guidance during the transitions from the ICU to a general ward and to home, or a follow-up facility.

More focus is needed on the themes of mixed feelings, the sense of not being involved, limited information provision, lack of acknowledgement as a caregiver, and an uncertain future perspective. This increased focus might improve the guidance during these transitions.

Relevance to clinical practice: The insights from this study may help to improve the care of patients and their relatives during the transitions.

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2023 The Authors. *Nursing in Critical Care* published by John Wiley & Sons Ltd on behalf of British Association of Critical Care Nurses.

KEYWORDS

critical care, ICU, PICS-F, relatives' experiences, transition process

1 | BACKGROUND

The number of patients admitted to and surviving intensive care units (ICUs) is increasing worldwide,^{1,2} and research indicates that ICU admission negatively affects quality of life in terms of long-term physical, cognitive, and psychological impairment.¹ Moreover, relatives suffer from the consequences of ICU admission after the patient is discharged from hospital.^{1,2}

ICU's are intended for critically ill patients facing vital organ dysfunction and potential threats to their life. Advanced monitoring, diagnosis, and treatment are required.^{3,4} These patients are often physiologically unstable and require complex invasive treatment.⁴

Several studies have reported that 50%–70% of ICU patients suffer from long-term physical, cognitive, and psychological impairment after discharge from hospital. This is known as post intensive care syndrome (PICS).^{2,5,6}

The impact of critical illness on family members, referred to as PICS-family (PICS-F), includes anxiety, depression, sleep deprivation, and complicated grief.^{2,5,6} The relatives of more than half of all former ICU-patients become informal caregivers after the patient transitions home.² Relatives play a significant role in patients' physical and emotional recovery in the acute phase and during rehabilitation or discharge home. In addition, relatives are a crucial link in the health care continuum, and a more caring atmosphere with continuous, straightforward information and family participation would be considered an improvement.⁷

Transitions from the ICU to a general ward and from the general ward to home after an ICU admission are both known to be challenging and stressful for patients and their relatives.^{7,8}

The transition from the ICU, featuring the highest level of medical technology, to a general ward with less acute care, is one of the most challenging and stressful experiences for patients and relatives.^{7,9,10} During these transitions, many health care providers are involved in exchanging information and responsibility, but according to Häggström et al., discharge planning often lacks guidelines and tends to be ad hoc and influenced by patient acuity.⁴

A previous study found that patients and relatives experienced the transition from ICU to a general ward as confusing, tiring, and stressful, and the study concluded that nurses must attend to the psychological adjustments that patients and relatives face.⁷ How patients and relatives experience the transition is influenced by how it is organized, communicated, and executed by health care professionals.^{7,11}

The transition from a general ward to home after ICU admission can be accompanied by feelings of abandonment after hospital discharge because of a lack of contact.¹ Patients without a primary caregiver have been found to experience more anxiety and fear, while those with relatives and other support have been found to be more optimistic and positive about their discharge.¹

What is known about the topic

- There is little literature about experiences of relatives of ICU patients during care transitions;
- The impact of critical illness on family members, referred to as PICS-family (PICS-F), includes anxiety, depression, sleep deprivation, and complicated grief;
- Transitions from the ICU to a general ward and from the general ward to home after an ICU admission are both known to be challenging and stressful for patients and their relatives.

What this paper adds

- The results of this study provide a greater understanding and insight for nurses and doctors during care transitions of ICU patients, which may lead to more sense of involvement for relatives and a better acknowledgement as a caregiver.
- Relatives need more guidance during the transitions from the ICU to ward to home, or a follow-up facility. This might be improved by more focus on themes of mixed feelings, sense of not being involved, limited information provision, lack of acknowledgement as a caregiver and uncertain future perspective.

Researchers have argued that the concept of transition is key to the nursing discipline.^{12,13} Some have suggested redefining nursing in terms of facilitating transitions and helping people who are undergoing them. Based on the principles of the transitions theory, Meleis et al., argue that transitions can make people vulnerable to health risks and that nursing interventions can facilitate transitions and thereby affect the outcome of these transitions.^{12,14,15}

Research into the transition from the ICU to a general ward indicates that nurses could make this experience more positive on general wards by involving patients and relatives in treatment plans, goal-setting, decision-making, and daily care.² Interpersonal relationships, the intensity of care, and the amount of information that patients and relatives receive differ between the ICU and the general ward.² As for the transition from the general ward to home (after an ICU admission) there are indications that ICU follow-up care such as intensive care follow-up clinics, or the possibility of revisiting the ICU ward services seem to benefit patients and relatives.¹⁶

When discharged home, the risk of re-admission is increased if information is provided hastily and inadequately, leaving relatives and

patients with an incomplete understanding of the diagnosis, medication-changes, and care plan.^{9,11}

Flink et al. found that these problems are associated with discharge communication and conclude that patients are unprepared for discharge and the self-management activities that follow hospitalization.⁹

Other studies have indicated that these problems are associated with lack of communication upon discharge.^{9,2,7,17,18} Furthermore, relatives of acutely admitted ICU patients may be affected by the negative consequences of an ICU admission. However, little is known about relatives' experiences during this transition.

2 | AIM

This study aimed to explore the experiences of relatives of acutely admitted ICU patients as they transition from the ICU to a general ward and are then discharged home.

3 | DESIGN AND METHODS

3.1 | Design

This qualitative study was grounded in a descriptive, phenomenological design. This approach is suitable to develop an understanding of the 'lived experiences' of relatives of acutely admitted ICU patients and give an accurate description of these experiences.^{19,20}

The findings of this study are reported according to the consolidated criteria for reporting qualitative research (COREQ).^{21,22}

3.2 | Sample

The population of interest was relatives of acutely admitted ICU patients who transitioned from the ICU to the ward or from the ward to a follow-up facility or home.

Acutely admitted ICU patients were selected between December 2020 and April 2021 who met the following criteria: (1) older than 18 years; (2) ICU stay of >48 h; (3) Dutch speaking; (4) the intensivist had made the decision that the patient could be discharged from the ICU to a ward or to home or follow-up facility; and (5) had at least one relative. Patients were excluded if they met the following criteria: (1) COVID-19 diagnosis; (2) required end-of-life care; (3) had a mental disorder, or (4) were chronically dependent on a ventilator.

If the ICU patient agreed to participate, the contact details of the relatives were collected. The relatives were contacted by the research nurse, checked for eligibility, and asked to participate. A relative was eligible if they met the following criteria:

(1) were an informal caregiver of an acutely admitted ICU patient; (2) were able to speak and understand Dutch; and (3) were at least 18 years old. In this study, the term 'relatives' refers to informal caregivers such as children, spouses, or siblings.

3.3 | Setting

Participants were enrolled from the ICU unit of a university hospital in the Netherlands from December 2020 to April 2021. Nine participants were interviewed after the respective patients were transferred to a follow-up facility for rehabilitation, and three participants were interviewed after the respected patients were discharged to home. Because of COVID-19 precautions, the interviews took place online by video-conference or phone and were videotaped and/or audiotaped. The interviews lasted 35–70 min, with an average length of 49 min.²⁰

3.4 | Procedures

The identification and recruitment of participants was performed by a team of experienced research nurses. Patients were screened based on the inclusion criteria. Eligible patients were approached after being transferred to the general hospital ward. Patients were given verbal and written information about the study and were asked to approach a close family member to determine their interests. Once informed consent was obtained, the researcher contacted the participants by phone and planned the interviews. Recruitment ceased when no new insights were obtained during the interviews.

3.5 | Data collection

The data were collected through in-depth interviews, which enabled the participants (relatives) to recount their experiences as fully as possible, in line with the explorative character of the study.^{19,20} Interviews were conducted 3 to 5 weeks after the patients' discharge from hospital. This time frame was chosen so that the participant could provide a clear and thorough description of the experiences during these transitions.

The interviewer (AN) was a registered nurse who had no professional relationship with the participants.

An interview guide was used, including open-ended questions which were developed on the basis of a literature review and were discussed by the research team (Table 1).^{2,7,19}

Participants were asked to describe their experiences during the transitions of the ICU patient from the ICU to a general ward and from the general ward to home. The interviewer began with the following request: 'Please tell me about your experiences as a relative of an acutely admitted ICU patient during the transfer from the ICU to the ward.' To strengthen the dependability of the data,^{20,23} the interview guide was evaluated after the first two interviews; the interview guide appeared to be sufficient and no adaption was needed. Demographic variables were obtained during the interviews, facilitating the transferability of the study results.²⁴

3.6 | Data analysis

Despite the fact that four interviews were related to a single patient, we considered these interviews as an individual and unique

TABLE 1 Demographic variables of the study sample.

Participants					ICU patients					
Participant number	Age	Gender ^a	Level of education ^b	Relationship with patient	Age	Gender ^a	ICU LOS ^c (days)	General ward LOS ^c (days)	Hospital LOS ^c	Follow-up facility
1	50–60	F	8	Partner	50–60	M	8	7	22	Rehabilitation
2	40–50	F	3	Partner	40–50	M	2	14	16	Home
3	50–60	M	3	Brother	50–60	M	10	53	63	Rehabilitation
4	50–60	F	7	Partner	60–70	M	3	11	14	Rehabilitation
5	50–60	F	2	Partner	40–50	M	2	6	8	Home
6	30–40	M	7	Partner	30–40	F	3	19	22	Rehabilitation
7	30–40	F	7	Daughter	50–60	F	7	21	28	Rehabilitation
8	50–60	M	3	Partner	50–60	F	6	36	42	Home
9 ^d	60–70	M	2	Father	30–40	M	28	21	49	Rehabilitation
10 ^d	60–70	F	3	Mother	30–40	M	28	21	49	Rehabilitation
11 ^d	30–40	F	3	Sister in law	30–40	M	28	21	49	Rehabilitation
12 ^d	30–40	M	6	Brother	30–40	M	28	21	49	Rehabilitation

^aM = male, F = Female.

^bLevel of education = ISCED 2011 levels of education; 0: early childhood education, 1: primary education, 2: lower secondary education, 3: upper secondary education, 4: post-secondary non-tertiary education, 5: short-cycle tertiary education, 6: bachelor's or equivalent level, 7: master's or equivalent level, 8: doctoral or equivalent level.

^cLOS, length of stay.

^dMembers of the same family, interviewed separately.

experience, especially because the interviews were conducted individually with each of these family members.

The data were transcribed and analysed using the phenomenological method of Colaizzi, which consists of seven steps^{24,25}:

- In the first step, interviews were independently transcribed verbatim, and all transcripts were (re)read to allow familiarization with the data.²⁴ To strengthen the credibility of the study, member checking was performed by inviting participants to review the transcripts of their interviews and giving them an opportunity to identify any discrepancies in the information or to request that sensitive data be removed. All participants affirmed that the interview transcripts provided their views, feelings, and experiences and that the information reflected in the interviews was accurate and complete.²⁶
- The second and third steps involved reviewing each interview transcript, extracting significant statements, and formulating meanings of each significant statement.²⁴ The interviews were guided by an interview guide based on the literature and expert knowledge.^{2,7,19} Guided by the results from the preliminary analysis, the interview guide did not need adjustments.
- Simultaneously with Steps 2 and 3, the transcripts were open-coded (AN). The first step was made in labelling, composing, and organizing the data gathered from significant statements.²⁴ These statements were compared and discussed by the research team (IM and MLL), and meanings were formulated.²⁴ Disagreements were mainly about whether statements were consistent with the aim of the study and were resolved through discussion.

- Steps 4, 5, and 6 of Colaizzi's method involved organizing the formulated meanings into clusters of themes. These steps were performed through collaboration among the researchers (AN, IM, and MLL). Meanings were organized into clusters of themes and were grouped together. Meetings were organized with the researchers to reach a consensus about the group codes.²⁴
- Step 7 of Colaizzi's method was a final validating step, which involved returning the transcripts to the participants for a final check of the interviews.²⁴ This member check was performed in Dutch, and the results were then translated into English.
- All data analysis steps were discussed by the research team.

Data analysis was conducted using AN in Atlas. TI version 9.0.²⁷

3.7 | Ethical considerations

The study was conducted according to the principles of the Declaration of Helsinki.²⁸ The Medical Ethics Review Committee at the University of Groningen approved the Follow-up Intensive Care Study (FICS) of which this is a sub-study (ref no: 2018/627). Because participants were not subject to treatment, the Medical Research Involving Human Subjects Act did not apply for this study.²⁹ All participants and relatives were provided with verbal and written information about the study and all participants as well as the researcher (AN) signed an informed consent form.

4 | FINDINGS

4.1 | Study population

A total of 19 participants met the inclusion criteria. Seven declined to participate, leaving 12 participants to be interviewed. Seven participants were female, which is consistent with the mean gender distribution of patients admitted to the ICU. The mean age of participants was 47 years (32–61 years). Four of the 12 participants were related to one patient. All four family members were interviewed individually. Data of these four family members were considered as individual experiences and therefore also analysed as separate data (Table 1).

Five main themes emerged from the data that reflected the lived experiences of the relatives of acutely admitted ICU patients during transitions from the ICU to a general ward and home. These five themes are presented below:

4.2 | Mixed feelings

The relatives experienced negative and positive feelings during the patients' transitions. Positive feelings mostly corresponded with the patient's recovery; if improvement was indicated, positive feelings were predominant. In particular, the transition from the ICU to the general ward was experienced as a relief and with happiness, because it was a significant step towards recovery. Additionally, feelings of peace and calm were experienced during transitions to the ward.

'We were relieved that he was transferred to the ward, because he was moving forward. He did well, another step up. In essence you're happy, because he's recovering.' (P9).

Both, the transition from the ICU to the general ward, and to home or follow-up facility also created negative feelings, such as fear and stress. From the general ward to home or a follow-up facility, relatives felt uncertain about further recovery of their loved-one.

From the ICU to the general ward, relatives felt frightened and uncertain about whether the transition was too soon, and they worried that the ward care would be of a lesser quality than the ICU care. Furthermore, the general ward did not have the same medical monitoring as the ICU and such monitoring provided a sense of safety. When patients were first transferred to a medium-care or high dependency unit, the relatives considered it to be a more positive and safe experience than direct transfer to a general ward:

'It's nice to see on the cardiac care unit (CCU) that he's still being monitored, with all the machines. That was our fear that it would happen again. First, it has to be investigated what the cause of the illness was.' (P4).

4.3 | Sense of not being involved

The relatives felt a low level of involvement during transitions both from the ICU to the ward, but also from the ward, and from the ward to home or follow-up care. Opportunities for communication with health care professionals were missed, which led to unexpected and unprepared transitions. One family member described how at first, he felt that they were involved in the transition from the ward to follow-up care; however, at the last moment, the treatment plan was changed and so they felt confused about their caregiving role during the transition from the ward to a follow-up care facility:

'We said to each other, How is that possible? Is he really moving to that rehabilitation clinic? No one ever said anything about this clinic. Then we get a phone call that he's moving. We were in shock.' (P10).

Most participants said that they were not involved during the transitions. If the relatives were included during the nurses' handover, they felt involved and supported. Some participants were informed about the transition by telephone, and felt that this was sufficient. However, when the relatives arrived at the general ward, they saw the patient's vulnerability:

'Well, you're not really involved during transition. You follow the bed to the general ward. You have to contact the ward nurse yourself' (P2).

4.4 | Limited information provision

In both transitions, relatives experienced limited information provision. Concerning the transition from the ICU to the ward, the relatives said that they had insufficient knowledge about the treatment plan and that they would have liked to be involved in the medical visits. One participant described this experience as follows:

'The information about the treatment plan and care is discussed between the specialist and my husband. As a partner, you would like to join these visits. The visiting hours are in the afternoon, but by then the doctor's visit has already taken place.' (P4).

During the transition from the ward to the follow-up facility, participants described the information provided as confusing and incomplete. Medical and nursing transfer documents lacked details about the patient's illness, and to what extent the patient had recovered. That made the relatives feel insecure.

Some relatives enjoyed a relationship with a permanent contact nurse in the department, and said that this made them feel safe and free to ask questions. Others had conversations with the doctor, rating this as a highly positive experience that gave them the opportunity to ask questions and receive information about the treatment plan:

'In particular, the conversations we had every Friday with the specialist, were very pleasant. They were very good conversations that also helped you. And every-time we left, we had a more positive feeling than when we went in.' (P6).

4.5 | Lack of acknowledgement as a caregiver

The relatives experienced the patients' transitions as life-changing and, expressed a need to be better acknowledged as caregivers. They described the nursing and medical staff as being mainly focused on the patient in all transitions, giving them, relatives, no attention or time to ask questions, or expressing their feelings. Some participants spoke with a social worker and had a positive experience:

'It's important to take care of loved ones too, as they feel limited in their own options due to the whole situation.' (P5).

However, not all participants were offered a social worker. These participants lost an opportunity to express their feelings.

Participants said that the more a patient recovers and works towards discharge, the greater the role of the relative becomes as they will be taking care of the patient at home. They understood this role to be natural, but they missed the necessary guidance on care related activities:

'I missed the attention for me as a relative. I missed the attention of how I was doing. Just to acknowledge that.' (P8).

4.6 | Uncertain future perspective

When discharge from the hospital was mentioned, the participants had new worries about the coordination of care at home or at the rehabilitation facility. The relatives said that they were worried because their son (the patient) lived alone, and first needed to complete his rehabilitation. If they were expected to be caregivers, they wondered how they would manage this new role. One relative described this feeling:

'We just have to wait and see how far the recovery will get. If he stays in a wheelchair, it doesn't have to be a problem that he can't move in his own house. But he must be able to live at home by him self. He can't rely on us, visiting five times a day.' (P10).

The relatives felt the need to be informed about what they could expect in the future. They said they felt a lack of guidance in the skills to cope with the new situation and indicated that they felt there were barriers to approaching a professional for help. They also mentioned a

need to regain confidence about the patient's health and the new situation at home. Some of the relatives said that they were still struggling with the patients' limitations:

'In rehabilitation, he's still a patient. That's really difficult to see. A big tough guy who now walks behind a walker. Then you think, 'This is like a really, really bad movie'. You'll get another person at home.' (P1).

5 | DISCUSSION

This study aimed to explore the experiences of the relatives of acutely admitted ICU patients as they transition from the ICU to a general ward and are eventually discharged to home. The relatives' experiences described in this study can be summarized into five main themes: (1) mixed feelings, (2) a sense of not being involved, (3) limited information provision, (4) lack of acknowledgement as a caregiver, and (5) an uncertain future perspective.

The findings reveal that the relatives experienced mixed feelings (positive and negative at the same time) during the transitions. Positive feelings were related to the patient's mental and physical recovery. These were also reported by Op 't Hoog et al., where relatives described a transition to the general ward as a relief, as it was considered a positive step towards recovery.²

The transition from the ICU also caused negative feelings of fear and stress in relatives, as described in other studies.^{2,19,30,31} Op 't Hoog et al., describe how negative feelings have three main causes: the unexpected transfer to the general ward, no medical monitoring on the general ward, and the differences between the ICU and the general ward.² These findings are in line with the findings of the present study, where relatives also felt uncertainty during the transitions.

Strahan et al, described how fear and anxiety can be related to uncertainty about what will happen next, and feelings of doubt about the patient being healthy enough to be discharged.¹⁹ In the present study positive feelings and negative feelings have been described as separate emotions, which is in line with previous studies.^{2,19} The participants in the present study described having both positive and negative feelings at the same time, indicating strong emotional confusion and ambivalence. Further research is needed to explore the intersection of these mixed feelings.

The sense of not being involved, as found in the present study, was often related to feelings of not being prepared for the patient's transition and a lack of contact with nurses and health care professionals. Other studies found that the sense of not being involved increased feelings of fear in family members and their perception of gaps in their knowledge.^{2,32} An ICU transfer is a complex and emotional process, where preparation, information and emotional support during transition is important.³³

The participants in the present study also described limited information provision. Information provision has been claimed to be the greatest need of relatives of ICU patients.³⁴ Furthermore, Op 't Hoog et al. found that when relatives are involved in communication

between the ICU and ward nurses, they feel supported by the professional care.² In the present study, communication in terms of information provision was often described as confusing and/or incomplete. Assigning a permanent contact person or having a conversation at a fixed time each day or week may be helpful in providing structure and consistency in information provision for patients and their relatives.

Furthermore, the present study showed that the relatives experienced changes in the delivery of care during transitions, such as reduced monitoring of the patient and less attention from nurses. This finding is in line with earlier studies, which also showed that relatives experienced differences in safety and trust during the transition from ICU to the general ward.^{2,33} To improve care for patients and their relatives during transitions, nurses should be aware of this transfer anxiety in family members and know how to prevent or reduce.³⁰

In addition, the relatives in the present study reported a lack of acknowledgement of their role as caregivers. They felt neglected and craved involvement. Chaboyer et al. also described relatives' feelings of not being acknowledged, especially during transition phases.³³ It is of great importance for nurses to be aware of caregivers and the impact of an ICU admission and, more specifically, transitions on their emotional well-being. Acknowledging relatives in the transition process might involve explaining the next steps and encouraging relatives to ask questions.³⁵ Nurses can help patients and their caregivers by fulfilling their need for information and support during admission and especially during transitions and discharge.³²

Finally, the relatives expressed the burden of an uncertain future.^{2,23} They expressed their worries about the future and how to organize life at home. They mentioned a need for information and guidance. The literature indicates that the use of a liaison nurse can decrease anxiety and uncertainty during transitions among the relatives of neurological ICU patients.^{32,36} Contact with a liaison nurse may also help the relatives of patients in other ICU categories by heightening their sense of involvement during transitions.

6 | LIMITATIONS

Some limitations of this study should be acknowledged. The results may be prone to selection bias; 4 out of the 12 interviewees were related to one single patient. Although we considered these interview data as individual experiences, these individual experiences are coloured by the same patient context which may have influence the overall picture. However, the variation in demographic variables of the relatives was sufficient to draw conclusions. The online interviews may have led to a lack of non-verbal communication. Subjectivity may have influenced the identification of the topics; however, we attempted to enhance the credibility of the study by using triangulation. All transcripts were considered and analysed independently by two researchers. Where interpretation diverged, a third researchers was involved. The research team all together discussed the interim and final analysis. By doing this, we attempted to minimize the influence of subjectivity.

7 | IMPLICATIONS CLINICAL PRACTICE

Having knowledge about the experiences of relatives of former ICU patients can provide by nurses and doctors with a greater understanding during care transitions. This knowledge can be used to guide nurses and other health care professionals in improving the care for the relatives of ICU patients, including communication and information provision during care transitions. This may lead to a greater sense of involvement for relatives and better acknowledgement of relatives as caregivers, which is important both for the relatives and for the patient.

8 | CONCLUSION

In the transition from the ICU to a general ward, relatives experienced mixed feelings. They felt fear and uncertainty about whether the transition was too soon, and if the ward care would be of lower quality than the ICU care. When improvement was indicated, however, positive feelings were predominant. In the transition to home or a follow-up facility, the relatives felt a lack of guidance in the skills to cope with the new situation and indicated that they felt there was a barrier to approaching a professional for help.

Identifying the needs of relatives can help improve of experiences their experiences during transition.

ACKNOWLEDGEMENTS

We gratefully acknowledge all family members for participation in this study. We also thank the research nurses in the ICU who were involved in the recruitment of the participants. In particular we are grateful to Hetty Kranen and Janneke van der Veen for their contribution to this research. Furthermore, we thank Saskia Weldam for the input from the master clinical nursing science University Utrecht.

DATA AVAILABILITY STATEMENT

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

ETHICS STATEMENT

The Medical Ethics Review Committee at the University of Groningen approved the Follow-up Intensive Care Study (FICS) of which this is a partial investigation (ref no: 2018/627). All participants and relatives were provided oral and written information about the study and all participants as well as the researcher signed an informed consent form. Permission to reproduce material from other sources.

REFERENCES

- King J, O'Neill B, Ramsay P, et al. Identifying patients' support needs following critical illness: a scoping review of the qualitative literature. *Critical Care BMC*. 2019;23:187.
- Op 't Hoog SAJ, Dautzenberg M, Eskes AM, Vermeulen H, Vloet LCM. The experiences and needs of relatives of intensive care unit patients during the transition from the intensive care unit to a general ward: a qualitative study. *Aust Crit Care*. 2020;33:1036-7314.

3. Stichting Nationale Intensive Care Evaluatie. Basisgegevens IC units voor het jaar 2019 [Internet]. Accessed September 1, 2020. Available from: <https://www.stichting-nice.nl/datainbeeld/public>
4. Häggström M, Bäckström B. Organizing safe transitions from intensive care. *Nurs Res Pract*. 2014;2014:175314.
5. Rawal G, Yadav S, Kumar R. Post-intensive care syndrome: an overview. *J Transl Int Med*. 2017;5:90-92.
6. Davidson JE, Jones C, Bienvenu JO. Family response to critical illness: Postintensive care syndrome-family. *Crit Care Med*. 2012;40:618-624.
7. Herling SF, Brix H, Andersen L, et al. Patient and spouses experiences with transition from intensive care unit to hospital ward: qualitative study. *Scand J Caring Sci*. 2020;34:206-214.
8. Grood de C, Leigh JP, Bagshaw SM, et al. Patient, family and provider experiences with transfers from intensive care unit to hospital ward: a multicentre qualitative study. *CMAJ*. 2018;190(22):669-676.
9. Flink M, Tessma M, Smastuen MC, Lindblad M, Coleman EA, Ekstedt M. Measuring care transitions in Sweden: validation of the care transitions measure. *Int J Qual Health Care*. 2018;30(4):291-297.
10. Chaboyer W. Intensive care and beyond: improving the transitional experiences for critically ill patients and their families. *Intensive Crit Care Nurs*. 2005;22(4):187-193.
11. Herbst LA, Desai S, Benscoter D, et al. Going back to the ward: transitioning care back to the ward team. *Transl Pediatr*. 2018;7(4):314-325.
12. Bohner K. Theory description. Critical reflection, and theory evaluation of the transitions theory of Meleis et al according to Chinn and Kramer (2011). *Adv Nurs Sci*. 2017;23(1):12-28.
13. Eun-OK I. Situation-specific theories from the middle-range transitions theory. *ANS Adv Nurs Sci*. 2014;37(1):19-31.
14. Meleis AI, Sawyer LM, Im E, Messias DKH, Schumacher K. Experiencing transitions: an emerging middle-range theory. *Advances Nurs Sci*. 2000;23(1):12-28.
15. Kralik D, Visentin K, van Loon A. Transition: a literature review. *J Adv Nurs*. 2006;55(3):320-329.
16. Svenningsen H, Langhorn L, Ågård AS, Dreyer P. Post-ICU symptoms, consequences, and follow-up: an integrative review. *Nurs Crit Care*. 2017;22(4):212-220.
17. Coyle MA. Transfer anxiety: preparing to leave intensive care. *Intensive Crit Care Nurs*. 2001;17:138-143.
18. Choi J, Lingler JH, Donahoe MP, et al. Home discharge following critical illness: a qualitative analysis of family caregiver experience. *Heart Lung J*. 2018;47:401-407.
19. Strahan EHE, Brown RJ. A qualitative study of the experiences of patients following transfer from intensive care. *Intensive Crit Care Nurs*. 2004;21:160-170.
20. Holloway I, Galvin K. *Qualitative Research in Nursing and Healthcare*. 4th ed. John Wiley & Sons; 2017.
21. Booth A, Hannes K, Harden A, Noyes J, Harris J, Tong A. COREQ (consolidated criteria for reporting qualitative studies). Guidel report health res: User's Man. [Internet]. 2014. Accessed October 13, 2020. doi:10.1002/9781118715598.ch21
22. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interview and focus groups. *Int J Qual Health Care*. 2007;19:349-357.
23. Nelderup M, Samuelson K. Experiences of partners of intensive care survivors and their need for support after intensive care. *Nurs Crit Care*. 2019;25:245-252.
24. Polit DF, Beck CT. *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. 10th ed. Saratoga Springs; 2017.
25. Morrow R, Rodriguez A, King N. Colaizzi's descriptive phenomenological method. *The Psychologist 'learning from the life world'*. 2015;8:643-644.
26. Creswell JW, Poth CN. *Qualitative Inquiry and Research Design: Choosing among Five Approaches*. 4th ed. SAGE publications; 2018.
27. Friese S. ATLAS.ti Workshop Booklet. Qualitative Research & Consulting. 2002 [Internet]. Accessed March 13, 2021. Available from: <https://atlasti.com>
28. World Medical Association. Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects [Internet]. Accessed October 29, 2020. Available from: <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>
29. Centrale Commissie Mensgebonden Onderzoek (CCMO). Uw onderzoek: WMO plichtig of niet [Internet]. Accessed March 13, 2021. Available from: <https://www.ccmo.nl/onderzoekers/wet-en-regelgeving-voor-medisch-wetenschappelijk-onderzoek/uw-onderzoek-wmo-pliktig-of-niet>
30. Mitchell ML, Courtney M, Coyer F. Understanding uncertainty and minimizing families' anxiety at the time of transfer from intensive care. *Nurs Health Sci*. 2013;5:207-217.
31. Cullinane JP, Plowright CI. Patients' and relatives' experiences of transfer from intensive care unit to wards. *Nurs Critical Care*. 2013;18(6):289-296.
32. Holden J, Harrison L, Johnson M. Families, nurses and intensive care patients: a review of the literature. *J Clin Nurs*. 2002 August;11:140-148.
33. Chaboyer W, Kendall E, Kendall M, Foster M. Transfer out of intensive care: a qualitative exploration of patient and family perceptions. *Aust Crit Care*. 2005;18(4):138-145.
34. Cypress BS. Transfer out of intensive care. An evidence-based literature review. *Dimens Crit Care Nurs*. 2013;32(5):244-261.
35. Al-Mutair SA, Plummer V, O'Brien A, Clerehan R. Family needs and involvement in the intensive care unit: a literature review. *J Clin Nurs*. 2012;22:1805-1817.
36. Yun SH, Oh GE, Yoo YS, Kim SS, Jang YS. Development and effects of a transition nursing program for patients and family caregivers at a neurological ICU in Korea. *Clin Nurs Res*. 2017;26(1):27-46.

How to cite this article: Meiring-Noordstra A, van der Meulen IC, Onrust M, Hafsteinsdóttir TB, Luttik ML. Relatives' experiences of the transition from intensive care to home for acutely admitted intensive care patients—A qualitative study. *Nurs Crit Care*. 2024;29(1):117-124. doi:10.1111/nicc.12918