

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

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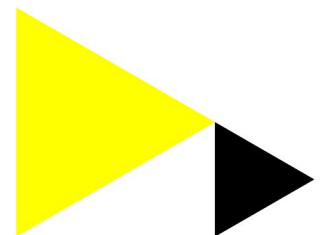
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Research paper

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



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ABSTRACT

Background: Relatives of intensive care unit (ICU) patients play an important role as caregivers and can experience emotional distress, also referred to as post-intensive care syndrome-family. A deeper understanding of what relatives go through and what they need may provide input on how to strengthen family-centred care and, in the end, contribute to the reduction of symptoms of post-intensive care syndrome-family.

Method: This is a qualitative descriptive study with semistructured face-to-face interviews after ICU transfers.

Findings: A total of 13 relatives of ICU patients participated. Relatives of ICU patients expressed five types of experiences after transfer from the ICU to the general ward: (1) relief, (2) uncertainty, (3) need to be acknowledged in becoming a caregiver, (4) sharing expectations, and (5) need for continuity in care. Relatives experience major uncertainties and prefer to be more actively involved in care and care decisions.

Conclusion: Relatives of ICU patients experience gaps in care during the transition from the ICU to a general ward. Nurses can play a crucial role in the need for continuity of care by proactively involving relatives during the care pathway of ICU patients.

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1. Introduction

Intensive care unit (ICU) survival rates are increasing, affecting the quality of life and daily functioning of patients after discharge from the hospital.¹ Research has shown that 50–70% of ICU survivors suffer from long-term physical, cognitive, and psychological impairments, the so-called post-intensive care syndrome (PICS).³ Not only patients but also their families suffer as they play an important caregiving role during the recovery after ICU discharge.² The burden of family caregivers of ICU patients has been described as PICS-Family (PICS-F), including complaints about anxiety, depression, sleep deprivation, and complicated grief.³

More than half of the relatives of ICU survivors become informal caregivers after patients are discharged and feel a heavy burden of care.^{4,5} This emphasises the importance of meeting family needs during ICU stay and after ICU discharge as this might reduce the impact of the ICU on family caregivers and complaints related to PICS-F.³

Based on a large inventory, evidence shows that relatives of ICU patients find that experienced empathy, information, and support are important items during ICU stay.⁸ However, research on the experiences and needs of relatives of ICU patients during the transition to the general ward is almost nonexistent. The few studies that do exist focus on patients and family and report mainly negative experiences without a broader insight into underlying needs.^{9,10} However, from the patient's perspective, transfers from the ICU to general wards may give experiences with highly emotional impact because the ICU often gives feelings of reassurance, security, and safety.¹⁰

Streator et al.¹¹ describe that interpersonal relationships, the level of care, and the amount of information that patients and relatives receive differs between the ICU and general wards. This contrast often results in feelings of anxiety and relocation stress.¹¹

Hence, in this article, we describe the findings of a qualitative study on the relatives' experiences and the relatives' need for support during the transfer from the ICU to the general ward. A deeper understanding of what relatives go through and what they really need may provide input on how to strengthen family-centred care and, in the long run, contribute to the reduction of symptoms of PICS-F.

2. Method

We conducted a qualitative study using a thematic analysis to describe themes of experiences and needs. The findings of this study are reported according to the criteria for reporting qualitative research (COREQ).¹² In this study, the term 'relatives' refers to family such as adult children, spouse, siblings, and close friends.

2.1. Setting and sampling

The study took place in a hospital setting, a level 1 trauma centre with 996 beds at Elisabeth Hospital in Tilburg, the Netherlands. This hospital has a 36-bed level 3 ICU. This is the highest level of ICU care according to Dutch standards. Level 3 indicates high-intensity care for the most severe illnesses and extremely complicated illnesses, with constant access to specialized nurses and intensivists.¹³

Data were collected between March and June 2018. During this study period, the researcher, a nurse practitioner at the hospital, using a convenience sample based on the availability and willingness to participate, screened participants. All eligible relatives were personally approached and interviewed by the researcher. Relatives of ICU patients were included if the ICU patient was admitted and stayed in the ICU for a minimum of five days, with an acute indication. The five-day minimum was considered important as this

duration of stay may provide relatives with sufficient experiences in a highly monitored ICU environment.

Relatives who had been registered in patient records as 'first person to contact' for the patient were selected as eligible. If more than one person was registered, the researcher selected the person who seemed most close to the patient. When more than one relative was eligible for participation, they were given the option to conduct an interview together. Other inclusion criteria were the ability to understand and speak Dutch and a minimum age of 18 years.

Relatives were excluded if the ICU patient received end-of-life care.

2.2. Data collection

Data were collected by means of semistructured face-to-face interviews of 30–60 min each. Based on previous studies, we used the following topics: experiences, emotions, worries, and experienced support.²² Each interview was conducted similarly with four main questions:

- 1 *How did you experience the transfer from the ICU to the general ward?*
- 2 *What does the transfer from ICU to the general ward mean to you?*
- 3 *Which emotions do you recall during this transfer?*
- 4 *How would you describe ideal care at this stage of care?*

The researcher invited the participants to tell their story and probed for more detail after each question. Data collection stopped when no new findings emerged from the data and a saturation point was reached. To ensure that the participants could recall their experiences and emotions, all interviews were conducted in the first week after transfer from the ICU to the ward. The interviews took place in a secluded room outside the ICU and wards. All interviews were audiotaped, transcribed verbatim for analysis, and processed anonymously.

2.3. Data analysis

We performed an inductive qualitative thematic analysis as described by Boeije,¹⁴ with the help of ATLAS.TI, version 8.1.2.¹⁵ First, open codes and labels were assigned. Second, we grouped the codes into categories using axial coding. Data were analysed in an iterative way by rereading and coding data and sorting these into categories. The first three transcripts were independently analysed by a second researcher, who compared the findings with those of the first researcher, and differences were discussed until consensus was reached. The categories were reduced to an abstract level of themes using a visual analysis scheme. To maintain integrity and trustworthiness, the researchers discussed until they reached a consensus on the themes and the analysis scheme. By the 11th interview, no new themes were identified, and data saturation was reached. To gain new insights, themes were compared with those found in similar studies.

2.4. Validity and credibility

To ensure validity and deeply understand the experiences of the relatives, the researcher tried to elicit deeper experiences to describe the contextual aspects from the perspective of the participants. The appropriate interpretation was established by using interview techniques and by repeatedly checking the interpretation of the interviewer with what the participant said. To ensure credibility, we selected relatives from differing backgrounds. We provided transparency and auditability by documenting and sharing comments by means of memos and notes.

2.5. Ethical considerations

For this study, the local ethics committee (Medical Research Ethics Committees of Noord- Brabant) granted medical ethical approval, and the local hospital research protocol was provided with the research number: L0441.2017. All participants were informed by a patient letter with information about the aim of the study, ethical considerations, and their right to withdraw from the study without giving any reason. Informed consent was obtained by asking potential participants to complete an informed consent form.

This study included personal experiences, and we were aware of the possible emotional and psychological consequences. All participants were informed about the opportunity to receive psychological support. To meet the requirements of the European General Data Protection Regulation, we used serial numbers to ensure that no personal data can be traced back to the persons involved. Only the researcher had access to the coded data.

3. Findings

In total, 23 participants were considered eligible during the inclusion period; of whom, 10 were excluded. Six participants were transferred to another hospital, two received end-of-life care, and two declined participation. The remaining 13 participants were approached for an interview, with 11 individual interviews and one joint interview with two relatives. The demographics of the relatives are shown in Table 1. The demographics of the ICU patients to whom the relatives were related are shown in Table 2. To categorise the severity of illness, we used the acute physiology and chronic health evaluation (APACHE) IV score, which is commonly used to assess the severity of illness and prognosis in the ICU with a cut-off value of the middle (>41) to high (>61) score.¹⁶

4. Experiences

We found five main experiences during the transfer from the ICU to a general ward as shown in Table 3.

4.1. Relief

For the relatives, the transition to the general ward evoked a positive feeling of relief as it was considered a positive step towards recovery. Experiences corresponded with the patient's physiological and mental condition. If improvement of the relatives' loved one was shown and communication was possible, their 'feelings of gratefulness' were predominant.

Then I heard she was allowed to go to the other ward and that was actually good news, I did not expect that (husband, 46 years).

Two relatives did not see any improvements because of various medical complications. Even then, the transfer to the general ward was experienced as positive, despite concurrent feelings of uncertainty. The medical decision for the transfer out of the ICU was considered positive and a step towards recovery.

The transfer to a general ward implied a new phase of sailing into calmer waters and letting go of their 'twenty-four seven alertness'.

That I just can sleep. For a long time, I had the feeling, if someone called, something is wrong, again, it's wrong again (brother, 41 years).

Table 1
Demographics of the study sample.

Variable (range)		(N = 13)
Sex	Male	6
	Female	7
Age in years (28–82)	<40 years	2
	41–65 years	7
	>65 years	4
Ethnic background	Native Dutch	11
	Migrant Dutch	2
	Spouse	4
Relationship with the patient	Parent	2
	Child	4
	Brother/sister	2
	Other family	1
	Lower degree	7
Level of education	Bachelor or higher	5
	No degree	1
Travel time to the hospital (15–120)	<30 min	3
	30–60 min	8
	>60 min	2

Table 2
Demographics of related ICU patients.

Variable (range)		(N = 11)
Sex	Male	4
	Female	7
Age in years (27–83)	<40 years	3
	41–65 years	2
	>65 years	6
Ethnic background	Native Dutch	9
	Migrant Dutch	2
Diagnosis	Pneumonia	2
	Sepsis	1
	Brain injury	7
	Other	1
ICU length of stay in days (5–41)	<10 days	6
	10–20 days	3
	>21 days	2
Mechanical ventilation in days (1–14)	<10	4
	>10	2
	No ventilation	5
Hospital length of stay in days (9–122)	<20 days	5
	20–50 days	4
	>50 days	2
APACHE score IV (26–113)	<40	2
	41–60	4
	>61	5
APACHE IV SMR mortality risk (6–50)	<30%	8
	≥30%	3
Medical specialty	Neurosurgical	4
	Neurology	3
	Pulmonology	2
	Medical	2

APACHE, acute physiology and chronic health evaluation; ICU, intensive care unit; SMR, standardised mortality ratio.

The feeling of more stability gave room to process what had happened and made it possible to resume at least some of their daily activities.

Yes, in the last weeks we all lived on adrenalin. Now we try to process and carry on. We hope and assume that the situation will continue to improve (son, 46 years).

Table 3
Main themes of relatives' experiences and needs (N = 13).

Experiences	Needs
1. Relief	3. Acknowledged in becoming a caregiver
2. Uncertainty	4. Sharing expectations
	5. Continuity of care

Support by the relatives' social network was considered crucial. They reported that if they had not had this support, they were sure they would not have been able to cope. In addition to relief, relatives expressed a strong sense of gratitude and appreciation towards the healthcare professionals.

4.2. Uncertainty

An explicit negative feeling after the transfer was uncertainty, caused by three main factors.

First, the transfer was often felt as rather unexpected. Relatives felt shocked and to some extent frightened. They asked themselves if the transfer was perhaps too soon or worried if the care at the general ward was of a less quality than the ICU care. Relatives with a longer travel time to the hospital received information about the transfer too late and felt a bit taken by surprise.

She is very weak, the step from ICU to the general ward, it was surprising, oh, it's such a big step. It's positive she has left the ICU, but, on the other side, I ask myself, is it safe (daughter, 56 years)?

Second, the general ward did not have medical monitoring as in the ICU. They missed this intensive care at the general ward because it had given them a feeling of safety. If the medical prognosis was not clear, worries about the health state of the patient were predominant.

That screen, her heart rate and her oxygen, things like that. We can no longer see these things. Are the signs good? We wonder, it is probably part of the transfer, but it creates more uncertainty (husband, 82 years).

When patients were first transferred to a medium care unit, relatives considered it a positive experience.

Third, differences between the ICU and a general ward caused uncertainty. Six relatives had never been in a hospital before and did not know what to expect at all.

4.2.1. Insufficient communication

The most difficult change was the communication by the general ward staff. All relatives experienced the communication by the ICU staff as better in the sense that they were more present and visible than the general ward staff. In the general ward, nurses have much less time. They were reluctant to ask for help as the nurses seemed to be 'busier' than the ICU nurses. They felt uncomfortable with requesting additional information or making an appeal to the nurses' limited time.

But obviously you will agree, I think, you will have to look for it yourself, [...] I found it difficult to ask for some extra time (daughter, 56 years).

Relatives experienced miscommunication or a lack of communication in the general ward. After transfer, one family was waiting at a different general ward after receiving wrong information.

If relatives were involved (passive or active) during the nurses' handover during the transfer, relatives felt supportive as it gave them a feeling of safe and professional care. If relatives were not present during the transfer, they worried whether they had missed important information such as information about medication and diet. Relatives wanted to be informed of the treatment and the care plan. Relatives explained the need to be involved with the treatment of their loved ones to prevent mistakes. The majority of the relatives had no communication plan with medical staff at the general ward concerning future treatment.

One moment we made a list with our questions and left this for the doctor, because we did not have all answers [...] communication was different in ICU (daughter, age 38 years).

As their loved one arrived on the general ward, relatives suddenly became aware of the patient's vulnerability. They realised that they still had a long way to go and wondered about the recovery progress.

Typical for this stage was that relatives' focus shifted from survival mode towards the future to the impact of what had happened to them.

You want your mother to be herself. And yes, we have questions, our major concern; What will become of her after recovery from this brain injury (son, 46 years)?

Relatives wondered about the impact of this life event on their social life and work and income:

At first, I thought, will she come out of this? In addition, at this moment I think, how do we manage at home? She was starting up her own business, what will be the impact of all this (husband, 46 years)?

In some cases, hospital discharge was mentioned by the medical team, which gave new worries such as the coordination of care at home. One relative, being a parent, worried because her son lived alone and worried about his social support and the fear of social isolation. If a role as a caregiver was expected, they wondered how they would manage in this new role. Two relatives worried about their own health and had little confidence in their ability to cope with the new situation.

Yes, it certainly has impacted us, because we are already wondering how to move on from here, they still live independently in a terraced house. Can they live their life the way they did? On the other hand, should we, look for a residential home (daughter, 56 years)?

4.3. Be acknowledged in becoming a caregiver

All relatives describe the ICU experience as life-changing. Despite the relatives' social support, they expressed a need to be better acknowledged as caregivers by the nursing and medical staff who focused mainly on the patient.

First, relatives needed more involvement in the treatment or care plan. All relatives were disappointed in the level of their involvement in the care by the staff. Relatives expected a new plan and explicitly mentioned that they missed this during the patient's stay at the general ward. Sometimes information was shared only with the patient, which created sometimes more confusion than clarity as the patient was in a delirious state. They felt neglected in some way.

Maybe nurses only have attention for the patients and not the family who is worried ... or maybe they don't really care (husband, 69 years)?

If only I could have a moment with a nurse, just to have a small conversation ... (daughter, 48 years).

Second, relatives preferred to be able to discuss their own role as they strongly wanted to contribute to the recovery of their loved one and did not know how to participate. According to their perception, it should be natural to have a role in organising and taking care of their loved one. After the patient's transfer to another institution or a nursing home, relatives felt it was not clear who was responsible for further recovery.

On the one hand, relatives felt responsible for the patient, but on the other hand, they did not feel that they were part of the recovery plan and felt that the decisions were not taken jointly or in consultation with them.

Yes, we want to have a conversation with someone, what is the follow-up? (...) someone who gives us guides and advice in how to continue from here (father, 66 years).

To participate in care, one relative referred to the government policy and social expectations that he should participate in care; although he felt that he was completely willing to do so, he was not supported by the nursing staff.

The government expects us to provide care and live independently, but we are not facilitated by the nursing staff. They have the knowledge, so I would say: do not let us walk in the dark, show us the way (brother, age 41 years).

Finally, relatives experienced a lack of guidance in the skills to cope with the new situation.

I have my social network and they try to help and reassure me, and I understand that attention has to go to the patient [...]. But the partner has a hard time as well (husband, age 56 years).

4.4. Sharing expectations

Relatives spoke about a certain unawareness about what is going to happen in the future, now that the acute phase has passed.

Unaware what was yet to come? If you are used to a certain quality, in the ICU, you see the specialists there, you see the professionalism, you see how they deal with family ... then you have expectations (brother, 41 years).

Despite the fact that they had little experience with hospital care, relatives had their own expectations. They felt the need to talk about their expectations and be informed of what they could expect in this phase, for instance, an introduction to the general ward and the new nursing and the medical staff. Five relatives explained they did not know what the future treatment plan was or who was responsible for this plan.

When we arrived in the ICU, we were told, we could ask the staff anything. But when we arrived in this ward, we did not know how care was organised. And we did not know what we could expect or could ask, it felt like I was more dependent of the staff (daughter, age 38 years).

4.5. Continuity of care

Each interview ended with the same question to invite the relative to speak out their ideals or wishes. Repeatedly, each relative preferred to receive more continuity of care.

And how can you deal with this? What else can you do about it and things like that ... where you should go with those questions (father, 66 years).

Relatives preferred someone who knew their situation from a professional point of view and followed up with them along their care pathway. They explained professionals should be focused on patients and their relatives.

A kind of contact person [...] who follows the whole process of my mother during her hospital stay (daughter, age 56 years).

One relative expressed this need for continuity of care by requesting a professional who would guide him/her through the whole process.

Getting guidance, or at least ... show us the way (brother, 41 years).

5. Discussion

The aim of this study was to get a deeper understanding of the experiences and needs of relatives of ICU patients during the patients' in-hospital transition from the ICU to a general ward. Relatives' experiences can be summarised into two main themes: relief and uncertainty. The needs are as follows: (1) the need to be acknowledged, (2) the need to align expectations, and (3) the need for a contact person. Clearly, the relevance for clinical practice is to understand the ambiguity between the positive and negative experiences during the transfer from the ICU to general wards and is in line with the studies of Cullinane and Plowright¹⁷ and Cypress.¹⁸ Relatives experienced the differences between the ICU and general wards as mainly negative and mentioned the lack of contact moments with healthcare providers in general wards. Several studies^{19,20,21} assume this contrast causes stress and lack of knowledge for the patients' relatives. Chaboyer et al.²² describe relatives' feelings of unimportance and being ignored by staff, and the findings seem to be in line with our findings of the needs to be acknowledged and involved.

The two major themes in needs, information and support, are confirmed in the literature as the greatest universal need of relatives of ICU patients, regardless of the educational level or culture background.²³

Compared with other studies, we found that anxiety of relatives appeared to be less prominent regarding the contrast between the ICU and general wards.^{24,25} Perhaps, the relatives who were included in our study were better at putting the new context into perspective, or they might have had a different coping style.

In our study, we made no distinction between relatives of ICU patients with trauma or general ICU patients, although this could have influenced the degree of uncertainty identified by the relatives. Mitchell et al.²⁶ described relatives experienced more personal distress of not knowing the prognosis according to ICU patients with trauma.

Chaboyer et al.²² described the feeling of being not important as a relative in a transition phase. Similarly, we found in our study the need for acknowledgement in becoming a caregiver. According to Chaboyer et al.,²² this might be caused by a higher patient-to-nurse ratio in the general ward. The reluctance of relatives to ask for help because they feel that nurses are 'too busy' is perhaps due to the same reason. Although Dutch studies report on this reluctance, we do not know whether it also applies in a situation of critical care.²⁷ In addition, in this study, relatives clearly voiced a need to participate more in care and mentioned the social expectations of the current society's citizens who have more personal responsibilities in health.^{28,29} A possible explanation might be the culturally determined expectations of the society. Relatives also explicitly needed more guidance and suggested a kind of liaison nurse for patients and relatives throughout all care transitions of the care path. This need for a contact person has not been reported in previous studies. In our study, we did not investigate which factors may influence this need. The need for guidance might be triggered by feelings of uncertainty and previously has particularly been reported by ICU patients with trauma.^{26,30} Several studies

found that transition anxiety scores of relatives of ICU patients decreased after implementing a liaison nurse service.^{10,31,32}

The patient- and family-centred care (PFCC) policy causes a culture shift in hospitals.³³ This study shows the needs for PFCC interventions and the need to practice this policy not only within the walls of the ICU but also through the whole hospital system. Family presence decreases family anxiety which might be an important factor in preventing symptoms of PICS-F.

Davidson³⁴ suggests in a recent editorial about PFCC that healthcare providers should proactively explore the relatives' needs and expectation. Nurses must be aware of the relatives' expectations and proactively ask relatives' needs. Finally, nurses and relatives both seek a contact person to secure continuity and communication lines. The instalment of liaison nurses should be seriously considered and needs further investigation. In Dutch critical care, these concepts are not part of standard care. In cardiology and oncology, case managers or advanced nurse roles are already implemented and show positive outcomes with reduced readmission rates, improved quality of life, and higher family satisfaction levels.^{35,36,37} We recommend more research in strategies for continuity of care during transitions after ICU discharge.

6. Limitations

There are some potential drawbacks associated with our study. First, the study population is limited to one trauma centre, and therefore, these results cannot be generalised to other ICU populations. We stopped data collection after saturation. We aimed heterogeneity in our population; however, a number of aspects remained underexposed such as culture and family composition with, for example, young children. Further research should give more insight into factors such as culture and family situations. In one case, a relative expressed his role as a mediator between healthcare providers and his own family. Cultural aspects might have influenced the experiences in this particular case. The majority of the interviewed relatives were highly educated, which could possibly give a blurred view on the need for guidance. To our knowledge, highly educated citizens are more willing to participate in research and would have fewer needs with regard to supervision than relatives who did not complete a higher degree.^{22,38} Similar to the studies of Cullinane and Plowright¹⁷ and Cypress,¹⁸ we deliberately collected data during hospitalisation to make sure the relatives could describe their experiences as they recalled. The timing of data collection was crucial because participants might have still been overwhelmed by emotions when contact in addition, soon.³⁹ In one case of no-show, the relative mentioned lack of time for attending the interview and might have been able to provide rich data in terms of needs because this relative experienced high burden in her role as a caregiver. Some were also initially positive in their statements, but after further questioning, their underlying, more negative experiences were shared, which can implicate signs of social desirability bias which can occur in face-to-face interviews.⁴⁰

7. Conclusion

Building on recent studies, the aim of this study was to understand the experiences of relatives in the transfer from an ICU to a general ward. Relatives of ICU patients still experience gaps in care. Relatives seek for continuity during the transfer from the ICU to a general ward. Nurses can play a crucial role in meeting needs in family-centred care by being proactive. Nurses should better facilitate continuity of care, especially during the various transitions and transfers ICU patients make.

Declaration of competing interest

There are no conflicts of interest to declare.

CRediT authorship contribution statement

Sabine Adriana Johanna Josepha op 't Hoog: Conceptualisation, Methodology, Funding acquisition, Formal analysis, Investigation, Writing - original draft, Writing - review & editing. **Maike Dautzenberg:** Conceptualisation, Methodology, Funding acquisition, Formal analysis, Supervision, Validation, Writing - original draft, Writing - review & editing. **Anne Maria Eskes:** Writing - original draft, Writing - review & editing. **Hester Vermeulen:** Writing - original draft, Writing - review & editing. **Lilian Christina Maria Vloet:** Conceptualisation, Methodology, Writing - original draft, Writing - review & editing.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.aucc.2020.01.004>.

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References

- [1] Brinkman S, Abu-Hanna A, de Jonge E, de Keizer NF. Prediction of long-term mortality in ICU patients: model validation and assessing the effect of using in-hospital versus long-term mortality on benchmarking. *Intensive Care Med* 2013;39(11):1925–31.
- [2] Beusekom I, Bakhshi-Raiez F, de Keizer NF, Dongelmans DA, van der Schaaf M. Reported burden on informal caregivers of ICU survivors: a literature review. *Crit Care* 2016;20(16). <http://doi:10.1186/s13054-016-1185-9>.
- [3] Needham DM, Davidson J, Cohen H, Hopkins RO, Weinert C, Wunsch H, et al. Improving long-term outcomes after discharge from intensive care unit: report from a stakeholder's conference. *Crit Care Med* 2012;40(2):502–9. <https://doi.org/10.1097/ccm.0b013e318232da75>.
- [4] Herridge MS. Fifty years of research in ARDS. Long-term follow-up after acute respiratory distress Syndrome. Insights for managing medical complexity after critical illness. *Am J Respir Crit Care Med* 2017;196(11):1380–4.
- [5] Ågård AS, Egerod I, Tønnesen E, Lomborg K. Struggling for independence: a grounded theory study on convalescence of ICU survivors 12 months post ICU discharge. *Intensive Crit Care Nurs* 2012;28(2):105–13. <https://doi.org/10.1016/j.iccn.2012.01.008>.
- [6] Mitchell M, Chaboyer W, Burmeister E, Foster M. Positive effects of a nursing intervention on family-centered care in adult critical care. *Am J Crit Care* 2009;18:543–52.
- [7] Uhrenfeldt L, Aagaard H, Hall EOC, Fegran L, Ludvigsen MS, Meyer G. A qualitative meta-synthesis of patients' experiences of intra and inter-hospital transition's. *JAN* 2013;69(8):1678–90.
- [8] Chaboyer W, James H, Kendall M. Transitional care after the intensive care. *Unit Crit Care Nurs* 2005;25(3):16–29.
- [9] Streater C, Colledge J, Sutherland J, Easton J, McNamara R, MacDonald R, et al. The relocation experiences of relatives leaving a neurosciences critical care unit: a phenomenological study. *Nurs Crit Care* 2001;6:163–70.
- [10] 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* 2014. <https://doi.org/10.1002/9781118715598.ch21>.
- [11] Dutch Association for Anesthesiology [Nederlandse Vereniging voor Anesthesiologie]. Guideline Organisation and work process in the adult ICU in The Netherlands. 2006.
- [12] Boeije H. Analysis in qualitative research. London: SAGE; 2010. p. 93–121.
- [13] ATLAS.ti Version 8.1.2. Apache License; January 2004., Version 2.0.
- [14] Dutch national intensive care evaluation [stichting nationale intensive care evaluatie] yearbook 2016. Amsterdam: Stichting NICE; 2017. p. 29.

- [17] Cullinane JP, Plowright C. Patients' and relatives' experiences of transfer from intensive care unit to wards. *Nurs Crit Care* 2013;18(6):289–96. <https://doi.org/10.1111/nicc.12047>.
- [18] Cypress BS. Transfer out of intensive care: an evidence-based literature review. *Dimens Crit Care Nurs* 2013;32(5):244–61. <https://doi.org/10.1097/dcc.0b013e3182a07646>.
- [19] Holden J, Harrison L, Johnson M. Families, nurses and intensive care patients: a review of the literature. *J Clin Nurs* 2002;11(2):140–8. <https://doi.org/10.1046/j.1365-2702.2002.00581.x>.
- [20] Leith BA. Transfer stress and medical intensive care patients and family members. *Dynamics* 2001;12(3):22–7.
- [21] Wetzig K, Mitchell M. The needs of families of ICU trauma patients: an integrative review. *Intensive Crit Care Nurs* 2017;41:63–70. <https://doi.org/10.1016/j.iccn.2017.02.006>.
- [22] 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):138–43. [https://doi.org/10.1016/s1036-7314\(05\)80026-8](https://doi.org/10.1016/s1036-7314(05)80026-8).
- [23] Al-Mutair AS, Plummer V, O'Brien A, Clerehan R. Family needs and involvement in the intensive care unit: a literature review. *J Clin Nurs* 2013;22(13–14):1805–17. <https://doi.org/10.1111/jocn.12065>.
- [24] McKinney AA, Melby V. Relocation stress in critical care: a review of the literature. *J Clin Nurs* 2002;11(2):149–57. <https://doi.org/10.1046/j.1365-2702.2002.00577.x>.
- [25] Coyle MA. Transfer anxiety: preparing to leave intensive care. *Intensive Crit Care Nurs* 2001;17(3):138–43. <https://doi.org/10.1054/iccn.2001.1561>.
- [26] Mitchell M, Dwan T, Takashima M, Beard K, Birgan S, Wetzig K, et al. The needs of families of trauma intensive care patients: a mixed methods study. *Intensive Crit Care Nurs* 2019;50:11–20. <https://doi.org/10.1016/j.iccn.2018.08.009>.
- [27] Linders L. De betekenis van nabijheid. Een onderzoek naar informele zorg in een volksbuurt. University of Tilburg; 2010. [https://pure.uvt.nl/portal/publications/de-betekenis-van-nabijheid\(ed50d521-a23f-4de3-b2f3-4615e6832a3e\).html](https://pure.uvt.nl/portal/publications/de-betekenis-van-nabijheid(ed50d521-a23f-4de3-b2f3-4615e6832a3e).html).
- [28] The Netherlands Institute for Social Research (SCP). Combinatiedruk neemt toe in participatiesamenleving. *Tijdschrift voor Arbeidsvraagstukken 'Arbeid en zorg in de participatiesamenleving* 2016;34(4). https://www.scp.nl/Nieuws/Combinatiedruk_neemt_toe_in_participatiesamenleving.
- [29] Borg C, Hallberg I. Life satisfaction among informal caregivers in comparison with non-caregivers. *Scand J Caring Sci* 2006;20(4):427–38.
- [30] Verhaeghe S, Defloor T, Van Zuuren F, Duijnste M, Grypdonck M. The needs and experiences of family members of adult patients in an intensive care unit: a review of the literature. *J Clin Nurs* 2005;14(4):501–9.
- [31] Yun SH, Oh EG, 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* 2015;26(1):27–46.
- [32] Son YJ. Development and effects of the collaborative transitional care program for continuity of care in patients transferred to general wards from ICUs. *J Kor Clin Nurs Res* 2009;15:143–55.
- [33] Gasparini R, Champagne M, Stephany A, Hudson J, Fuchs MA. Policy to practice: increased family presence and the impact on patient- and family-centered care adoption. *J Nurs Adm* 2015;45(1):28–34. <http://doi:10.1097/NNA.0000000000000152>.
- [34] Davidson JE. The future of family-centered care in intensive care. *Intensive Crit Care Nurs* 2019;50:3–4.
- [35] Ozcelik H, Fadiloglu C, Karabulut B, Uyar M. Examining the effect of Case management model on patient results in palliative care of cancer patients. *Eur J Oncol Nurs* 2012;16(1):19–20. <https://doi.org/10.1097/NCM.0000000000000359>.
- [36] McCants K, Reid K, Williams I, Miller D, Rubin R, Dutton S. The impact of case management on reducing readmission for patients diagnosed with heart failure and diabetes. *Prof Case Manag* 2019;24(4):177–93.
- [37] Umbrell CE. Trauma Case Management: a role for the advanced practice nurse. *J Trauma Nurs* 2006;13(2):70–3.
- [38] Bijttebier P, Delva D, Vanoost S, Bobbaers H, Lauwaers P. Reliability and validity of the critical care family needs inventory in a Dutch-speaking Belgian sample. *Heart Lung* 2000;29(4):278–86. <https://doi.org/10.1067/mhl.2000.107918>.
- [39] Melville A, Hincks D. Conducting sensitive interviews: a review of reflections. *Law and Method*. 2016. <http://doi/10.5553/REM/000015>.
- [40] Kaushal K. Social desirability bias in face to face interviews. *J Postgrad Med* 2014;60(4):415–6. <https://doi.org/10.4103/0022-3859.143989>.