# TRANSITIONS

## Improving patients’ and families’ journeys during ICU pathways with Nurse-led interventions

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Sabine op 't Hoog

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HAN_UNIVERSITY
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# Transitions

## Improving patients' and families' journeys during ICU pathways
## with
## Nurse-led interventions

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# PROLOGUE

*Just Imagine, being in Intensive Care Unit, who will be there at your side? Being admitted in ICU is explained as a life event; it will change your life irreversibly. The moment you are in the role of a patient or family member in a hospital, you are all of the sudden dependent. Human needs will take over, yearning to feel safe, to feel seen and heard by someone who will listen to your story. These moments are crucial for professionals to choose what role you fulfil. Are you aware of seeing the other to be one of the most inestimable values as a professional and as a human being?*

*I started to work as an ICU nurse in 2013, after a study for Intensive Care Nursing I was most interest in the 'human' sides of intensive care medicine. Personally, people's names and stories moved me, more than the technical parts of the job. I looked at our healthcare system from patient and families' perspective, because of their stories. Patients and families come and go, moving from ICU to a general ward. Sometimes after transferred to a new case, name and story, I had concerns and some doubts when I gave a handover to a colleague from another ward and crossed my fingers that I did not see them back in ICU. Right there, I was aware of my intrinsic motivation to strive for more continuity of care and to improve patients' and families' journeys during ICU pathways with Nurse-led interventions.*

*I started a master advanced nurse practice with the aim: more continuity of care for ICU patients and their relatives. For this pioneer role, I was inspired by an Australian Liaison Nurse ICU role who acts as a 'liaison' between ICU and nursing departments. This brought me to Melbourne and Brisbane in 2017 to explore the context of everyday work of these liaison nurses. I visited seven Australian hospitals and brought back a based practice concept.*

*My journey to make impact and improve care by innovation evoked the following motivation to take steps and substantiate them with research. What is the direction? How can we value the perspective of patients and families? What outcomes are valuable and what do we learn in the meantime from this journey? This led to this contribution to the continuity of care for ICU patients and their family in a broader perspective, quality improvements and how to learn from the journey of innovations.*

*We see, we hear and we care for people's stories and by doing that repeatedly, we are aware of the impact of life events such as an ICU admission for the patients and their family. I encourage my colleague professionals to cherish this perspective, it is the way to learn today and do better tomorrow.*

*- it will change everything -*

# 1

# General introduction

# GENERAL INTRODUCTION AND THESIS OUTLINE

To keep the healthcare system sustainable, one of the major social challenges is to transform health care systems into patient- and family-centered care organizations that rely on the self-reliance and adaptability of individuals and social systems (1). From the moment a patient needs intensive care, the balance of self-reliance is irrevocably changed. Patients and their family members are dependent on the care of professionals, and they hope to move step-by-step toward recovery. How this path to recovery evolves is often very different for everyone, but the overarching pattern is that each patient goes through several transitions.

The crucial need for sufficient Intensive Care medicine became more visible to all citizens and society due to COVID-19. Over time, Intensive Care medicine has faced a paradigm shift from a primary focus on saving lives through highly technical healthcare medicine to a focus on the quality of survivorship after critical illness. Due to advanced care and despite the growing and aging ICU population, almost 90% of ICU patients survive. However, recent Dutch studies showed that 58% of the ICU patients with an unplanned ICU admission suffer new physical, cognitive or psychological impairments after one year, the so-called Post Intensive Care Syndrome (PICS) (2, 3). In addition, family members of ICU patients can experience a range of symptoms, including sleep deprivation, anxiety, depression, complicated grief and symptoms of posttraumatic stress disorder (PTSD). These long-term effects are termed the PICS-Family (PICS-F); 25 to 50% of the family members of ICU survivors need long-term family care (4). Symptoms of PICS can arise at any stage during or after an ICU admission and is nowadays accepted that PICS and PICS-F can have long-term effects on the lives of patients and their families, particularly on their health-related quality of life (HRQOL). The numbers of PICS and PICS-F (2, 4), indicate that critical care is more than a single admission to the ICU but a pathway towards recovery and adaptation to long-term impairments, with multiple transitions along the way. Since PICS is caused by several factors, a multidisciplinary approach is recommended, but in practice, such an approach is hampered by several obstacles, such as a lack of organization, adequate resources, appropriate personnel, and high-quality evidence for effectiveness. In view of these obstacles, there is a strong need for prevention, early recognition and continuity of care during transitions in care. The COVID-19 pandemic placed PICS into a new perspective because ICU survival after a COVID-19 infection was shown to be related to an even higher risk of developing PICS (5). In addition, the COVID-19 pandemic has revealed that our healthcare system is still very fragmented and changing health systems seems complex.

To implement new evidence into practice was often conceived in linear terms. This straightforward thinking shifts into looking at healthcare as a Complex Adaptive Systems (CAS) (6). There is increasable evidence on the concept that bottom-up implementation strategy with attention and support for a complexity-informed approach is more successful than top-down initiatives (7). Any change process requires consideration of multiple variables influences and forces. The unpredictability of these multiple factors make them complex systems. This requires new methods and looking differently at how professionals may adapt change in clinical everyday practice (7, 8). The safety II theory stimulates non-linear methods to study the interactions that make up everyday work processes (9, 10). Professionals, policy makers and researchers should focus more on the work-as-done instead of what makes our processes extraordinary. Functional Resonance Analysis Method (FRAM) is a method to visualize the complexity of work-as-done and to study a complex system based on the interaction of variability between functions (10).

## AIM AND OUTLINE OF THIS THESIS

Health care professionals are dedicated to providing patients and families care and support that is appropriate to their needs which fits in their needs and situation; patient- and family-centered care. To make this possible, traditional implementation approaches need to be replaced by a focus on adapting existing systems with small changes that have the potential to have a large impact (7, 8, 11). To do justice to patients and their families, their needs must be clear before their care pathways can be organized within this complex system, including transitional care. This thesis firstly aims to inventorize patients' and their families' experiences and needs during transitions in the pathway of intensive care, and secondly to determine where processes and EBQI thinking can improve care with impact for ICU patients and their families in everyday clinical practice.

**The main research question of this thesis:**
What are the experiences of relatives of ICU patients during the patient's transition from the ICU to a general ward? How can transitional care be improved to create a better continuity of care after Intensive Care for ICU survivors and their relatives? The broader aim is to describe how bottom-up nurse-led evidence-based projects may improve continuity of care. We evaluate this by properly mapping the process in a safety II approach to give insight in the complexity of these processes.

In **part 1,** we describe the exploration of transitional care in the context of ICU patients' and their relatives' care pathways. **Part 2** describes nurse-led evidence-based quality projects to improve transitions for patients and families.

**Part 1: the transition for ICU patients and relatives**
**Chapter 1**. To gain a deeper understanding of the experiences and needs of relatives of ICU patients during the patient's transition from the ICU to a general ward, we first conducted a qualitative study **(Chapter 2).** As there are many different interventions

that aim to smoothen the transition from the ICU to wards and home, we systematically reviewed all the relevant literature and assessed the effectiveness of these interventions in the prevention of PICS and PICS-F in **Chapter 3**.

**Part 2: nurse-led evidence-based quality improvements to improve transitional care**
The second part of this thesis focuses on improving transitional care through nurse-led, evidence-based quality improvements that were initiated and designed by professionals, bottom-up.

First, we developed a nurse-led Critical Care Outreach Service (CCOS) and we evaluate this nurse-led intervention on the process and patient outcomes. **Chapter 4** describes

the CCOS as a case study of a complex intervention using the Functional Resonance Analysis Method (FRAM). To visualize the Work As Imagined (WAI) and the Work As Done (WAD), we described the process evaluation of a QI during two phases of the Deming cycle: design (Plan) and evaluation (Study). We explored how FRAM can help health care professionals learn from and reflect upon complex everyday clinical practices.

In **Chapter 5**, we describe a before-and-after study using interrupted time series to assess the effect of the nurse-led CCOS on ICU readmission rates, ICU LOS, and mortality rates.

Finally, **Chapter 6** presents the outcomes of an evidence-based quality improvement project designed and implemented during the first COVID-19 peak. The purpose of this QI project was to assist post-intensive care patients and their families in the transition from hospital to home by offering them structured telephone support.

**Chapter 7** describes the general discussion.

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# 2

# 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 semi structured 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.

# 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.[6] 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.[6],[7] 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.[8]

Streator et al.[9] 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.[9]

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.

# 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).[10] In this study, the term 'relatives' refers to family such as adult children, spouse, siblings, and close friends.

## 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.[11]

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.

## Data collection

Data were collected by means of semi structured face-to-face interviews of 30–60 min each. Based on previous studies, we used the following topics: experiences, emotions, worries, and experienced support.[20] 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.

### Data analysis

We performed an inductive qualitative thematic analysis as described by Boeije,[12] with the help of ATLAS.TI, version 8.1.2.[13] 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.

### 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.

### 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.

# 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.[14]

**Table 1.** Demographics of study sample.

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

**Table 2.** Demographics of related ICU patients.

| **Variable (range)** | | **(N = 11)** |
|---|---|---|
| Sex | M | 4 |
| | F | 7 |
| Age in years<br>(27-83) | < 40 years | 3 |
| | 41-65 years | 2 |
| | > 65 years | 6 |
| Etnic background | Native Dutch | 9 |
| | Migrant Dutch | 2 |

**Table 2.** CONTINUED.

| Variable (range) | | (N = 11) |
|---|---|---|
| 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 |

## Experiences

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

**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 |

## 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).*

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).*

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.

**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 as 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.

**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)?*

*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 goes the patient […]. But the partner has a hard time as well (husband, age 56 years).*

**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).*

**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).*

## 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 Plowright[15] and Cypress.[16]

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[17],[18],[19] assume this contrast causes stress and lack of knowledge for the patients' relatives. Chaboyer et al.[20] 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.[21]

Compared with other studies, we found that anxiety of relatives appeared to be less prominent regarding the contrast between the ICU and general wards.[22],[23] 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.[24] described relatives experienced more personal distress of not knowing the prognosis according to ICU patients with trauma.

Chaboyer et al.[20] 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.[20] 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.[25] 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.[26],[27] 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.[24],[28] Several studies found that transition anxiety scores of relatives of ICU patients decreased after implementing a liaison nurse service.[8],[29],[30]

The patient- and family-centred care (PFCC) policy causes a culture shift in hospitals.[31] 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.

Davidson[32] 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.[33],[34],[35] We recommend more research in strategies for continuity of care during transitions after ICU discharge.

**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.[20,36] Similar to the studies of Cullinane and Plowright[15] and Cypress.[16]

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.[37] 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.[38]

# 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.

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# 3

# The effects of intensive care unit-initiated transitional care interventions on elements of post-intensive care syndrome: A systematic review and meta-analysis

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# ABSTRACT

**Objective**

The aim of the study was to assess the effectiveness of intensive care unit (ICU) initiated transitional care interventions for patients and families on elements of post-intensive care syndrome (PICS) and/or PICS-family (PICS-F).

**Review method used**

This is a systematic review and meta-analysis

**Sources**

The authors searched in biomedical bibliographic databases including PubMed, Embase (OVID), CINAHL Plus (EBSCO), Web of Science, and the Cochrane Library and included studies written in English conducted up to October 8, 2020.

**Review methods**

We included (non) randomised controlled trials focussing on ICU-initiated transitional care interventions for patients and families. Two authors conducted selection, quality assessment, and data extraction and synthesis independently. Outcomes were described using the three elements of PICS, which were categorised into (i) physical impairments (pulmonary, neuromuscular, and physical function), (ii) cognitive impairments (executive function, memory, attention, visuo-spatial and mental processing speed), and (iii) psychological health (anxiety, depression, acute stress disorder, post-traumatic stress disorder, and depression).

**Results**

From the initially identified 5052 articles, five studies were included (i.e., two randomised controlled trials and three non-randomised controlled trials) with varied transitional care interventions. Quality among the studies differs from moderate to high risk of bias. Evidence from the studies shows no significant differences in favour of transitional care interventions on physical or psychological aspects of PICS-(F). One study with a nurse-led structured follow-up program showed a significant difference in physical function at 3 months.

**Conclusions**

Our review revealed that there is a paucity of research about the effectiveness of transitional care interventions for ICU patients with PICS. All, except one of the identified studies, failed show a significant effect on the elements of PICS. However, these results should be interpreted with caution owing to variety and scarcity of data.

**Prospero registration**

CRD42020136589 (available via https://www.crd.york.ac.uk/prospero/display_ record.php?ID¼CRD42020136589).

## BACKGROUND

There is growth in the number of patients surviving intensive care unit (ICU) admission, but they frequently face prolonged physical, cognitive, and psychosocial impairments, summarised as post-intensive care syndrome (PICS).[1] Notably, data before the coronavirus disease 2019 (COVID-19) pandemic already showed that 50% of ICU survivors experience new physical, mental, and/or cognitive problems. New research during the COVID-19 pandemic shows even more severe outcomes after ICU admission and endorses the need for patient- and family-centred strategies to help ICU survivors recover.[2] Not only ICU survivors suffer from PICS, but also up to 75% of the family members report psychological burden (so-called PICS-family [PICS-F]), such as anxiety, depression, or post-traumatic stress disorder (PTSD). PICS and PICS-F are a public health burden with socio-economic consequences.[3-5] PICS-(F) can manifest even years after an ICU event.

Delirium, duration of ventilation, gender, previous physical and mental health state, and negative ICU experiences are significant risk factors for PICS.[6-9] Most of these risk factors appeared also as important risk factors in a recently published large cohort study with 4700 patients. This study showed that pre-ICU physical, psychological, and/or cognitive health status are strongly associated with long-term problems of PICS. In more detail, male patients reported less frailty and fatigue than female patients, and patients with pre-existent anxiety had a higher chance of suffering from symptoms of depression and PTSD after ICU admission after 1 year.[9] Because of the wide range of variety in PICS problems, a strategy with an individually approach is preferred. To ensure continuity of care, guidelines advice coordination of patients' recovery pathway by healthcare professionals with appropriate competencies and frequently screening on elements of PICS during transitions of care settings across the continuum of critical illness and recovery.[8,10-12]

Transitions of care can be defined as 'a set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care within the same location". [13-15] Patients and their families experience complex transitions as complex, and need proper information and continuity of care during transitions in their recovery journey.[16-18] The first major transition during their journey is transfer from the ICU to the general ward and is accompanied by risks of physical deterioration and psychological complaints such as transfer anxiety.[14]

There is some knowledge about how to smoothen the journey to recovery. For example, preparation by informing patients and families, improving handovers, and investing in personalised care contributes to a safer and effective transfer.[19] Improving structured handovers and implementing ICU liaison nurses or transition programs seem promising interventions to improve continuity of care, reduce ICU readmission, and reduce the risks on the development of PICS and

PICS-F.[20,21] A systematic review is not available for ICU initiated interventions started within 1 month after ICU discharge and that liaise the transition between intramural and extramural healthcare organisations, defined as transmural care. Both ICU aftercare and follow-up services are varied worldwide and developed in order to help patients come to terms and understanding with their illness and if needed address goals.[22-24] Although these interventions can be beneficial to recovery, transition care interventions emphasise identification of patients' health goals and design and implementation of a streamlined individualised plan of care to strike for continuity of care across settings and between providers throughout episodes of acute illness.[25,26] Thus, to further build this knowledge on transitional care interventions for ICU patients and their families, systematically gained overall insight is needed into which ICU-initiated interventions are effective. Therefore, we performed a systematic review to answer the following research question: "Which ICU-initiated interventions designed to improve the transition of care from to wards and home are effective to prevent elements of PICS and/or PICS-F for ICU survivors and their families?

## METHOD

We conducted a systematic review based on the Cochrane Handbook for Systematic Reviews of Interventions.[27] This systematic review is reported according to the Preferred Reporting Items for Systematic Review and Meta-Analyses statement and registered with PROSPERO (CRD42020136589; available via https://www.crd.york.ac.uk/prospero/display_record.php?ID¼CRD42020136589).[28]

### Database and literature search strategy

We searched for studies in biomedical bibliographic databases including PubMed, Embase (OVID), CINAHL Plus (EBSCO), Web of Science, and the Cochrane Library with the help of a clinical librarian. We used the following search terms: Critical illness, Intensive Care Units, Critical Care Nursing, Trauma Care, Hospital Emergency Service, transitional care, transition care, continuity of patient care, rehabilitation, continuum of care, patient discharge, discharge planning, patient handoff, health care transition, patient dumping, patient-centered care, patient focus, person centered, family leave, family nursing, caregivers, adult.

We included studies written in English conducted up to October 8, 2020. In addition, reference lists from the included studies were screened to identify any other relevant articles. We searched the www.clinicaltrials.gov/ website for ongoing or unpublished trials (see Appendix 1 for the search strategy)

Studies were eligible if they (i) had an experimental design (i.e., [non]randomised controlled trials [RCTs], stepped-wedge studies, interrupted time series analysis, and before after studies), (ii) were published in English, (iii) included ICU patients and/or family members, and (iv) described at least one component of the transitional care model (TCM), initiated from the ICU for patients and/or family members.[26] In addition to this, eligible studies should report on at least one of the PICS-related physical, cognitive, or psychological outcomes.

Studies that described an intervention as ICU follow-up or aftercare, or an intervention for paediatric populations or patients who received end-of-life care who were admitted at the ICU were excluded. We used the definition of the United Kingdom (UK) National Institute for Health and Care Excellence (NICE) to define aftercare[[12]], as a golden standard on ICU aftercare and ICU follow-up care is lacking.[[24]] Aftercare according to the UK NICE criteria is scheduled 2 to 3 months after ICU discharge, whereas transitional care interventions should be initiated within 1 month after hospital discharge, and include PICS screening as per the recommendations of the Society of Critical Care Medicine (SCCM).[[11]]

### Screening and selection process

Two reviews authors (L.C.M.V. and S.A.J.J.H.) independently selected potentially relevant articles based on titles and abstracts of the articles identified by the search using a free web and mobile app (http://rayyan.qcri.org). Full-text versions were obtained when the eligibility criteria matched or if further scrutiny was needed with regard to eligibility. Disagreement about study eligibility was resolved through consensus discussion or resolved by an arbiter

(H.V.). All potentially relevant articles were retrieved in full-text and again independently screened by two team members (M.P.J.v.M. and S.A.J.J.H.) to check if the articles fulfilled the inclusion criteria. Disagreements were resolved through consensus, with a third person from the research team acting as an arbiter when agreement could not be reached (L.C.M.V.).

### Quality appraisal

Three review authors (A.M.E., M.P.J.v.M., and S.A.J.J.H.) independently assessed risk of bias for each study using the criteria outlined in the Cochrane Handbook for Systematic Reviews of Interventions.[[28]] Again, we resolved any disagreements by discussion, or by involving another author (L.C.M.V.).

The revised Cochrane risk-of-bias tool for randomised clinical trials, version 2, was used to assess the risk of bias of randomised clinical trials and included the following domains: random sequence generation, allocation concealment, baseline imbalances, blinding of participants and personnel, blinding of outcome assessment, incomplete outcome data, selective outcome reporting, and other sources of bias.[29]

For non randomised trials, Risk Of Bias In Non-randomized Studies of Interventions assessment tool 1 was used to assess the risk of bias.[30] Again, we resolved any disagreements by discussion or by involving another author (L.C.M.V.). We graded each potential risk of bias as high, low, or unclear. We summarised the risk of bias judgements across different studies for each of the domains listed.

### Data extraction

Three review authors (A.M.E., M.P.J.v.M., and S.A.J.J.H.) independently undertook manual data extraction of the included studies. Therefore, we used a structured Microsoft Excel spreadsheet data extraction form to collect the following characteristics of the included studies: design; research methodology; setting; intervention type, categorised into the nine components of the TCM; and professionals who fulfilled a role in the interventions (e.g., ICU nurses or rehabilitations practitioners).[26] The nine components of the TCM are (i) screening, (ii) staffing, (iii) maintaining relationships, (iv) engaging patients and caregivers, (v) assessing/ managing risks and symptoms, (vi) educating/promoting selfmanagement, (vii) collaborating, (viii) promoting continuity, and (ix) fostering coordination.[26]

In addition to this, we collected primary outcome data of elements of PICS, measured in quantified scales: (i) physical impairments on pulmonary, neuromuscular, and physical function; (ii) cognitive impairments on executive function, memory, attention, and visuospatial and mental processing speed; and (iii) psychological outcomes on anxiety, acute stress disorder, PTSD, and depression.[4]

There are more than 250 unique instruments to evaluate ICU outcomes.[31] We defined for each outcome relevant outcome measures, with a selection of the most used validated measurement instruments as summarised by the Society of Critical Care Medicine.[11] We considered the following secondary outcomes as relevant: ICU or hospital readmission rates (in days), number of readmissions (within 30 days), length of stay (LOS; in days), healthcare consumption such as direct and indirect costs, and patient and family satisfaction (by self-reported numerical rating scales). Any differences were discussed and resolved by a fourth reviewer if required (H.V.). In case of multiple time points at which the outcome was measured within a time frame (short-, middle-, long-term), the data of the last measurement were collected. Short-term follow-up was defined as 0 to 3 months, middle-term follow-up was defined as 3 to 6 months, and long-term follow-up was defined as 6 to 12 months.

### Data analysis and synthesis

We used the program Review Manager (version 5.4; The Cochrane Collaboration,

2020) to analyse the data. For each primary outcome measurement, mean differences with 95% confidence intervals were estimated using random-effects models. Owing to inaccuracy, reported medians and interquartile ranges were not converted into means and standard deviations. If more than one outcome measurement was assessed for a given intervention, we conducted a meta-analysis. When there was any unacceptable clinical or statistical heterogeneity (i.e., $I^2$ higher than 75%), we presented the results descriptively.[27]

# RESULTS

## Search results

The search strategy elicited 5052 articles after duplicates were removed. Thirty-nine full-text articles were reviewed by two review authors (M.P.J.v.M. and S.A.J.J.H.) to assess eligibility. For one article, no full text was available, and therefore, it was excluded. In total, five full-text articles fulfilled the inclusion criteria (see Fig. 1).

## Characteristics of the included studies

The included studies had different study designs: two studies were RCTs,[32,33] one was a block intervention study,[34] one had a pretest-post-test control group design,[35] and one was a non-RCT.[36] Walsh et al.[32] and Bench et al.[33] published their study protocol separately.[37,38] The studies were conducted in Australia[34,35] and Western Europe[32,33,36] (see Table 1). All studies included adult ICU patients. The minimal LOS in the ICU ranged from 10 h up to 72 h. Only one study described duration of mechanical ventilation as an inclusion criterion.[32] Four studies investigated transitional care interventions in which families participated.[32-35] The other study was patient focused.[36]

## Characteristics of the interventions under study

The transitional care interventions, ordered by the TCM, varied across the five studies.[26] An overview of the interventions can be found in Table 2. Two studies implemented an (personalised) information pack to prepare the transition from the ICU to a general ward provided by ICU nurses.[33,35] One study implemented ICU liaison nurses who communicated with ward staff, assessing ward staff skill mix and resources, preparing both the ICU and ward staff for patient transfer, and assessing bed status.[34] In one study, a rehabilitation assistant coordinated a highly individualised rehabilitation therapy plan in combination with a self-help ICU rehabilitation manual.[32] Another study provided a structured nurse-led follow-up until 3 months after ICU discharge, with (i) a booklet delivered at ICU discharge, (ii) ward visits from a ICU clinical nurse specialist, (iii) contact during the first week after discharge from the ward to home, and (iv) an appointment 3 months after discharge from the ICU.[36] All studies compared the interventions with care as usual.

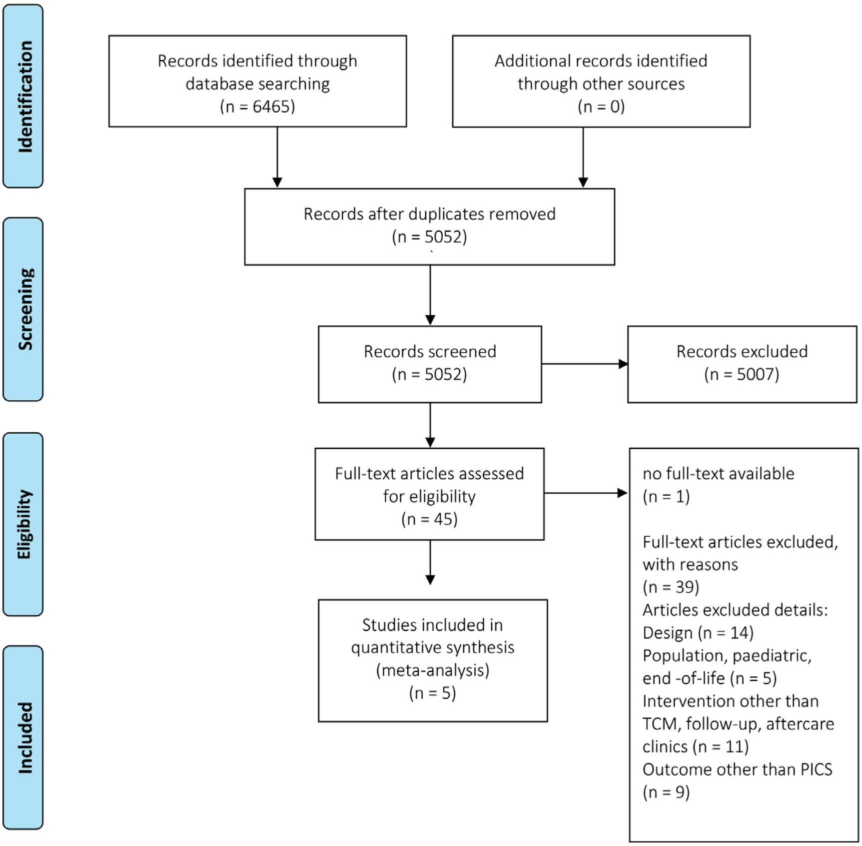


**Figure 1.** Flow diagram of the search, and screening and selection processes. PRISMA 2009 Flow Diagram[23]. TCM = transitional care model; PRISMA[23] = Preferred Reporting Items for Systematic Review and Meta-Analyses.

## Quality assessment

The overall risk of bias of both the RCTs was high[32,33], and the overall risk of bias of the non randomised studies varied between moderate and serious (see Table 3 and more detailed judgement in Appendies 2 and 3).[34-36] In both RCTs, the randomisation process and report of the outcomes were adequate (see Appendix 2, Tables 1a-1f).[32,33] In addition to this, both RCTs did not describe possible deviations from the intended interventions explicitly. Two of three non randomised experimental studies scored an overall moderate risk of bias but scored a low risk of bias on most of the domains.[34,35] Only one non randomised study scored an overall serious risk of bias.[36] All three non-RCTs may have potential confounding of the effect of the intervention because of the nature of the interventions and the lack of baseline measurements (Appendix 3, Tables 1a-1i).[30,34-36]

### Heterogeneity

Owing to heterogeneity of the studies with regard to outcome assessment, pooling was not possible on the primary outcomes (i.e., $I^2$ higher than 75%).[27] We were only able to pool data on readmissions, which was one of the secondary outcomes. All other results are reported from single studies.

### Results of the study: primary outcomes

The primary outcome data are presented in Table 4.

### Physical function and general health

Two studies[32,36] measured only physical function of the elements of PICS using the SF-36-V2[32] and 12-item Short-Form Health Survey (SF-12) Physical Component Summary (PCS) instruments on different time points (short-, middle-, and long-term).[39,40] Jonasdotitir et al.[36] only found a significant difference in physical function at 3 months after ICU discharge in favour of the structured nurse-led follow-up (MD = 10.00; 95% confidence interval [CI] = 0.48 to 19.52), but there were baseline imbalances between the study groups, and no differences were found at all other time points.[36] The overall SF-36 health score (General Health) did not show significant differences at 3 months (Mean Difference =-1.70; 95% CI =-8.10 to 4.70), 6 months (MD =-0.80; 95% CI =-7.85 to 6.25), and 12 months (MD =-0.50; 95% CI =-9.19 to 8.19).[36] In addition, Walsh et al.[32] reported no significant difference in the SF-12 PCS score, with an individualised rehabilitation therapy plan in combination with a self-help ICU rehabilitation manual compared with usual care at all time points.

**Table 1.** Characteristics of the included studies.

| First author (year) | Country | Study design | Setting | Clusters/ participants | Participants at baseline (n) | Participants at follow-up (n; %) |
|---|---|---|---|---|---|---|
| Walsh et al. (2015)[32] | Scotland | Two-center RCT | Acute care hospitals with a combined medical and surgical department (excluding cardiac surgery and pediatric critical | *Clusters:* A single general critical care unit in each hospital<br>*Patients:* Adult patients (>18 years) who received a least 48h of continuous ventilation (via an endotracheal and/or tracheostomy tube) in the ICU and if they were considered to be fit for discharge. | Intervention: 120 (56%)<br>Control: 120 (58%) | Intervention<br>At 3 months: 118/120 (98%)<br>At 6 months: 99/120 (83%)<br>At 12 months: 94/120 (78%)<br>At 3 months: 110/120 (92%)<br>At 6 months: 90/120 (75%)<br>At 12 months: 91/120 (76%) |
| Bench et al (2015)[33] | England | single-center pilot cluster RCT | Teaching hospital with a combined medical and surgical ICU department | *Clusters*: two ICUs within one hospital providing care for mixed medical, surgical and trauma patients requiring level 2 (high dependency) or level 3 (intensive) care. Both units functioned as one department, staff rotated between units and patients were allocated based on availability of a bed.<br>*Patients:* Adult patients (>18 years) who spent at least 72h in the ICU and who were declared medically fit for discharge to a general ward and a normative relative. | *Intervention UCCDIP:* 51 (in 36 clusters) (52% M)<br>*Intervention ICUsteps:* 48 (in 31 clusters) (51% M)<br>*Control Ad-hoc verbal info:* 59 (in 33 clusters) (53% M) | Intervention UCCDIP at hospital discharge or 28 days: 45 (88%)<br>Intervention ICUsteps at hospital discharge or 28 days: 36 (75%)<br>Control Ad-hoc verbal info at hospital discharge or 28 days: 48 (81%) |
| Chaboyer et al. (2007)[34] | Australia | single-center repeated before and after design study | Tertiary hospital with a combined medical and surgical ICU department | *Block design:* Four blocks were conducted on the one ICU, with each block lasting for 4 months duration. The first two blocks consisted of a control and intervention period, which were followed by a 1-month wash-out period.<br>*Patients:* Adult patients (>18 years) who spent a least 72h in the ICU and if they were able to provide consent and their family member | *Intervention*<br>*Patients:* 53 (59% M)<br>*Family members:* 48<br>*Control*<br>*Patients:* 62 (58% M)<br>*Family members:* 52 | Intervention at the point of physical preparation for the transfer from ICU to ward: 48 (91%)<br>Control at the point of physical preparation for the transfer from ICU to ward: 52 (84%) |

**Table 1.** CONTINUED.

| First author (year) | Country | Study design | Setting | Clusters/ participants | Participants at baseline (n) | Participants at follow-up (n; %) |
|---|---|---|---|---|---|---|
| Mitchell et al. (2004)[35] | Australia | before and after design study | Tertiary referral hospital with a combined medical and surgical ICU department | *Cluster:* One ICU<br>*Patients:* Adult patients (>18 years) who spent a least 10h in the ICU and if they were able to provide consent | In total 177 of which 162 completed the questionnaires<br>*Intervention:* 82 (68% M)<br>*Control:* 80 (74%) | In total: 162/177 (92%) – no details per group given. |
| Jónasdóttir et al. (2017)[36] | United Kingdom | single-center quasi-experimental study | Tertiary hospital with a combined medical and surgical ICU department | *Clusters:* Two ICUs located in two separate buildings (buildings I & II)<br>*Patients*: Adult patients (>18 years) who spent a least 72h in the ICU and if they were able to provide consent | *Intervention*<br>83<br>(data reported at baseline 73 (60% M)<br>*Control:*<br>85<br>(data reported at baseline 75 (64% M) | Intervention<br>At discharge: 73/83 (88%)<br>At 3 months: 68/83 (82%)<br>At 6 months: 62/83 (75%)<br>At 12 months: 56/83=67%<br>Control<br>At discharge: 75/85 (88%)<br>At 3 months: 75/85 (88%)<br>At 6 months: 69/85 (81%)<br>At 12 months: 63/85=74% |

ICU = intensive care unit; M = male; N = number; RCT = randomised controlled trial; UCCDIP = User-Centred Critical Care Discharge Information Pack.

**Table 2.** Description of interventions, comparisons, and outcomes.

| First author(year) | Intervention | | Comparison | Outcomes | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Components of Transitional Care Model | | Patients physical outcomes | Patients ‘cognitive outcomes | Patients ‘psychological outcomes | Patients ‘quality of life | Patient satisfaction | Readmission | Length of stay | Healthcare consumption | Costs |
| Walsh et al. (2015)[32] | Hospital-Based Physical Rehabilitation and Information Provision delivered during the post–intensive care unit hospital stay by rehabilitation assistants plus a self-help ICU rehabilitation manual.<br>Key differences with usual care were greater coordination, intensity, and frequency of individual rehabilitation therapies. | Staffing, maintaining relationships, engaging patient and caregivers, educating promoting self-management | Usual care, rehabilitation by ward-based multidisciplinary teams plus a self-help ICU rehabilitation manual as recommended in UK guidelines. | √ | | √ | √ | √ | √ | √ | | √ |
| Bench et al (2015)[33] | (1) UCCDIP: user-centred critical care discharge information pack existing out of two booklets (one for patient and one for family) without opportunities to reflect/ report on experiences or feelings.<br>(2) ICU steps: information booklet that covered the whole trajectory of critical illness from ICU admission to after hospital discharge, without opportunities to reflect/ report on experiences or feelings | Educating, promoting self-managing | Usual care, containing out of ‘ad hoc’ verbal ICU discharge information provided by a variety of healthcare professionals. | | √ | √ | | | | √ | | |
| Chaboyer et al. (2007)[34] | ICU liaison nurse intervention: Primarily focus on the coordination of ICU patient transfer and liaison with ward staff. Tasks included communicating with ward staff, assessing ward staff skill-mix and resources, preparing both the ICU and ward staff for patient transfer and assessing bed status. | staffing, maintaining relationships, engaging patient and caregivers, educating, promoting self-management.<br>Coordinating | Usual care | | | √ | | | √ | √ | | |

**Table 2.** CONTINUED.

| First author(year) | Intervention | | Comparison | Outcomes | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Components of Transitional Care Model | | Patients physical outcomes | Patients 'cognitive outcomes | Patients 'psychological outcomes | Patients 'quality of life | Patient satisfaction | Readmission | Length of stay | Healthcare consumption | Costs |
| Mitchell et al. (2004)[35] | Written brochure individualised by the bed-side nurse to prepare families for patient transfer from ICU | Engaging patients and caregivers. Promoting continuity. educating / Promoting self-management. | Usual care | | | √ | | | | √ | | |
| Jónasdóttir et al. (2017)[36] | Structured nurse-led follow-up, existing out of four components for patients from ICU discharge to 3 months thereafter: (1) a booklet delivered at ICU discharge; (2) ward visits; (3) contact during the first week after discharge from the ward to home and (4) an appointment 3 months after discharge from the ICU. | Promoting continuity, educating / promoting self-management. collaborating, Assessing managing risks and symptoms | Usual care, patients and/or relatives received a booklet with printed, standardized information about the discharge from the ICU and  ward stay. If they needed continuing surveillance, they got ward visits from (ICU) clinical nurse specialists. After discharge from the general ward they received no further ICU follow-up. | √ | | | | | √ | √ | | |

ICU = intensive care unit; UCCDIP = User-Centred Critical Care Discharge Information Pack.

**Table 3.** Quality assessment per domain.

| First author (year) | Quality Assessment | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Quality assessment – Summary of Risk of bias (Revised Cochrane risk-of-bias tool for randomized trials (RoB 2)[29] | | | | | | | | |
| | Risk of bias arising from the randomization process | | Risk of bias due to deviations from the intended interventions (effect of assignment to intervention) | | Risk of bias due to deviations from the intended interventions (effect of adhering to intervention) | Risk of bias in measurement of the outcome | Risk of bias in selection of the reported result | Overall risk of bias |
| Walsh et al. (2015)[32] | Low | | Some concerns | | Some concerns | High | Low | High |
| Bench et al. (2015)[33] | Low | | Some concerns | | High | High | Low | High |
| Quality assessment – Summary of Risk of bias (the Risk Of Bias In Non-randomized Studies- of Interventions (ROBINS-I) assessment tool[30] | | | | | | | | |
| | Bias due to confounding | Bias in selection of participants into the study | Bias in classification of interventions | Bias due to deviations from intended interventions | Bias due to missing data | Bias in measurement of outcomes | Bias in selection of the reported result | Overall bias |
| Chaboyer et al. (2007)[34] | Moderate | Low | Low | Low | Low | Moderate | Low | Moderate |
| Mitchell et al. (2004)[35] | Serious | Low | Low | Low | Low | Moderate | Moderate | Serious |
| Jónasdóttir et al. (2017)[36] | No Information | Low | Low | Low | Low | Moderate | Moderate | Moderate |

### *Psychological outcomes*

Psychological outcomes (i.e., anxiety and/or depression) of patients were reported in all five studies.[33-35] Only two studies reported also anxiety rates of family members.[34,35]

### *Anxiety*

Four studies measured patients' anxiety; two studies[32,33] used the Hospital Anxiety and Depression Scale[41] and two studies[34,35] used the State-Trait Anxiety Inventory.[42] None of the studies reported significant differences in favour of the transitional care intervention compared with the control on short-term follow-up.[33-36] Only Walsh et al.[32] reported anxiety rates after 6 (mid-term) and 12 months (long-term) after ICU discharge, but again, no significant differences were found between the individualized rehabilitation therapy plan in combination with a self-help ICU rehabilitation manual compared with usual care. The study of Bench et al.[33] found no significant difference in anxiety scores using a User-Centred Critical Care Discharge Information Pack compared with a booklet published by ICU-steps and verbal ad hoc information. Chaboyer et al.[34] did not demonstrate a statistically significant beneficial effect from the liaison nurses in terms of anxiety scores between groups for either patients or family members. Mitchell and Courtney[35] showed no significant difference in favour of the intervention (MD = -3.70; 95% CI = -7.91 to 0.51), which consisted of an individualised brochure by the bedside nurse to prepare families for imminent patient transfer from the ICU.

### *Depression*

Two studies measured depressive symptoms using the Hospital Anxiety and Depression Scale41 and reported no significant differences on short-term outcomes (MD = 0.5; 95% CI =-0.7 to 1.6).[32,33] Walsh et al.[32] also reported no differences on mid-term (MD =-0.12; 95% CI =-0.6 to 0.4) and long-term outcomes (MD =-0.13; 95% CI =-1.6 to 1.3).

### *Symptoms of PTSD*

Only Walsh et al.[32] reported symptoms of PTSD using a 17-item self-report measure, the Davidson Trauma Scale.[43] An individualised rehabilitation process coordinated by a dedicated rehabilitation practitioner did not show a significant effect on short-term (MD = 0.5; 95% CI =-0.7 to 1.6), mid-term (MD = 5.0; 95% CI =-3 to 15.0), or long-term outcomes (MD = 0.0; 95% CI = 8.0 to 10.0).[32]

### *Results of the study: secondary outcomes*

Data of secondary outcomes are presented in Table 5. All studies reported several secondary outcome measurements of this review, i.e., health-related quality of life (HRQOL)[32], patient satisfaction,[32] ICU readmission rates[32,34,36], ICU LOS[32-36], hospital LOS[32-34,36] and healthcare costs.[32]

### *Health-related quality of life*

Walsh et al.[32] measured HRQOL by using the Mental Component Summary scores of the 12-item Short Form Health Survey.[39] HRQOL scores were unchanged in both groups over time by the intervention (PCS: MD = 0.1; 95% CI =-3.3 to 3.1; Mental Component Summary: MD = 0.2; 95% CI =-3.4 to 3.8).[32]

### *Patient satisfaction*

Walsh et al.[32] used a non validated satisfaction questionnaire (including nine different domains) that was developed for patients who are discharged from the ICU. Patients who received the transitional care interventions scored significantly higher on six of the nine domains of the satisfaction questionnaire.

### *ICU readmissions*

Three studies reported the number of ICU readmission rates during the same hospital stay.[32,34,36] A significant reduction in the number of readmission rates was found in favour of a transitional care intervention (pooled risk ratio = 0.22, 95% CI = 0.07 to 0.70, $I^2$ ¼= 0%; see Fig. 2).

### *ICU- and hospital length of stay*

All studies described the ICU LOS in days, and four studies described total hospital LOS.[32-34,36] For both outcomes, no significant differences in favour of the transitional care intervention were found.

### *Healthcare costs*

Walsh et al.[32] reported the mean cumulative costs for the intervention group and control group. The intervention group showed a cost of £ 48.953, and the control group showed a cost of £ 49,057. They found no difference in mean quality-adjusted life years[44] be tween the intervention (mean = 0.54; standard deviation = 0.20) and usual care (mean = 0.54; standard deviation = 0.18) groups (mean difference: 0.00; 95% CI =-0.04 to 0.04)

**Table 4.** Primary outcomes.

| Physical Function | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Follow up | Measurement | Study | Timepoint | Intervention | | | | Comparison | | | | Results | |
| | | | | Mean | SD | Median (IQR) | N | Mean | SD | Median (IQR) | N | MD | Signifcance |
| Short term, 0- 3 months | SF-36-V2 Physical function | Jónasdóttir (2017)[36] | At ICU ward discharge | 27.2 | 26.2 | NR | 71 | 26.2 | 20 | NR | 74 | 1.00 [-6.61- 8.61] | NS |
| | SF-36-V2 Physical function | Jónasdóttir (2017)[36] | 3 months after ICU discharge | 54.4 | 31.5 | NR | 68 | 44.5 | 26 | NR | 75 | 10.00 [0.48, 19.52] | S |
| | SF-36-V2 General Health | Jónasdóttir (2017)[36] | At ICU ward discharge | 65.8 | 20.9 | NR | 70 | 67.5 | 18.1 | NR | 74 | -1.70 [-8.10, 4.70] | NS |
| | SF-36-V2 General Health | Jónasdóttir (2017)[36] | 3 months after ICU discharge | 60.5 | 21.4 | NR | 68 | 58.9 | 19.8 | NR | 75 | 1.60 [-5.18, 8.38] | NS |
| | SF-12 PCS | Walsh (2015)[32] | 3 months after ICU discharge | NR | NR | 34 (26-44) | 101 | NR | NR | 35(26-44) | 96 | −0.1 [−3.3- 3.1] | NS |
| Middle term, 3- 6 months | SF-36-V2 Physical function | Jónasdóttir (2017)[36] | 6 months after ICUdischarge | 55.7 | 30.9 | NR | 62 | 56.3 | 25 | NR | 68 | -0.60 [-10.32, 9.12] | NS |
| | SF-36-V2 General Health | Jónasdóttir (2017)[36] | 6 months after ICUdischarge | 55.7 | 21.7 | NR | 62 | 56.5 | 19.2 | NR | 69 | -0.80 [-7.85, 6.25] | NS |
| | SF-12 PCS | Walsh (2015)[32] | 6 months after ICU discharge | NR | NR | 38 (26-47) | 84 | NR | NR | 33 (25 -45) | 80 | -2.4 [-6.0- 1.2] | NS |
| Long term, 6- 12 months | SF-36-V2 Physical function | Jónasdóttir (2017)[36] | 12 months after ICUdischarge | 58.5 | 28.6 | NR | 56 | 56.1 | 27.5 | NR | 63 | 2.40 [-7.7]1, 12.51] | NS |
| | SF-36-V2 General Health | Jónasdóttir (2017)[36] | 12 months after ICUdischarge | 54.8 | 25.5 | NR | 56 | 55.3 | 22.5 | NR | 63 | -0.50 [-9.19, 8.19] | NS |
| | SF-12 PCS | Walsh (2015)[32] | 12 months after ICUdischarge | NR | NR | 36 (28-51) | 79 | NR | NR | 37 (27-46) | 76 | -2.0 [-5.9- 1.9] | NS |

ICU = intensive care unit; UCCDIP = User-Centred Critical Care Discharge Information Pack; HADS = Hospital Anxiety and Depression Scale; PTSD = post-traumatic stress disorder; DTS = Davidson Trauma Scale; STAI = State Trait Anxiety Inventory; PCS = Physical Component Summary;
SD = standard deviation; IQR = interquartile range.

[a] Intervention 1: UCCDIP; intervention 2: ICU steps.

[b] STAI measured on family members.

**Table 4.** CONTINUED.

| Psychological outcome | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Follow up | Measurement | Study | Timepoint | Intervention 1* | | | | Intervention 2* | | | | Comparison | | | | Results | |
| | | | | Mean | SD | Median (IQR) | N | Mean | SD | Median (IQR) | N | Mean | SD | Median (IQR) | N | MD | Significance |
| Short term 0- 3 months | Anxiety | | | | | | | | | | | | | | | | |
| | HADS anxiety | Bench (2015)[33] | on ward, 5 days post ICU discharge | NR | NR | 7 (17) | 31 | NR | NR | 7.5 (19) | 28 | NR | NR | 6 (19) | 42 | | NS |
| | HADS anxiety | Bench (2015)[33] | at hospital discharge or 28 days | NR | NR | 7 (18) | 17 | NR | NR | 6 (13) | 8 | NR | NR | 5 (16) | 13 | | NS |
| | HADS anxiety | Walsh (2015)[32] | 3 months after ICUdischarge | NR | NR | 7 (3-11) | 98 | . | . | . | . | NR | NR | 6 (3-10) | 87 | 0.2 [1.6- 1.4] | NS |
| | STAI anxiety | Chaboyer (2007)[34] | Prior to transfer ICU to ward | NR | NR | 37(18.5) | 53 | . | . | . | . | NR | NR | 40 (21.6) | 62 | | NS |
| | STAI anxiety Family | Chaboyer (2007)[34] | Prior to transfer ICU to ward** | NR | NR | 39 (16.7) | 48 | . | . | . | . | NR | NR | 40.7 (26.8) | 52 | | NS |
| | STAI anxiety Family | Mitchell (2004)[35] | Prior to transfer ICU to ward** | 37.11 | 13.45 | NR | 82 | . | . | . | . | 41.24 | 13.21 | NR | 80 | -4.13 [-8.24, -0.02] | Sign. |
| | STAI anxiety Family | Mitchell (2004)[35] | 24h after transfer ICU to ward** | 37.72 | 13.92 | NR | 82 | . | . | . | . | 41.42 | 13.42 | NR | 80 | -3.70 [-7.91, 0.51] | Sign. |

**Table 4.** CONTINUED

| Psychological outcome | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Follow up | Measurement | Study | Timepoint | Intervention 1* | | | | Intervention 2* | | | | Comparison | | | | Results | |
| | | | | Mean | SD | Median (IQR) | N | Mean | SD | Median (IQR) | N | Mean | SD | Median (IQR) | N | MD | Significance |
| Short term 0- 3 months | Depression | | | | | | | | | | | | | | | | |
| | HADS depression | Bench (2015)[33] | on ward, 5 days post ICU discharge | NR | NR | 6 (16) | 30 | NR | NR | 6.5 (18) | 28 | NR | NR | 7 (21) | 40 | | NS |
| | HADS depression | Bench (2015)[33] | At hospital discharge or 28 days | NR | NR | 6 (12) | 17 | NR | NR | 4.5 (16) | 8 | NR | NR | 7 (15) | 13 | | NS |
| | HADS depression | Walsh (2015)[32] | 3 months after ICU Discharge | NR | NR | 7 (4-9) | 98 | . | . | . | . | NR | NR | 7 (3-10) | 87 | 0.5 [−0.7 to 1.6] | NS |
| | HADS total | Bench (2015)[33] | on ward, 5 days post ICU discharge | NR | NR | 12.5 (32) | 30 | NR | NR | 16 (35) | 28 | NR | NR | 14 (39) | 40 | | NS |
| | HADS total | Bench (2015)[33] | at hospital discharge or 28 days | NR | NR | 11 (27) | 17 | NR | NR | 10 (23) | 8 | NR | NR | 12 (23) | 13 | | NS |
| | DTS | Walsh (2015)[32] | 3 months after ICU discharge | NR | NR | 11 (0-31) | 82 | . | . | . | . | NR | NR | 10 (2-22) | 78 | 0.5 [-0.7- 1.6] | NS |

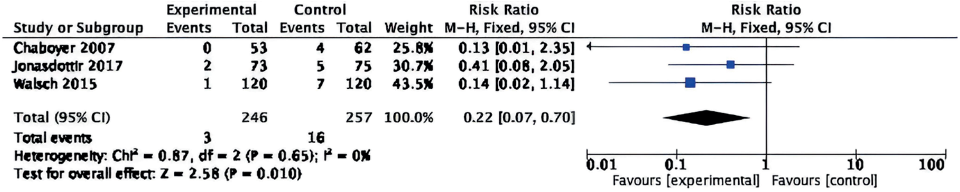
Legend
*Bench Intervention 1: UCCDIP, intervention 2: ICU STEPS
** STAI measured on family members

**Table 5.** Secondary outcomes.

| Measure-ment | Study | Time point | Intervention 1 | | | | Intervention 2 | | | | Comparison | | | | Results | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | Mean | SD | Median (IQR) | N | Mean | SD | Median (IQR) | N | Mean | SD | Median (IQR) | N | MD | Significance P Value |
| ICU LOS | | | | | | | | | | | | | | | | |
| ICU LOS | Bench (2015)[33] | in days | | | 7 (104) | 51 | | | 6 (62) | 48 | | | 6 (371) | 59 | | 0.24 |
| ICU LOS | Chaboyer (2007)[34] | in days | | | 6 | 53 | | | | | | | 6 | 62 | | 0.09 |
| ICU LOS | Jónasdóttir (2017)[36] | in days | 15 | 12 | . | 73 | . | . | . | . | 28 | 25 | . | 75 | -3.00 [-6.09, 0.09] | 0.39 |
| ICU LOS | Mitchell (2004)[35] | in days | 0.96 | 0 | . | 82 | . | . | . | . | 0.97 | 0 | . | 80 | | |
| ICU LOS | Walsh (2015)[32] | in days | | | 11 (6-18) | 120 | | | | | | | 11 (6-18) | 120 | | |
| Hospital LOS | | | | | | | | | | | | | | | | |
| Hospital LOS | Bench (2015)[33] | in days | | | 21.5 (132) | 51 | | | 16 (132) | 48 | | | 22 (166) | 59 | | 0.25 |
| Hospital LOS | Chaboyer (2007)[34] | in days | . | . | 18 (17) | 53 | | | | | | | 15.5 (16) | 62 | | 0.57 |
| Hospital LOS | Jónasdóttir (2017)[36] | in days | 35 | 40 | . | 73 | . | . | . | . | 41 | 44 | . | 75 | -6.00 [-19.54- 7.54] | 0.06 |
| Post-ICU Hospital LOS | Walsh (2015)[32] | in days | 11 | 6-22 | | 119 | | | | | 10 | 6-23 | | 119 | 0 [-2 – 2] | 0.90 |

| Readmission Rates* | | | | | | |
|---|---|---|---|---|---|---|
| Measurement | Study | Time point | Intervention 1 | Intervention 2 | Control | |
| | | | N (%) | N (%) | N (%) | RR (CI 95%) |
| ICU Readmission | Chaboyer (2007)[34] | ICU readmission during hospital stay | 0 (0) | | 4 (6.5) | 0.13 [0.01, 2.35] |
| ICU Readmission | Jónasdóttir (2017)[36] | ICU readmission within 48h | 0 (0) | | 0 (0) | |
| ICU Readmission | Jónasdóttir (2017)[36] | ICU readmission within 48-120h. | 2 (2.8) | | 5 (6.6) | 0.41 [0.08, 2.05] |
| ICU Readmission | Walsh (2015)[32] | ICU readmission during hospital stay | 1 (0.8) | | 7 (5.8) | 0.14 [0.02, 1.14] |

* = readmission rates in days; SD = Standard Deviation; CI = Confidence interval; RR = Risk Ratio; IQR = Interquartile Range; LOS = Length Of Stay.



| Study or Subgroup | Experimental Events | Experimental Total | Control Events | Control Total | Weight | Risk Ratio M–H, Fixed, 95% CI |
|---|---|---|---|---|---|---|
| Chaboyer 2007 | 0 | 53 | 4 | 62 | 25.8% | 0.13 [0.01, 2.35] |
| Jonasdottir 2017 | 2 | 73 | 5 | 75 | 30.7% | 0.41 [0.08, 2.05] |
| Walsch 2015 | 1 | 120 | 7 | 120 | 43.5% | 0.14 [0.02, 1.14] |
| Total (95% CI) |  | 246 |  | 257 | 100.0% | 0.22 [0.07, 0.70] |
| Total events | 3 |  | 16 |  |  |  |

Heterogeneity: Chi² = 0.87, df = 2 (P = 0.65); I² = 0%
Test for overall effect: Z = 2.58 (P = 0.010)

**Figure 2.** Forest plot of pooled readmission rates. CI- confidence interval.

# DISCUSSION

Evidence from currently available RCTs and non-randomized experimental studies of varied methodological quality shows no significant differences in elements of PICS and PICS-F in favour of ICU-initiated transitional care interventions. In this review, we found a variety of transitional care interventions, but even studies that implemented multiple interventions did not show a positive effect on elements of PICS and PICS-F. Notably, none of the studies described cognitive impairment outcomes. Larger RCTs are therefore needed to demonstrate if and how transitional care interventions are able to decrease the components of PICS-(F). In this review, we only found significant reduction in readmission rates in favour of the transitional care interventions (i.e., intervention including at least one component of the TCM).[26]

Evidence for the most commonly described psychological impairments of PICS-(F) by patients and family, which are anxiety, depression, and PTSD, is lacking.[45] Nevertheless, physical rehabilitation, the use of diaries by ICU patients, and a patient- and family-centred care environment are promising interventions.[46-48] Furthermore, the provision of information by healthcare professionals and adequate communication seems pivotal for treatment of PICS-F.[49]

Transmural transitional care interventions remain underexposed in this review because collaboration between intramural and extramural health care organisations was seldom described. Currently provided ICU aftercare is not the same as transitional

care, evidence of effectiveness of ICU aftercare is scarce, and guidelines are not available.[50] However, ICU aftercare and follow-up services can be beneficial to predict and recognise patients (at risk for) with PICS.[8,50] For trauma and cardiac populations, transmural interventions are effective in the form of care pathways, home visit programs, and structured telephone support (STS) in reducing hospital readmissions, reducing pain, improving functional status, and improving disease-specific HRQOL.[51,52] More evidence for transmural interventions for ICU patients and their families are needed as these are needed to prepare patients and especially family members returning to daily life at home in their possible role as a caregiver.

Although the currently described transitional care interventions in our review show no effect on PICS and PICS-F, we recommend that after the current COVID-19 crisis, further research on the multiple transitions for ICU patients should continue. Many patients have gone through multiple transitions during this COVID-19 crisis, sometimes even between institutions in different countries, with limited visitation of family. This raises the question which role these multiple transitions play in the development of elements of PICS. Earlier studies from the post-Severe Acute Respiratory Syndrome (SARS) era show that patients develop long-term impairments such as fatigue, weakness, and depression.[53] Experts expect that higher rates of depression and PTSD are likely for patients and their families. Family members' needs in this population in a still-limited-care landscape confirm the need for good transition care. Family members should receive better information and guidance in preparing for a caregiver role that can last for years.[54]

### *Strengths and limitations*

This review has some strength and limitations. A strength of this review is that we used a comprehensive sensitive literature search and that each stage of the review was conducted by at least two or three independent reviewers and the use of established tools for quality assessments. None of the studies was designed to examine elements of PICS as an outcome measure. Another strength is that we used the most used and validated instruments summarised by the SCCM.[11] However, we realise that there are many more instruments to evaluate ICU outcomes (more than 250).[31] Therefore, we may have missed some outcome data of PICS that were measured using other instruments.

Since the SCCM introduced the term PICS(-F) in 2012, there is growing awareness in the wide range of symptoms of ICU patients and their family.[4] We used PICS-(F) as an underpinning framework to which outcomes were mapped. The variety in elements of PICS suggests preferring an individual-based plan of care and giving guidance to patients and their families during their recovery pathway. Yet, transitional care interventions as defined by the TCM emphasise streamlined plans of care and continuity of care across settings and between professionals and are not primary focused on patient outcomes.[26]

None of the studies had previously selected a risk group for the development of elements of PICS which are important in the development of post-ICU problems,[8,9] which may influence the results. In addition, some studies had a very short ICU admission, and all studies had a relatively short follow-up, which means that possible complaints may not be measurable until later. Another factor that might influence the results of this review is that we included randomized and non-randomised clinical studies, with some studies showing substantial differences in baseline characteristics.[34-36] The difficulty in an appropriate evaluation of complex interventions in RCTs such as a transitional care intervention includes implementation strategies and process evaluations.[55,56] We found substantial clinical heterogeneity that made pooling for primary outcomes unfeasible. At last, in this review, we used the definition of the TCM to define the interventions; however, it is possible we could have missed relevant studies that used other definitions.

# CONCLUSIONS AND RECOMMENDATIONS

There is a general paucity of data on the effects of ICU-initiated transitional care interventions on the elements of PICS. Although none of the studies reported a positive effect on elements of PICS and PICS-F, there is still insufficient evidence to draw firm conclusions owing to the small number of studies available and the heterogeneity between the studies. Larger studies are needed as these studies confirm the burden of patients' and family's experiences on multiple aspects of PICS. A clear adapted framework or model may be helpful to share more evidence-based intervention strategies to offer continuity of care to ICU patients and families.

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*Conflict of Interest*

The authors declare that they have no conflict of interest.

*Appendix A. Supplementary data*

Supplementary data to this article can be found online at https://doi.org/10.1016/j.aucc.2021.04.010.

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# 4

# Learning by the visualization of a nurse-led Critical Care Outreach Service using the Functional Resonance Analysis Method

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# ABSTRACT

**Objectives**

Quality improvements (QI) in dynamic and complex health care contexts requires resilience and adaptability in everyday practices. The Functional Resonance Analysis Method (FRAM) helps us understand resilience and gain insight into (un-)desirable variability in the complex system of daily practice. We explored how using FRAM in the Deming cycle of QI project can help professionals and researchers learn from, reflect upon and improve complex processes. We used FRAM in a Dutch hospital to study a QI: Critical Care Outreach Service (CCOS).

**Methods**

The aim was to use FRAM before and after implementation to create a FRAM model and reflect health care professionals on the mismatch between Work As Imagined (WAI) and Work As Done (WAD). WAI FRAM model was co-created with the professionals before to the implementation of CCOS. We used descriptions of tasks and processes for ICU nurses and verified in 30-minute semi-structured interviews (N=2). WAD was created by input of semi-structured interviews with key professionals in CCOS (N=21) and three non-participant observations of trained CCOS nurses. We validated WAD in two dialogue sessions with key professionals (N=11).Data collection continued until saturation point.

**Results**

Juxtaposing the WAI and WAD models showed WAD contained additional functions and highlighted unexpected complex functions. Reflecting on the application of FRAM with healthcare professionals, revealed opportunities and challenges, especially time investment.

**Conclusion**

FRAM helps professionals to outline processes and tasks (WAI), learn from, and reflect upon daily practice (WAD). FRAM models helps professionals identify variability and improve practices that enhance resilient performance.

# BACKGROUND

Healthcare professionals, processes, and systems need to adapt to continuously varying circumstances[1] to successfully design and implement long-term quality improvement (QI). The ability to adapt is described as resilience and refers to the 'mechanism' to proactively "adjust its functioning prior to, during, or following changes and disturbances so that it can sustain [the] required operation".[2] Key to this definition is the ability of systems to act upon disturbances as unforeseen, unpredicted, and unexpected demands.[2] Resilience also refers to a personal ability to adapt to complex dynamics in context and hence resume everyday operations.[3,4] Healthcare is a complex environment that demands resilience in everyday processes – resulting in performance variability – as most care processes cannot be fully standardized in a predictable linear manner,[5] as is sometimes incorrectly assumed by traditional QI methods. Even in straightforward processes supported by information and communications technology, deviation is common, as ethnographic studies have shown.[6,7] Thus, the ability to adapt and adjust to match conditions and contexts is critical for sustainable QI.[3] It is important to gain insight into how professionals, teams, and organizations act resiliently in the complex context of designing and implementing QI.[1] To study this in depth and understand more about the 'value' of FRAM we collected data in a case study where a nurse-led Critical Care Outreach Service (CCOS) is designed and implemented. [8,9]

Traditional QI evaluation methods usually focus on judging success by measuring the compliance of people and the effectiveness of the improvement. The effectiveness of QI is measured linearly: at the beginning (T-0 situation) and after a certain timeframe (T-1 situation) to measure the pursued results. This fits hospitals' traditional approach to accounting and compliance in quality and safety. However, the success of QI should include the ability to adapt to the complex healthcare context, which needs resilience and variability to perform well.[10,11] Hence, some argue the necessity of including methods to comprehend everyday performance, especially those that enable a profound understanding of how people, processes and systems are related and interact.[12] After all, dealing with the tension field between the ideal (documented) care and the reality is important. Studying interacting mechanisms in the design and implementation process of QI projects teaches us more about resilience and the tailoring to envisioned changes in complex dynamic healthcare practices.[1,12] This understanding stimulates reflection and learning and thereby reveals desirable and undesirable variability in everyday practices,[1,13] which in turn can add to success in dealing with the tension field.

The Functional Resonance Analysis Method (FRAM) can be used to understand resilience in everyday practices of a complex dynamic system and gain insight into both desirable and undesirable variability.[5,14] Originating from socio-technical engineering, it is used in the Safety II paradigm that focuses on the presence of safety in complex dynamic systems, learning about everyday practices, and managing error rather than just analyzing and preventing error.[5,10] Using FRAM we can gain a deeper understanding of everyday performance, referred to as work-as-done (WAD) and how it relates to the envisioned processes, called work-as-imagined (WAI). FRAM visualizes complexity by overseeing essential process activities and their interactions or interrelatedness to reveal resilience and variability.[11,13,15]

Research shows FRAM has been useful for healthcare professionals, policymakers, and management to improve quality and safety of care, as it helps them understand current practices (WAD) and learn about the effects of variability and the barriers/enablers to handle complexity.[11,14] Specifically, identification of specific workarounds, personal aids, and incrementally developed control mechanisms are helpful in quality improvements.[16] In healthcare, FRAM has been used for multiple aims, such as prospective risk assessment,[17] improving persistent safety issues,[18] incident investigation,[15] translation of guidelines into local policy,[19] or as participatory improvement intervention.[20]

Our research question was: How can FRAM support reflection and learning on the implementation and evaluation process of a QI project of healthcare professionals?

# METHODS

This case study was approved by [blinded for peer review]. Participants gave voluntary informed consent. For reporting we used the revised Standards for Quality Improvement Reporting Excellence 2.0 framework.[24]

## Design and setting

We describe a QI project on implementing a Critical Care Outreach Service (CCOS) led by CCOS-trained nurses (CCONs) in two phases of the Deming cycle: design (Plan) and evaluation (Study).[23] Generally, the CCOS included five components of outreach derived from a recent international Delphi study. Box 1 (appendix 1) describes the aim and components of the Dutch CCOS.[9] In the Plan phase, FRAM was used to visualize the desired process (WAI) of CCOS. In the Study phase, FRAM was used to visualize the results (WAD) three months after CCOS implementation, based on semi-structured interviews and observations.

The setting was a Dutch teaching hospital with 782 beds, including a 36-bed level 3 ICU, 540,000 outpatient visits annually, approximately 1550 vocational and/or bachelor-trained nurses and 394 doctors.

## Functional Resonance Analysis Method

FRAM design starts by identifying the main actions (functions) in the complex process. Each function contains six aspects, depicted as a hexagon that displays the complexity.[11]

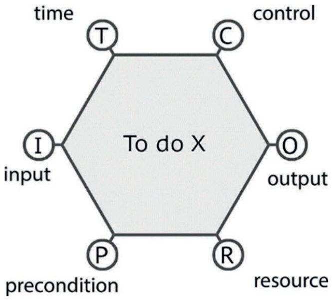

**Figure 1. The six aspects of a function**[11]

Legends:

- Input: initiating stimulus of the activity
- Output: outcome of the stimulus and emerging change
- Time: time aspects affecting the function
- Control: controlling or monitoring aspects
- Precondition: conditions that must be met before the function begins
- Resource: materials and people needed for executing the function.

Multiple linked hexagons show the interrelatedness of functions. An entire process is visualized by coupling functions through the input and output of hexagons. This provides insight into variability and interdependency.

### Data collection

#### *Plan Phase (WAI)*

The aim of the QI project was to improve an existing ICU outreach service into a structured nurse-led CCOS based on the evidence provided by an Australian ICU Liaison nurse.[8,9] Two months before implementation, we constructed the WAI model, collecting digital and printed documents describing the usual care processes of the existing service and conducted a literature review on the ICU liaison nurse role. Existed literature and process descriptions were input for the CCOS project team for the first draft of the CCOS design and making an education plan for ICU nurses. A focus group, comprising the project leader, team members and the ICU manager discussed the draft and a summary of their group output was used to refine the CCOS project design. The final CCOS design was visualized in a draft WAI model, as imagined by the initiators. Then an experienced FRAM researcher (ND) used the FRAM Model Visualizer (FMV) 0.4.1 to create the final WAI. The CCOS was introduced in October 2019, based on this WAI model. The professionals and the organization learned to work with the CCOS system in the following three months.

#### *Study Phase (WAD)*

The WAD model was based on semi-structured interviews and observations and used to evaluate the implementation.

## Interviews

One researcher (ND: female, PhD) with expertise in FRAM modeling conducted interviews with 20 professionals involved in the CCOS process, including the CCONs, using a predefined topic list (see appendix 2). All invited agreed to participate (see table 1). In accordance with FRAM, at least two professionals per involved discipline were interviewed to gain insight into variability in their role in the CCOS process and their interactions with others involved. Interviewees were purposively selected: the ICU and general ward team leaders provided the initial point of approach for recruitment, and additional professionals were recruited through interviewees. Through the team leaders we recruited the ward nurses from two wards that often consulted CCONs. Interviews lasted 30–60 minutes. All interviews were audiotaped and summarized. We conducted interviews until no new information emerged (saturation).

**Table 1.** Interviewees: key professionals in CCOS (n=20).

| | |
|---|---|
| ICU nurse with specialist ICU trainingTrained CCONs. | 4 |
| ICU nurse practitioner (NP) | 2 |
| General ward nurse | 4 |
| Nursing coach in clinical reasoning skills | 3 |
| Nurse coordinator<br>A general nurse coordinating admissions from Emergency Room (ER) to general wards during evening and night shifts. She also supports ER staff in regular nursing activities. | 2 |
| Intensivist | 2 |
| Physician assistant / general ward NP | 3 |

## Observations

Adopting an open, curious yet neutral stance,[26,27] one researcher (MM: female, MSc) undertook non-participant observation of CCONs (N=3) for 20 hours in total, to understand the CCOS processes. Non-participant observation is “a way to understand the complexity of healthcare work that might otherwise be poorly understood or ignored, how workarounds influence work practices and safety, and is of fundamental importance, to practitioners wishing to understand resilience in the face of conflicting workplace pressures.”[28] Eligible participants had worked at least two shifts as a CCON and had not been interviewed previously. We invited eight CCONs by email and included the first five who responded. Two day shifts and one nights shift were observed for 5–8 hours per shift. The field notes taken during non-participant observation were written up afterwards in thick descriptions, which were sent to participants as a member check.[29,30] All respondents agreed with the thick descriptions.

## Dialogue sessions

Next, we held two dialogue sessions to discuss WAD and potential clinical implications.

We invited all the interview participants as well as other professionals and managers involved in the CCOS process (N=46). Of the 67 potential participants invited, [11] (16,4%) accepted the invitation: CCONs (N=6), ICU nurse practitioners (N=2), nurse practitioner on general ward (N=1), nurse managers (N=1) and nursing coach (1). Due to the COVID-19 ban on in-person meetings, the second dialogue session was held online. Both sessions lasted an hour. Notes were taken, transcribed and summarized. The dialogue sessions successfully validated WAD and identified ideas for further improvement of CCOS.

### Analysis (WAI and WAD)

We (MM and ND) analyzed the data from interviews and observations in three steps. First, we identified the main activities and professionals who executed these functions. If a function was present in WAD, we identified the six aspects of its hexagon (see figure 1).

The second step was to interpret the model and understand how resilient performance is shaped throughout the CCOS process. We analyzed variability and interdependency in terms of both functions and aspects by juxtaposing WAD and WAI, and tried to understand the resilient behavior of professionals. We also conducted theoretical thematic analysis[32] on the interview and observation data to flexibly yet systematically identify common themes across different data sources.[32,33] We used Hollnagel's potentials of resilience (monitoring, responding, anticipating, learning) as sensitizing concepts to understand and interpret data.[11] All data were coded and, subsequently, axial coding identified the common themes. Finally, a focus group including the CCOS project team and researchers reflected on the value of FRAM for quality improvement.

## RESULTS

First, an overview is presented of both models based on the functions, aspects, and executing professionals (figures 2 and 3, table 3). Then, we discuss the most apparent themes derived from the thematic analysis. Finally, we reflect on the use of FRAM in the QI processes and how it fits with the Safety II paradigm.

### Comparing WAD and WAI

Figures 2 and 3 show the FRAM WAD and WAI models. Table 2 provides an overview on how WAD and WAI are mutually related.

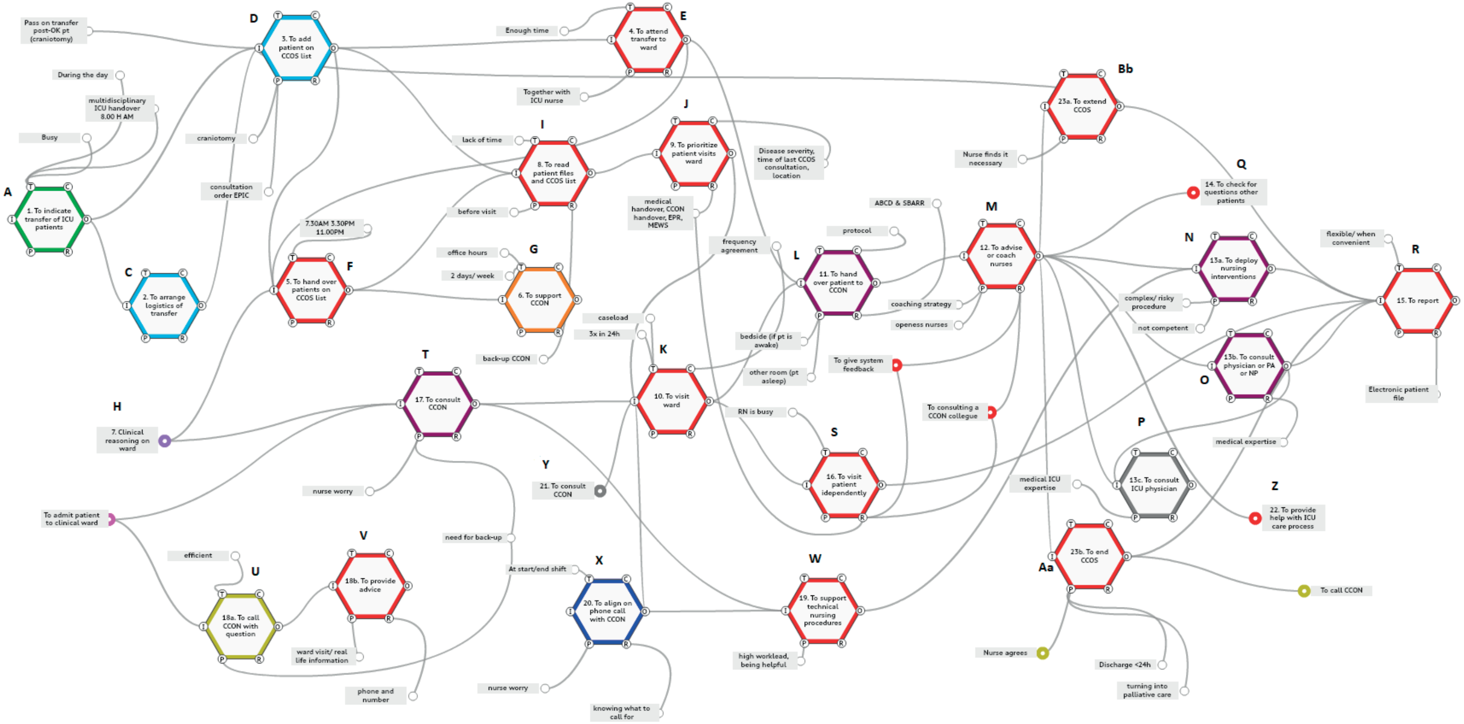

**Figure 2.** Work As Done.

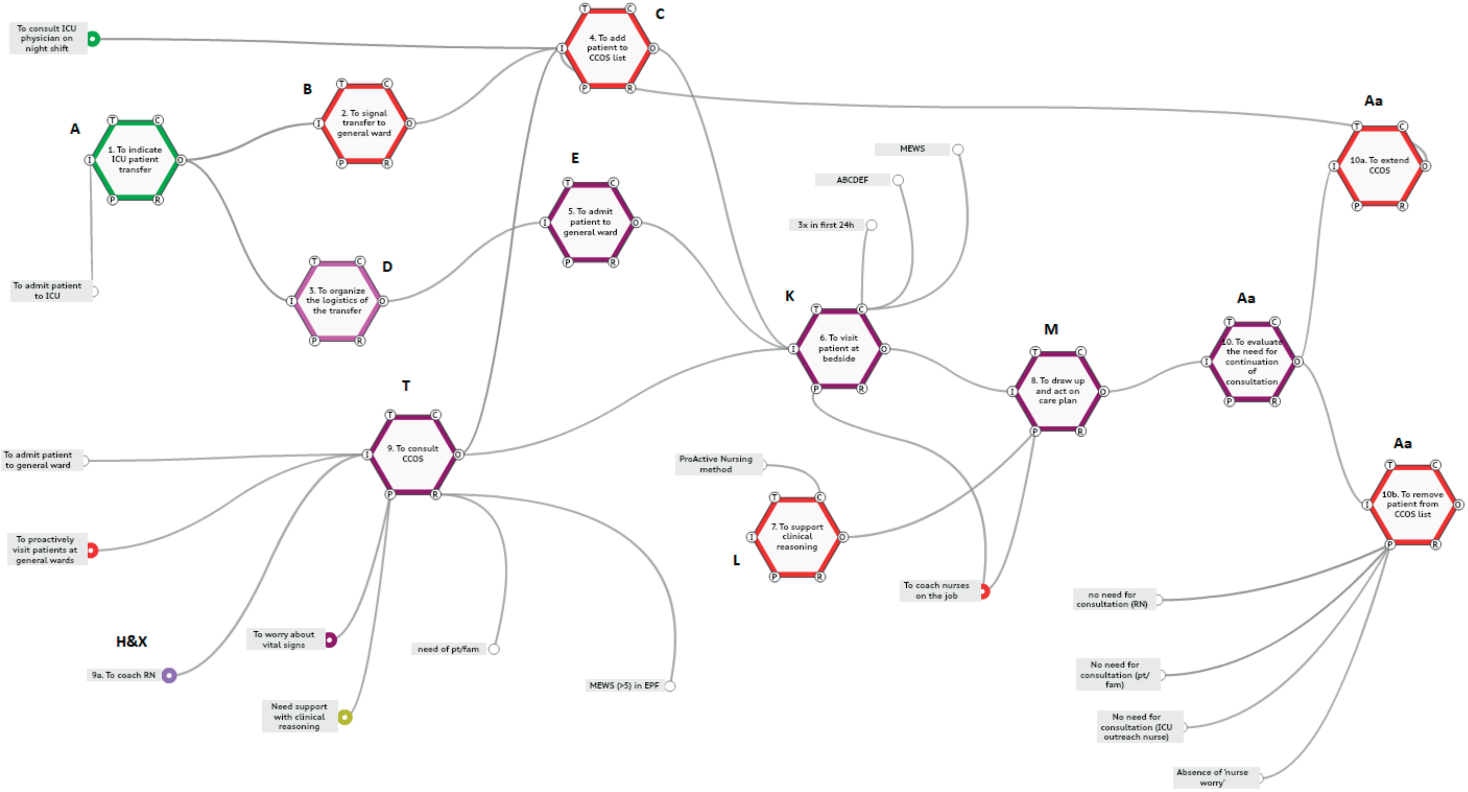

**Figure 3**. Work as Imagined.

**Legend hexagon colors** (Figures 2&3)

- Red: CCON
- Burgundy: ward nurse
- Orange: ICU nurse practitioner
- Light blue: ICU manager
- Dark blue: nurse coordinator
- Purple: nursing coach (in WAI also nurse coordinator)
- Gray: physician/assistant physician / nurse practitioner
- Green: ICU physician (intensivist)

**Table 2.** Overview of WAD and WAI: variability, interdepence and relatedness.

| | **Work as done (WAD)** | | **Work as imagined (WAI)** | |
|---|---|---|---|---|
| | **Function*** | **Professionals** | **Function*** | **Professionals** |
| **A**<br># | **Function 1: Indicate ICU patient transfer.**<br>CCONs are mostly used in the 8.00AM handover.<br>**Signal potential patients. CCONs** not used when there is no time (T). Then ICU NPs do the honors.<br>Intensivist and ICU NP decide on transfers to the ward (O). | Intensivist, ICU NP, CCON<br>♣ | **Function 1: Indicate ICU patient transfer.**<br>CCON used in the handover of every shift, during which intensivists discuss all ICU patients and decide who will be discharged.<br>**Function 2: Signal patients fit for transfer**.<br>CCON notes the patients the intensivist has assessed as 'fit for transfer' and adds them to the CCOS list. | Intensivist, NP ICU, CCON |
| **F**<br># | **Function 5. Handover of patients on CCOS list.**<br>**S**hift handovers between CCONS take place 7.30 AM, 3.30 PM and 11.00 PM (T). Handovers share co-worker knowledge of a patient's condition and coaching requests (R), which helps to anticipate and prioritize (O). | CCON # | | |
| **H**<br>♥ | **Function 7. Clinical reasoning support.**<br>Nursing coaches decide whether nurses should call a CCON (O) if they are worried about a patient's condition (P).<br>Due to time constraints (T) coaches do not participate in the medical transfer. | Nursing coach ♣ | | |
| **I**<br># | **Function 8. Read patient files and CCOS list.**<br>Patients' files (R) provide a global overview of patients on the CCOS list (O), which helps to anticipate and prioritize the patients at risk. CCON tries to read before ward visits (T) but cannot always and if she lacks time postpones reading until the patient visit (T). | CCON # | | |
| **J**<br># | **Function 9. Prioritize ward visits.**<br>CCON prioritizes which patients must be visited first (O), based on insight into the patient's condition (I) based on medical handover (R), CCON handover (R), MEWS scores (R) and patient file (R). | CCON # | | |
| **T**<br># | **Function 17. Consult CCON.**<br>Nurses consult a CCON when they need to make sense of a worrisome situation (P), especially outside office hours (T), when physicians have limited availability (P). CCON is quickly on site (P) and has the expertise to structure and interpret the situation (R). | Ward nurse ♣ | **Function 9. Coach nurses on the job.**<br>If a ward nurse is worried about the condition of a patient, needs support in clinical reasoning, and/or the patient/family needs support, the ward nurse may ask for a consult and pages a CCON. | Ward nurse |

**Table 2.** CONTINUED.

| | Work as done (WAD) | | Work as imagined (WAI) | |
|---|---|---|---|---|
| | **Function*** | **Professionals** | **Function*** | **Professionals** |
| **U**<br>♥ | **Function 18a. Call CCON for quick questions**.<br>Ward nurses consult CCON by telephone for quick questions on technical interventions and protocols, which do not need a visit (P). Sometimes it is more efficient (T) to call someone with much technical expertise (R), than searching protocols for relevant information. | Ward nurse ♥ | | |
| **X**<br>♥ | **Function 20. Align with CCON on telephone.**<br>Nurse coordinators do not attend the medical handover as it is time consuming (T). They sometimes advise nurses to call CCONs (O) or will call CCONs (O) themselves if they are concerned about the patients' condition (P).<br>Nurse coordinators consider the CCON a certain backup, especially when technical help is needed (e.g., inserting IV) (P). Some CCONs try to be helpful (P) if they have time (T). Other CCONs consider such tasks not their job. | Nurse coordinator ♣ | **Function 9a. Advise: call the CCON.**<br>A nursing coach or nursing coordinator might be concerned about a patient and advises the ward nurse to ask for help from a CCON.<br>Nursing coaches/coordinators attend ICU handovers where they might signal patients potentially at risk for deterioration so that these patients get placed on the CCOS list. | Nursing coach, Nursing coordinator |

**Legend:**

- Functions are numbered and suggest a certain sequence. Please interpret this sequence very loosely to respect the complexity of practice.
- Green (♣): WAD function and/or professional is the same as in WAI
- Blue (#): WAD function and/or professional differs slightly from WAI, but does not change the process much
- Red (♥): WAD function and/or professional differs from WAI Function aspects

- (P): Precondition
- (C): Control
- (T): Time
- (R): Resource
- (I): Input
- (O): Output

**Medical abbreviations**

- EPR: electronic patient record
- SBARR: situation, background, assessment, recommendation, reflection
- ABCDE: airway, breathing, circulation, disability, exposure
- MEWS: modified early warning score for clinical deterioration

### WAD and WAI: variability and interdependence

Table 2 shows that WAI functions 1 and 2 were done together in practice (WAD function 1), which the interviews and observations confirmed. WAD also contained new functions, such as mutual handover between CCONs (WAD function 5), reading patient files (WAD function 8) and prioritizing ward visits (WAD function 9). Data showed that gathering and using information was a more complex process than initially imagined (WAI function 1).

In WAD some red (♥) functions were either unexpected (see WAD functions 1 & 18a) or showed major changes in content (see WAD functions 7, 17 & 20).

### Interpreting and reflecting on variation in WAD: thematic analysis

Five main themes emerged from the thematic analysis: 1) easy access, 2) communication, decision making, and anticipation, 3) efficiency, 4) coaching styles and learning, and 5) collaborative ventures.

#### *Easy access*

Overall, the interpretation of WAD made it clear that nurses experienced the new CCOS version as a positive improvement. Nurses said that the CCONs helped them respond better when they felt worried. We define worry as "recalling intuition or gut feeling that they felt when they recognize that their patient is deteriorating clinically."[34] If nurses felt worried, they knew they could call on the CCON, because they could trust their ICU expertise and quick response. Outside office hours, when doctors were hard to access, nurses found this very helpful. Having to wait for a physician is why nurses wanted to execute meaningful assessments and interventions, also so that they could give a complete picture of the patients' situation before disturbing a physician.

#### *Communication, decision making and anticipation*

Physician assistants (PAs) and nurse practitioners (NPs) felt that the handovers were more structured and complete with CCON interventions. Nurses said that 1-on-1 bedside coaching by CCONs in the ABCDE method (Airway, Breathing, Circulation, Disability, Exposure) was helpful in structuring observations, and coaching on SBARR (Situation, Background, Assessment, Recommendation, Reflection) helped their patient assessment. CCON interventions enabled nurses to present handovers coherently and allowed Pas and NPs to make better decisions on preventing clinical decline or the need for a rapid response team.

#### *Efficiency*

Standard post-ICU follow-up seemed to benefit because ward nurses could rely on the expertise of ICU nurses. However both nurses and CCONs considered visiting low-risk, stable patients three times within 24 hours of transfer from ICU to the ward as excessive and thus unnecessary. It became clear that some stable patients were removed from the CCOS list after the second visit to make more time available for sicker patients. This happened more often with big caseloads. Nevertheless, CCON support was guaranteed. As soon as a nurse called, the CCON came. However, in the case of clinical deterioration, some PAs and NPs regarded CCON interventions as a risky delay. This was why some worried nurses on these wards rarely consulted the CCONs.

### Coaching styles and learning

Nurses reported that CCONs had widely different coaching strategies. For example, some CCONs had a clear focus on interactively guiding nurses in interpreting, assessing, and intervening. Others used a master-apprentice approach and just told nurses what to do. Nurses preferred the first strategy. It helped them understand what was happening right now, how to intervene, what to observe, and how to assess future situations. Dialogue sessions revealed that coaching needs skill, which is lacking and caused the different coaching approaches.

Interviews revealed that CCONs used individual learning strategies among themselves, such as informal chats to solve problems and keeping a list of things to improve processes. This list served as a communication aid for the CCOS project team.

#### *Collaborative ventures*

Frictions were observed in collaborations between nurse coordinators and CCONs. Some nurse coordinators did not know that they were expected to identify patients at risk, or when to call a CCON for help. As a result, the CCON was not informed when a patient was eligible for a CCOS consultation. Therefore, some CCONs took the initiative to check whether there were any other eligible patients, which often turned out to be the case. Or CCONs were called for tasks that fell outside their responsibility, such as IV insertion. Some CCONs took over these tasks to be helpful, especially when nurse coordinators were busy. As a result, it was assumed by default that certain tasks were done by CCONs.

### Reflecting on using FRAM in QI

FRAM is a comprehensive QI tool that helps reveal system complexity.[5,10] However, our study was more labor-intensive than anticipated. The QI advisers and researchers spent 60 hours in total on data collection (45h), analysis (13h) and dialogue sessions (2h). The scale of the process and the unexpected large number of professionals involved exceeded the average time investment for conducting FRAM (25-35 hours).[11] However, this great investment, combining data from interviews and observations, offered richer insights into the complexity of everyday practices. Observations provided real-time understanding of the variations beyond interviews and, in turn, interviews provided insights into ‘the why’. WAI and WAD visualizations were helpful in that they made practices tangible. Providing the time and space to reflect with those involved on how WAD allowed professionals to develop an understanding of each other’s story was beneficial, as it created awareness about their processes, and how quality was ensured. We learned that applying FRAM requires training [35] in both the methodology and the theoretical background of resilience. Especially, the discussion leader must grasp resilience and variability to interpret data well. Without this knowledge, the project risks becoming an 'old school' process analysis focused on input and output (Safety I thinking) instead of on variability.

## DISCUSSION

This paper shows how FRAM helps healthcare professionals in a QI process to learn from and reflect on everyday practices. By using FRAM during the design (Plan) and evaluation (Study) phases of the Deming cycle of QI health care professionals were able to reflect on every aspect of the complex mundane practices visualized in WAI and WAD FRAMS. Our findings show that WAD differed from the upfront 'designed' process (WAI) and consisted of considerably unexpected functions and aspects. Closer inspection revealed that WAD also highlighted unexpected more complex functions or were overlooked or taken for granted in the initial development of our CCOS; activities that are common to healthcare professionals, but are vital for resilient performance in the complex daily practice. In addition, WAD showed strong variation. Variation was induced by easy access to CCONs, availability of physicians, coaching styles of CCONs, friction between roles, and expectations in the partnerships involved.

Naturally, WAD in our study differed from what had been conceived in WAI, much like the results of studies reported by Clay-Williams[19] and McNab et al.[20] However, previous CCOS studies have reported varying patient outcomes.[38-40] Unlike most other studies limited to describe WAD only,[35] our study made WAI explicit and comparable with WAD to provide a deeper understanding of everyday practices. We realized that WAI mainly presented the main features while WAD provided insight into how a CCOS is embedded in complex organizational structures and systems. Our WAD made variations visible so that the professionals involved were able to address both desirable and undesirable variability, and resilience during dialogue sessions. This gave direction to improvements, which is precisely the relevance of using FRAM for QI in complex systems[15,20,36] where linear approaches fall short.[20,37] Applying the Safety II approach, our unique visualization of WAI and WAD includes lenses on complexity and resilience, which clarify the dynamics of a complex context that affects a QI, in this case the CCOS.[11,20,37]

Implementation science has the triple aim to describe, understand influences, and evaluate intervention outcomes in practice.[37] As a paradigm, Safety II is based on complexity science[41] and the FRAM methodology is used to visualize this everyday practice complexity.[11] We used FRAM in a novel way, to learn how this method can contribute in a learning cycle with healthcare professionals as co-creators. Our study builds on the evidence[19,20] that FRAM is a promising method to use during multiple phases of implementing a QI. However, we agree on Sujan et al.[50] that a reporting guideline may help both researchers and professionals to get used to work with FRAM and to interpret it correctly with the multiple characteristics of FRAM.

### Strengths and limitations

Our study combined observations and interviews, which we know yield different types of data.[29,42] This strength of our study gave us insight into both 'work as reported' and 'work as observed', which resulted in a more nuanced and complete picture of WAD. Clay-Williams et al.[43] state that a FRAM model should contain a maximum of 20 activities because it could easily become overwhelmingly complex. However, complex systems cannot be reduced in a model with limited activities, because it is representation of one moment and only show a small part of reality.[48] Wiig et al (2019)[49] therefore state that to achieve improvement, it is important to understand the interactions between people and between different organizational levels. FRAM does not provide enough room for this in our opinion. Therefore, our findings on CCOS and functions/actions of CCONs should be interpreted with caution, as our FRAMs do not explain the (systemic) processes entirely.[11] We observed only three CCONs due to the COVID-19 pandemic. The pandemic forced us to stop observing as part of the national and hospital regulations. More observations and including different healthcare professionals would provide other insights.[46-47] This study illustrates the clinical relevance of putting FRAM into practice, to learn how it can contribute to the adapting process of professional-led changes in complex systems. FRAM could potentially enhance the professionals' capability to deal with changes over which people have little control, such as a pandemic.

In process of creating FRAM, we found engaging the expertise of professionals essential to increase the impact of the process and QIs, because of their understanding of practice.[11,19,20] Their knowledge contributed greatly to local adaptations.[19,20] Although, as researchers, we highly valued their relevant insights, in this study it was not feasible to conduct an evaluation of the process that included reflection on the experiences of the professionals involved in these elements. We strongly recommend taking this into account in future research and checking on this in the practical application of FRAM in QI.

## CONCLUSION

FRAM supports health care professionals to understand the complex processes and systems in the acute hospital care setting. FRAM contributes to engage healthcare professionals in this reflecting and learning cycle during the process of a QI. It helps users proactively identify desirable and undesirable variability and make improvements that foster resilient performance. Also, adding ‘work as observed’ is very helpful in gaining nuanced, detailed insight in WAD. Although this study shows the cross-fertilizing benefits of combining implementation science and (Safety II) complexity science in bringing research into practice, future studies could further explore FRAM as an implementation tool.

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# APPENDIX 1.

## COMPONENTS OF THE DUTCH CRITICAL CARE OUTREACH SERVICE (CCOS)

The nurse-led CCOS is a scientifically proven9 proactive service by a partial team of 50 trained ICU nurses supervised by nurse practitioners ICU. The aim is to ensure a smooth transition of a patient from the ICU to a general ward and to prevent clinical deterioration. CCOS does this by:

- CCONs follow-up visits during the first 24 hours after discharge from ICU to general wards three times to monitor patients' condition and detect clinical deterioration. CCONs monitor patients together with the nurse responsible for the care on the general wards. This also ensures bedside peer-to-peer coaching.

- CCONs provide low-threshold consultation for all patients on nursing wards in non-emergency situations. While rapid response teams provide care for clinical deteriorated patients or the need for basic or advanced life support, the CCONs provide also support and ICU knowledge and expertise.

- CCON provides also share expertise regarding clinical reasoning and care planning.

# APPENDIX 2.

## TOPIC LIST INTERVIEWS SEMI-STRUCTURED INTERVIEWS

| **Opening**<br>**Tell me about your professional role in the process of the CCOS ?** | |
|---|---|
| Input | What/ who starts the activity? |
| | What changes the activity? |
| Output | What is the result (or output) of the activity? |
| | Do you inform someone about this output? If yes: how? |
| | Do you record the output? If yes: how and where? |
| | Who uses/ needs your output and is it used? |
| Precondition | What must be arranged before you can carry out the activity? |
| | What do you do if these condition(s) are not met? |
| Resources | What do you need to carry out the activity? |
| | What do you use during the activity? Think of staffing, materials, buildings/ space, software, etcetera. |
| | What do you do if these resources are not available? |
| Control | How is the activity monitored or controlled (e.g. guidelines, mission/ vision) |
| | Do formal procedures or instructions affect the activity? |
| | Are there specific persons, such as supervisors, who monitor/ check the activity? |
| | Are there aspects that limit the activity, such as a budget? |
| Time | What is the influence of time on the activity? |
| | Is there a specific time when the activity is performed? |
| | What happens under time pressure: do you still perform the activity or not? |

# 5

# The impact of a nurse-led critical care outreach service to reduce ICU readmissions: an interrupted time series analysis.

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# ABSTRACT

**Objectives**

Readmission to the Intensive Care Unit (ICU) is associated with poor outcomes. Nurse-led critical care outreach Services (CCOS) are introduced to recognize and early respond to deteriorating patients on wards to prevent readmission to the ICU.

**Design**

A before-and-after study using interrupted time series.

**Setting**

A large teaching hospital in the Netherlands.

**Patients**

ICU patients

**Intervention**

The CCOS was implemented on October 19, 2019. The CCOS comprises a team of 50 trained ICU nurses, who peer-coach nurses on wards during proactive rounds and structured follow-up of ICU patients in the first 24 hours after ICU discharge. Patients were eligible for inclusion if they were admitted for at least 24 hours to the ICU during the study period. Retrospectively, we collected monthly data over 12 months before the implementation (October 18, 2018 - October 18, 2019) and for 4 months after the implementation of the intervention (November 1, 2019 - February 28, 2020). No data was collected during the implementation phase (19 - 31 October 2019). The primary outcome was ICU readmission within 24, 48, or 72 hours. Secondary outcomes were ICU, and hospital length of stay in days, and mortality rates.

**Measurements and main results**

We compared the number of ICU readmissions before and after the implementation of a nurse-led critical care outreach service (CCOS). In total, 3448 patients were admitted during the study period, October 18, 2018- February 28, 2020. 1613 were admitted for at least 24 hours to the ICU and included in the study, 1206 of whom in the baseline group and 407 in the intervention group (see figure 1). During the implementation phase (19- 31 October 2019) we did not include patients. Of the 407 patients in the intervention group, 162 patients did not receive the intervention. Unplanned readmissions within 24 hours occurred in 2.4% (29/1206) of the baseline group and 1.2% (5/407) of the intervention group. It was unable to perform a formal statistical analysis on the 24 hours readmission rates because the number of events was too small. ICU readmission rates after 48 or 72 hours, ICU LOS, hospital LOS, and mortality rates were not significantly reduced after implementation.

**Conclusion**
ICU patients who received a critical care outreach service did not have significantly lower ICU readmission rates, ICU LOS, hospital LOS, or in-hospital or ICU mortality rates. ‘Not registered’*

**Key words**
Critical care nursing, Intensive care, Outreach, Patient readmission, Patient safety

## INTRODUCTION

In patients discharged from an Intensive Care Unit (ICU), the chance of being readmitted to the ICU during the same hospital stay is 4 to 10% (1, 2, 3). Patients who are readmitted have an increased ICU length of stay (LOS) and are at greater risk of dying(4, 5). Predictors for ICU readmissions are higher age, male gender, severity of illness, presence of comorbidities, and ICU LOS. Furthermore, ICU patients who received mechanical ventilation during the previous ICU admission have a higher risk for ICU readmission, as do ICU patients who needed emergency surgery or who developed sepsis during ICU admission (6, 7, 8). In addition, ICU discharge during weekends and nights also appears to be associated with a higher ICU readmission rate (4, 9).

In the last few decades, various transitional care interventions were developed to improve the transfer from the ICU to a general ward, including structured handovers, an ICU liaison nurse (ICU LN), and nurse-led Critical Care Outreach Services (CCOS) (10, 11). CCOS are mostly proactive and focused on preventing the deterioration of clinical patients. These teams can function separately from a Rapid Response Team (RRT) or a Medical Emergency Team (MET), which are more reactive for already deteriorating patients (15).

Although the CCOS is already an existing intervention, studies show there is still a diversity in the composition and elements of the tasks (12, 13, 14). Some CCOS teams are nurse-led, while others combine nursing and medical CCOTs. Overall, the aim is to help patients after ICU discharge to reduce the risk of avoidable ICU admissions, and to provide early detection of patients who deteriorate clinically and require ICU treatment (14, 15). In addition, CCOS offers several coaching elements, such as sharing critical care skills with nurses and empowering leadership (14, 16). CCOS plays a facilitating role in a learning continuum of professional development (14, 17).

Niven et al. concluded that critical care transition programs appeared to reduce the risk of ICU readmission for patients discharged to a general ward, based on nine before-after studies (range 451 to 5027 patients) (11). Österlind et al. reached the same conclusion based on 15 observational studies (range 186 to 32.234 patients) (12). When focusing on nurse-led critical care outreach teams, Garry et al. described a reduction in mortality rate, arrest calls, and length of stay, based on ten studies ( range 133 to7450 patients) (18). However, implementation of outreach teams is not yet a global standard of care (19).The optimal way of delivering transitional care is still unknown.

We developed an evidence-based nurse-led Critical Care Outreach Service (CCOS) (14). This Evidence-Base Quality Improvement (EBQI) was initiated by ICU nurses and was based on the evidence and content of the Australian ICU Liaison Nurse (20). We focused on the coaching elements, proactive rounding's, and family members. The CCOS was implemented in October 2019, just before the COVID-19 outbreak. The aim of this study was primarily to determine whether the nurse-led CCOS reduced ICU readmission rates and, secondarily, whether it reduced ICU Length of Stay (LOS) and mortality rates.

## MATERIALS AND METHODS

### Study Design and Patients

In this single-center, interrupted time series, we investigated the effects of a nurse-led CCOS on ICU readmission rates and ICU LOS using multilevel Bayesian regression analysis. The study was conducted in a large teaching hospital in the Netherlands with 996 beds and one 36-bed, level 3 intensive care service including 4 units with expertise in neurosurgical, trauma, and sepsis patients. ICU care is delivered by a 24/7 ICU nurse and intensivist team (the highest level of Dutch ICU standards) (21). Both the control group (before) and the intervention group (after) included adult patients (minimum age of 18 years) admitted at least 24 hours to the ICU. Patients were excluded from the intervention if they had been admitted shorter than 24 hours, if they were terminally ill or if patients had a documented no ICU return agreement.

### Nurse-led Critical Care Outreach Service (CCOS)

Before the implementation of the CCOS, ICU patients were transferred to the general ward without a structural follow-up service. Usual care included a Rapid Response Team RRT) and all ICU nurses participated in the RRT triggered by a Modified Early Warning Score (MEWS) (22).

In April 2019, we started to design and implement a 24/7 nurse-led CCOS, for which 50 ICU nurses were trained. Training consisted of a one-day course including clinical reasoning (Proactive Nursing Method) (25) and coaching. The CCOS  was based on the concept of the Australian ICU Liaison nurse (23) and consisted of two main components. The first component was a proactive follow-up service on a structural base ICU patients after the transition to the general ward. The second component was to support ward nurses with a proactive peer support system in general wards if they experienced "nurses' worry or any other concerns. Nurses' worry is defined as the recall of intuition or gut feeling that nurses may experience when they recognize their patient's clinical deterioration (24).

The CCOS nurse did visit post-ICU patients at least three times within the first 24 hours after being transferred to a general ward. Each proactive ward visit included a bedside assessment, in which both the CCOS nurse and the ward nurse methodically assessed the post-ICU patient. The CCOS nurse used the ABCDE method to structure the clinical assessment of vital signs. Besides, the CCOS nurse used Bakker's Dutch clinical reasoning cycle for coaching on clinical reasoning (25, 26). After this assessment, a nursing plan was made and documented in the electronic patient record. The CCOS nurse, ward nurse and patient decided together if there was a need to continue the service without limit. If needed, the CCOS nurse provided practical and emotional support to patients and their family members during the transfer period. The CCOS was fully implemented in October 2019.

### Data Collection and Variables

The following baseline demographic data of patients were retrieved from the Electronic Patient Records (EPR): age, gender, Body Mass Index (BMI), and pre-existing comorbidities and last scored Modified Early Warning Score (MEWS) before ICU readmission. MEWS is a measurement tool to assess a patient's vital status and a tool for nurses in general wards to help them detect early deterioration of patients and initiation of prompt action (27).

The three primary outcomes were readmission to the ICU within 24, 48, or 72 hours after discharge during the same hospital stay. Secondary outcomes were: hospital Length of Stay (LOS) in days, ICU mortality and hospital mortality.

### Analysis

Retrospectively collected data were analyzed using multilevel Bayesian regression (28). We collected data at 12 monthly time points before the intervention (October 2018 to October 2019) and at 4 monthly time points after the intervention (November 2019 to March 2020) (29). During the implementation phase (19 - 31 October 2019) no data were collected. For each of the three primary outcomes, ICU readmission within 24, 48, or 72 hours, we ran Bayesian multilevel logistic regressions using the *brms*-package in R (28). For correction, we ran analyses with readmission rates as the dependent variable and the following predictors: a) *intervention*, (b) *gender*, (c) *BMI*, (d) *MEWS*, and (e) *acute versus planned admission*. We also added all the two-way interactions to the model as well as the three-way interactions between interventions, gender, and BMI, and between intervention, gender, and MEWS. In the analysis, we accounted for the fact that observations are nested within months and the difference between the numbers of admissions per month. Missing MEWS scores were replaced using multiple imputations.

For the secondary outcomes (ICU, and hospital LOS, ICU mortality and in-hospital mortality), we ran similar analyses with similar predictors and interactions as for the primary outcomes, using log-normal regression to account for the distribution of the data. The choice for the lognormal distribution over a Poisson distribution or negative binomial distribution was based on the Posterior Predictive Checks of the model (30).

### Ethics

This study design was approved by the local ethics committee (Medical Research Ethics Committees Brabant) under the number NW2021-73, and the local hospital research protocol was approved under research number: L1339.2021.

### Funding

The CCOS project was funded by the Quality Impulse Personnel Hospitals (in Dutch: Kwaliteitsimpuls Personeel Ziekenhuiszorg). With this funding, the Dutch government invests in general hospitals and categorical institutions to improve nursing as a profession.

## RESULTS

Between 15 October 2018 and 28 February 2020, a total of 3448 patients were admitted to the ICU (see figure 1). Of these patients, 1613 were admitted for at least 24 hours of whom 1206 were included in the baseline group (n=1206) and 407 in the intervention group. Of the 407 patients in the intervention group, 162 patients did not receive the intervention (see figure 1). During the implementation phase (19- 31 October 2019) we did not include patients.  Data from the baseline group and intervention group were not normally distributed (table 1). Correction for gender, BMI and MEWS using multiple imputations did not change these findings.

**Table 1.** Baseline characteristics.

| | **Baseline group (N=1206)** | **Intervention group (N=407)** | **Total (N=1613)** |
|---|---|---|---|
| **Gender** | | | |
| Male | 699 (58.0%) | 231 (56.8%) | 930 (57.7%) |
| Female | 507 (42.0%) | 176 (43.2%) | 683 (42.3%) |
| **Age** | | | |
| Median [Min, Max] | 65.0 [16.0, 90.0] | 64.0 [17.0, 93.0] | 65.0 [16.0, 93.0] |
| **MEWS** | | | |
| Median [Min, Max] | 2.00 [0, 17.0] | 2.00 [0, 15.0] | 2.00 [0, 17.0] |
| Missing | 630 (52.2%) | 210 (51.6%) | 840 (52.1%) |
| **BMI** | | | |
| Mediaan [Min, Max] | 25.6 [14.5, 59.8] | 26.0 [12.5, 60.3] | 25.7 [12.5, 60.3] |
| Missing | 50 (4.1%) | 13 (3.2%) | 63 (3.9%) |
| **ICU admissions** | | | |
| Planned | 193 (16.0%) | 64 (15.7%) | 257 (15.9%) |
| Unplanned | 1013 (84.0%) | 343 (84.3%) | 1356 (84.1%) |

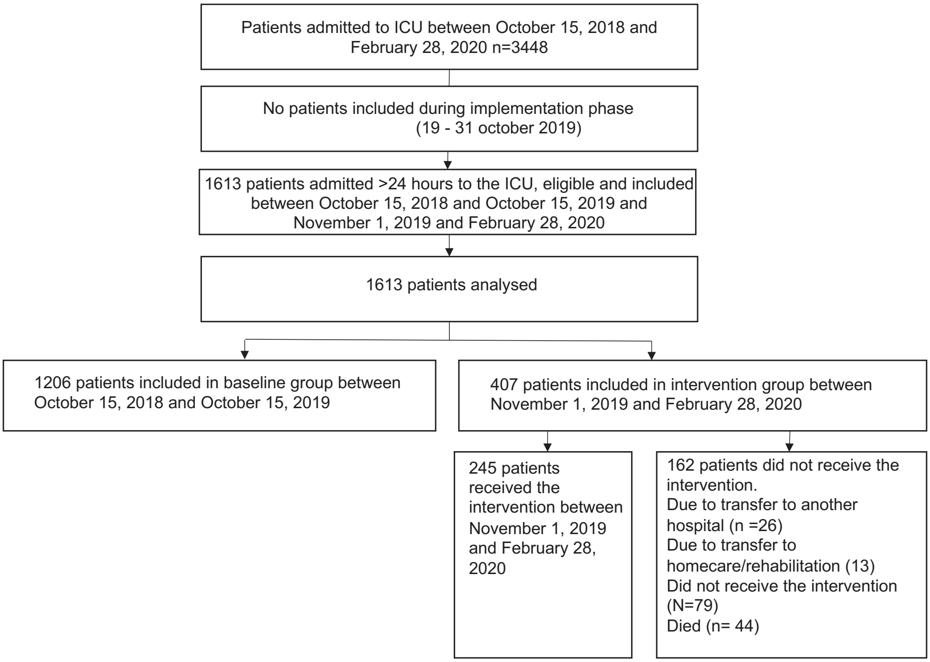

**Figure 1.** Patient Flow Diagram.

## Primary outcome ICU readmission rates

The absolute number of patients readmitted to the ICU within 24 hours in the baseline group was 29 (2.1%) and five (1.2%) in the intervention group. Due to the small number of events in the intervention group, statistical analysis of this variable (readmission within 24 hours) was not possible. There were no significant differences in the absolute proportions of patients readmitted to the ICU within 48 hours after ICU discharge (b=0.00, se=1.00, 95% CI [-2.12- 1.82] or within 72 hours (b=0.25, se=0.99, 95% CI [-2.41 - 1.49]. Primary outcomes are presented in Table 2.

## Secondary outcomes

There were no significant differences in ICU LOS (b=-0.10, se=0.18, 95% CI [-0.44- 0.24 ], hospital LOS (b=0.07, se=0.18, 95% CI [-0.29- 0.43], as well as for ICU mortality rates (b= -0.88, se=0.91, 95% CI [-2.90- 0.69]) and in-hospital mortality rates (b=-0.88, se=0.91, 95% CI [-2.90- 0.69]). Secondary outcomes were corrected for gender, BMI and MEWS, and the results are presented in Table 2.

**Table 2.** Primary and secondary outcomes.

| | Baseline group (N=1206) | Intervention group (N=407) | Total (N=1613) |
|---|---|---|---|
| **Primary outcomes**<br>**24h ICU Readmission** | | | |
| No Readmission | 1177 (97.6%) | 402 (98.8%) | 1579 (97.9%) |
| ICU Readmission 24h | 29 (2.4%) | 5 (1.2%) | 34 (2.1%) |
| **48h ICU Readmission** | | | |
| No Readmission | 1160 (96.2%) | 393 (96.6%) | 1553 (96.3%) |
| ICU Readmission 48h | 46 (3.8%) | 14 (3.4%) | 60 (3.7%) |
| **72h ICU Readmission** | | | |
| No Readmission | 1147 (95.1%) | 389 (95.6%) | 1536 (95.2%) |
| ICU Readmission 72h | 59 (4.9%) | 18 (4.4%) | 77 (4.8%) |
| **Secondary outcomes**<br>**ICU LOS in days** | | | |
| Median [Min, Max] | 2.70 [1.00, 99.0] | 2.89 [1.00, 94.5] | 2.77 [1.00, 99.0] |
| **Hospital LOS in days** | | | |
| Median [Min, Max] | 11.7 [1.00, 183] | 11.4 [1.00, 175] | 11.6 [1.00, 183] |
| **Mortality** | | | |
| ICU mortality | 179 (14.8%) | 45 (11.1%) | 224 (13.9%) |
| In-hospital mortality | 248 (20.6%) | 69 (17.0%) | 317 (19.7%) |

# DISCUSSION

In this interrupted time-series study on ICU patients who did or did not receive a critical care outreach service (CCOS), the numbers of ICU readmissions within 24, 48, and 72 hours were similar in the intervention group and the usual-care group. Furthermore, we found no effects of the CCOS on ICU LOS, ICU mortality, or in-hospital mortality.

These results are not in line with those of two previously published systematic reviews (SR)(11, 12). Osterlind et al. focused on CCOS that aimed to improve the clinical handover, and they included fifteen studies that implemented a CCOS, including RRTs as an intervention. They found that CCOS and RRT were associated with a reduced risk of readmission and in-hospital mortality (only CCOS) after ICU discharge. In our study, we implemented the CCOS in addition to the pre-existing RRT which suggests that high-risk patients were already detected by the RRT. This may be a possible explanation for our findings.

Another review by Garry et al. (2019) included ten studies, focused solely on a nurse-led CCOS, and reported a reduction in hospital mortality in 80% of the studies (18). However, in only four studies the reduction was significant (18). However, in this review, studies with a pre-existing MET service were included.

Another reason why our study showed no important effects, is that Dutch readmission rates are already very low. Among the 82 ICUs in the Netherlands, ICU readmission rates vary from 0.14 to 2.7, and further reductions are difficult to show.

In this study, we focused on ICU readmission as the primary outcome to evaluate

CCOS, a transitional care intervention. Therefore, we assumed that this outcome may be affected by otherwise improving continuity of care during the transition from the ICU to the general ward. However, the assumption that ICU readmission is a consequence of failures in the process of the transition from the ICU to the general ward is questionable in highly-rated ICUs (31).

In line with the reviews of Osterlind et al. and Garry et al. we offered the CCOS to all patients who were transferred from the ICU to the general ward. We did not make a risk assessment for high-risk patients, who could benefit more from this service. In our study, the CCOS continued for at least 24 hours after transfer from the ICU to the general ward. Although that both the CCOS and ward nurse agreed on ending the CCOS follow-up, it may be is possible the CCOS was prematurity stopped. There is no clear consensus on how long the follow-up service should be continued for optimal impact, particularly for high-risk patients (14). Also, we implemented a nurse-led CCOS, previous studies with more multidisciplinary teams did show a reduction in readmission rates and mortality rates (11).

Several other studies have shown that nurse-led services focusing on primary Family Caregivers (FC) engagement appeared to be effective in reducing re-hospitalizations (32, 33, 34). In addition, recent studies encourage the patient and their family to initiate a clinical review by a CCOS because they may be the first to identify ominous signs of clinical deterioration before this is detected by healthcare professionals (35, 36, 37). This raises new possibilities for future research, especially focusing on the effects of a CCOS on the prevention of PICS or PICS-F.

This study has some strengths and limitations that need to be considered. First, we used an ITS analysis, which is arguably a strong quasi-experimental design (38) and is considered to be a valuable alternative for randomized clinical trials (39, 40). Second, we included a large sample size of 3448 patients and had sufficient pre-intervention time points to gain insight into existing pre-intervention trends in readmissions rates. Furthermore, we did not include COVID-19 data, as this extraneous change in context could have influenced our outcomes (41). Third, we used Bayesian analysis, which can be valuable for providing new clinical insights, including clinically relevant probabilities (42).

The most important limitation is the retrospective study design, including all the eligible patients without a proper sample size calculation.

A second limitation is that this was a single-center study, with an already low readmission rate. Therefore, our results may not be generalizable to other ICUs with different readmission rates. We did not include severity of illness as a risk factor, and this may have resulted in bias.

Another limitation is that we had random incomplete data which is a known problem in retrospective studies (43). Therefore, we made use of multiple imputation which is considered as an appropriate strategy to deal with incomplete continuous data (44). The results on non-imputed data did not differ substantially from imputed data. Despite correcting for several factors, we cannot exclude other important factors as confounders.

Lastly, although we were unable to perform a formal statistical analysis on the 24-hour readmission rates, we noticed an absolute reduction in re-admission of almost 50% in the intervention group (from 2.4% to 1.2%). However, readmission rates after 48 and 72 hours were comparable between groups. In this study, our analysis was based on the intention-to-treat principle (45), but only 245 patients out of 407 received the intervention as intended. This may have influenced our results.

## CONCLUSION

In this study, ICU patients who received a critical care outreach service did not have significantly lower ICU readmission rates, ICU LOS, or mortality. In the future, it may be more valuable to focus both the intervention and evaluation on outcomes for patient and family members who are at risk for long-term burden such as PICS and PICS-F.

***CRediT Author Statement***

***SAJJ op 't Hoog, corresponding author:*** *Conceptualization, Methodology, Validation, Investigation, Resources, Data Curation, Writing - Original Draft, Project administration.* ***Lilian CM Vloet****: Conceptualization, Writing - Review & Editing, Supervision.* ***Mariëlle P.J. van Mersbergen-de Bruin:*** *Conceptualization, Methodology, Validation, Investigation, Resources, Data Curation.* ***Joran Jongerling****: Software, Formal analysis.* **Hans G. van der Hoeven:** Methodology, Writing - Review & Editing, Supervision. **Hester Vermeulen:** Writing- Review & Editing, Supervision. **Anne M. Eskes:** Conceptualization, Methodology, Writing - Original Draft, Writing- Reviewing and Editing, Supervision.

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**Data available on request from the authors**

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

**Conflicts of Interest**

The authors declare no conflict of interest.

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# 6

# A Quality Improvement Project to Support Post-Intensive Care Unit Patients with COVID-19: Structured Telephone Support

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# ABSTRACT

**Background**

More than 50% of intensive care unit (ICU) survivors suffer from long-lasting physical, psychosocial, and cognitive health impairments, also called "post-intensive care syndrome" (PICS). Intensive care admission during the COVID-19 pandemic was especially uncertain and stressful, both for patients and for their family. An additional risk of developing symptoms of PICS was feared in the absence of structural aftercare for the patient and family shortly after discharge from the hospital. The purpose of this quality improvement study was to identify PICS symptoms and to support post-intensive care patients and families in the transition from the hospital to the home. Therefore, we offered post-ICU patients and families structured telephone support (STS).

**Methods**

This was a quality improvement study during the 2019 COVID-19 pandemic. A project team developed and implemented a tool to structure telephone calls to identify and order symptoms according to the PICS framework and to give individual support based on this information. We supported post-ICU patients diagnosed with COVID-19 pneumonia and their family caregivers within four weeks after hospital discharge. The reported findings were both quantitative and qualitative.

**Results**

Forty-six post-ICU patients received structured telephone support and reported symptoms in at least one of the three domains of the PICS framework. More than half of the patients experienced a loss of strength or condition and fatigue. Cognitive and psychological impairments were reported less frequently. Family caregivers reported fewer impairments concerning fatigue and sleeping problems and expressed a need for a continuity of care. Based on the obtained information, the ICU nurse practitioners were able to check if individual care plans were optimal and clear and, if indicated, initiated disciplines to optimize further follow-up.

**Conclusions**

The implementation of the STS tool gave insight in the impairments of post-ICU patients. Surprisingly, family caregivers expressed fewer impairments. Giving support early after hospital discharge in a structured way may contribute to providing guidance in the individual care plans and treatment of the early symptoms of PICS (-F).

**Keywords**

Intensive care unit; family-centered care; nurse-led; evidence-based quality improvements; COVID-19

# INTRODUCTION

Since March 2020, the world has faced the outbreak of COVID-19 pneumonia, which has led to enormous pressure on the healthcare system.[1] Although the majority of individuals infected with COVID-19 develop mild symptoms and recover without hospitalization, some patients require intensive critical care.[2]

In the Netherlands, the first COVID-19 infection was confirmed on 27 February 2020. Since the outbreak, more than 13,550 patients with a COVID-19 infection have been admitted to the ICU.[3,4] Currently, 20% of all Dutch ICU beds are occupied by COVID-19 patients. On average, six ICU patients per day were admitted with COVID-19 in July 2022.[5] At the peak of the first "wave", hospitals gradually increased the number of ICU beds from 1150 (6.4 beds per 100,000 citizens) to 1700 during March and April 2020. The COVID-19 pandemic has directly affected local ICU hospital policies, including isolated nursing, increased visitor restrictions, and time restraints to give appropriate information to patients and their families.[6,7] Furthermore, patients with a COVID-19 infection can rapidly deteriorate to complete respiratory failure with severe consequences and a high risk of mortality.[8] This uncertainty of the progress of the disease and changing hospital policies may negatively influence the newly experienced health burden after ICU discharge for patients and family caregivers already at risk of developing post-intensive care syndrome (PICS)[9] and post-intensive care syndrome—family (PICS-F).[9]

During the COVID-19 pandemic, no structured aftercare was organized for post-ICU patients.[10] There is little evidence on the effectiveness of interventions to reduce the impact of PICS (-F) during the transition after ICU admission and follow-up care.[11,12] However, early follow-up during the transition may help to detect patients and families at risk for PICS early; improve the information provision to patients, families, and other healthcare professionals; and start early interventions.[11] Currently, COVID-19 patients occupy 20% of all Dutch ICU beds. On average, six ICU patients per day were admitted with COVID-19 in July 2022.[5] Due to the COVID-19 pandemic, access to healthcare and communication strategies are still limited. As a result, patients, family members, and healthcare workers experienced psychological symptoms such as stress, anxiety, depression, and fear, which may lead to burnout.[13,14] Virtual patient- and family-centered communication is recommended to improve meaningful communication between healthcare workers and patients and their family members.[15] Telehealth, including video or audio communication such as structured telephone support (STS), has been fully embraced as an intervention to keep the patient and family involved.[16,17] Several studies describe the positive impact of telehealth, which may reduce the impact of social isolation.[18–20] Negro et al. (2020) describes a structured intervention by video-calls in ICUs for patients and their family members.[21] Initiating communication between patients and close family members can improve the emotional experience and potentially reduce the psychological burden. In addition, several studies describe that meeting patients' and family members' needs also may reduce the stress systems of professionals.[22–24]

STS includes an individual assessment of the patient's and/or family's needs, which may be an appropriate intervention in the context of a persistent pandemic.[25] Based on previous research in heart failure patients, it has been shown that STS improves patient outcomes by reducing mortality and readmission rates.[26,27] It also results in higher patient satisfaction rates, better care experiences, fewer post-discharge problems, enhanced self-management, and lower costs.[28–31] A recent study showed that 90% of the post-ICU patients with COVID-19 who received STS follow-up reported symptoms within at least one PICS domain.[32] At 1 month after discharge, more than one-third of patients reported acute stress disorders or cognitive impairments.[32] Within 3 and 6 months after discharge, 90% of patients still reported symptoms within one PICS domain and reduced health-related quality of life (HRQoL).[33–35] Even after one year of survival after critical COVID-19, survivors reported frequent symptoms within at least one PICS domain.[36] The primary aim of this quality improvement project was to provide support to post-intensive care patients and families; therefore, we developed and implemented an STS tool for post-intensive care patients and families in the transition from the hospital to the home. The STS intervention was undertaken by ICU nurse practitioners and underpinned by the PICS framework.[9] It comprised several short questions focusing on the different post-ICU problems patients can experience with PICS (i.e., physical, mental, and cognitive consequences). Second, to provide a deeper understanding of the long-term impairments of post-ICU patients and their families, we report the findings of the STS in the PICS framework.[9]

## MATERIALS AND METHODS

In this quality improvement study, post-ICU patients treated for COVID-19 pneumonia received an STS within four weeks post-discharge to home. We used both quantitative and qualitative methods integrated in the Deming cycle, as reported by the criteria of the revised Standards for Quality Improvement Reporting Excellence 2.0 framework.[37]

### Study Design and Setting

This was a quality improvement initiative during the COVID-19 pandemic in a Dutch tertiary hospital. This hospital has a 34-bed, mixed medical (neuro) surgical ICU with a 24/7 intensive care service delivered by ICU nurses and intensivists.[38] During the outbreak of COVID-19, the ICU capacity in this hospital was upgraded to 40 beds to guarantee care for both COVID-19 patients and regular ICU patients.

## Population and Sampling

We offered STS to all post-ICU patients diagnosed with COVID-19 pneumonia, as proven by a reverse transcription–polymerase chain reaction (RT-PCR) test, who were discharged home in the period of 7 March 2020 to 15 May 2021. If family members were involved, they were also asked to participate.

## Description of the Intervention

### *Plan*

At the start of the COVID-19 pandemic, the project team, including three ICU nurse practitioners (SH, MO, MP), an ICU physician, and nurse researchers, rapidly developed an STS tool—the so-called "STS Post-ICU COVID-19 tool". The purpose of developing and implementing the tool was to structure a telephone support intervention to screen the symptoms experienced by post-ICU patients, divided into the three domains of the PICS framework. By asking about all the domains of PICS in a structured way, we tried to identify where the most symptoms and thus the greatest needs are in their individual treatment plan. During the phone interview, all symptoms were asked about in a structured way and noted using the STS Post-ICU COVID-19 tool. Then, the ICU nurse practitioner discussed with the patient and/or family whether there was sufficient support at home or whether additional support was required. Based on a rapid search of the literature from Medline/PubMed, focusing on systematic reviews, we identified evidence of the effectiveness of the use of STS intervention on patient outcomes.[26,27] Consequently, we combined the well-known PICS framework[9,39] and local knowledge of our team to define the content of the STS intervention for our population.

Figure A1, Appendix A visualizes the final developed STS Post-ICU COVID-19 tool, which is a structured digital pocket card that focuses on the three domains of the PICS framework (physical, cognitive, and psychological function).[9] In addition to this, we added one question about ICU experiences and two questions (5a and 5b, Figure A1, Appendix A) to assess the mental health and symptoms of the family caregiver.

### *Do*

After development, we implemented the STS Post-ICU COVID-19 tool into daily practice. To support the use of the tool, we developed smart phrases (i.e., blocks of text that can automatically be pasted into the patient's Electronic Health Record (EHR)).

Three ICU nurse practitioners (SH, MO, and MP) conducted the intervention within four weeks after the patients' hospital discharge to home. Due to the rapid implementation strategy due to COVID-19, the ICU nurse practitioners were not trained in the telephone support. Therefore, the ICU nurse practitioners discussed a strategy for the telephone call beforehand, and the tool provided sufficient structure for the telephone support to have a uniform procedure. All post-intensive care patients who were discharged from hospital to home were offered an STS within four weeks after hospital discharge.

Each STS call started with a short review of the patient's experiences in the ICU. All questions, per the PICS domain, were asked using the structured format of the STS intervention. The occurrence of PICS symptoms per domain was assessed by patients using a four-point scale ranging from "no burden" to "very much". In addition to this score, patients were asked to provide additional information to concretize the symptoms and report-initiated interventions or advice. This information was also reported in the EHR. Lastly, if family members were involved, they were asked about their psychosocial symptoms. If not, then patients were asked to assess the symptoms of their family members or next of kin. Each call lasted 20–60 min.

### *Check*

We described the gathered symptoms that patients and family caregivers reported during the STS. Therefore, we collected demographical data including age, gender, body mass index (BMI), and pre-existing comorbidities. Furthermore, we used the Acute Physiology and Chronic Health Evaluation IV (APACHE IV) to estimate the risk of short-term mortality and the length of the ICU stay.[40] The Sequential Organ Failure Assessment[41] was used to describe the severity of organ failure during ICU admission. We recorded the number of mechanical ventilation days, the length of stay (LOS) in the ICU, and the LOS in the hospital. All clinical data were retrospectively collected from the EHR. The data from the STS Post-ICU COVID-19 tool were used to describe identified domains of PICS in numbers and percentages. As appropriate, quantitative and continuous data were expressed as means with the standard deviation (SD) or as medians with interquartile ranges (IQRs). All data were analyzed using a statistical software package (SPSS Inc., version 24, Chicago, IL, USA). Additionally, we collected the free text of the reported consultations from the EHR and processed it anonymously into a text database for qualitative analysis. First, we checked if there was additional information reported about PICS symptoms according to the PICS framework (Supplementary Table A1, Appendix B). Second, we collected data on reported patients' needs, initiated interventions, and nursing problems. To support the data collection, we constructed an easy-to-use table that structured the data per patient. The data collection tables were pilot tested by three researchers (SH, AE, and JB) through independent data collection. Discrepancies in interpretation were resolved through discussion.

After pilot testing, two independent researchers read all of the notes from the structured telephone reports line by line (JB and SH). Both researchers (JB and SH) scrutinized the data by coding and extracting quotes [42]. In addition, a final category frame was made to structure all the relevant data into the three predetermined categories. The thematic matrix is attached in Supplementary Table S1. Both of the researchers categorized the data separately and discussed differences until a consensus was reached.

# RESULTS

In total, 49 post-ICU patients received an audio/video call in which the STS tool was used. The patient flow diagram shows the flow of patients (Figure 1); in three cases, data were missing because no information was reported. The first post-ICU patient who participated was admitted to the ICU on March 12, 2020, and the last patient was admitted on March 2, 2021. The median time between the ICU discharge and the interview was 37 days (IQR 24–54). The demographics and clinical characteristics of the included patients are presented in Table 1.

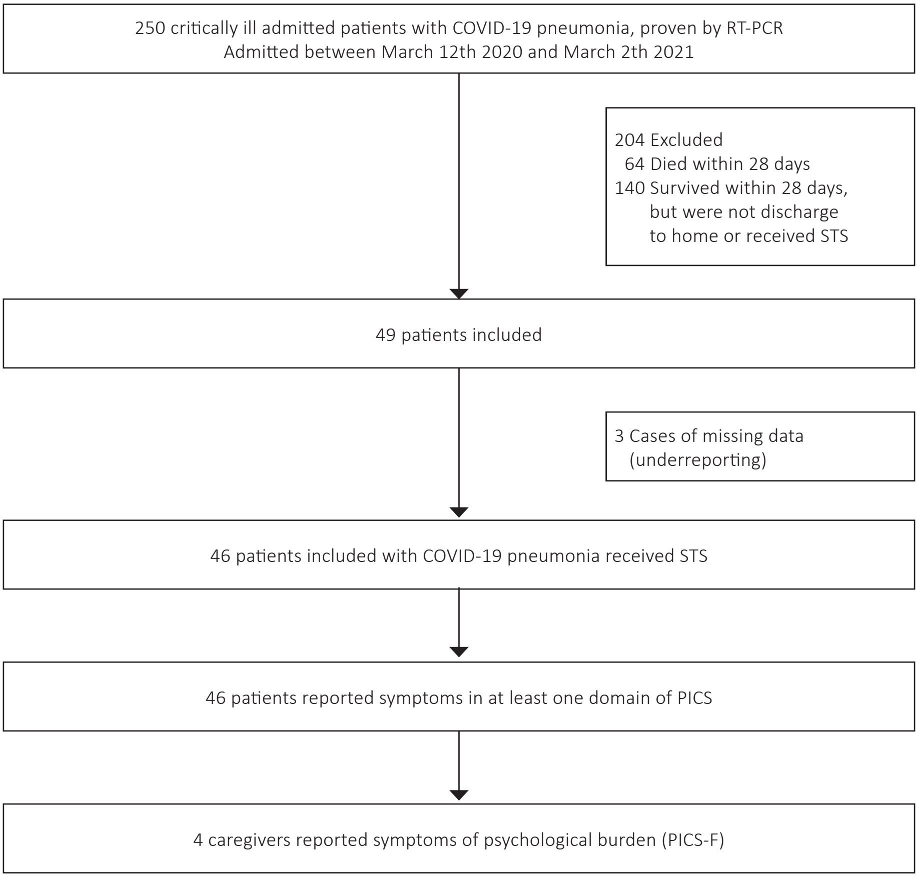

**Figure 1.** Patient flow diagram.

**Table 1.** Baseline characteristics of the patients with COVID-19 pneumonia.

| Received STS | Number of Patients |
|---|---|
| Age (years) (median, IQR) | 62 (56–67) |
| Male gender (N, %) | 35 (75%) |
| BMI (kg/m$^2$) (median, IQR) | 26.9 (24.6–31.7) |
| **Pre-existing comorbidities (N, %)** | 14 (30%) |
| Obesity (BMI$^3$ 30 kg/m2) | 13 (28%) |
| Hypertension | 4 (9%) |
| Congestive heart failure | 8 (17%) |
| COPD | 9 (19%) |
| Diabetes mellitus | 3 (6%) |
| Cerebrovascular disease | 7 (15%) |
| Malignancy | 3 (6%) |
| Chronic renal disease | 5 (11%) |
| Auto-immune disorder | 46 (100%) |
| **Severity of illness** | 6 (13%) |
| Sepsis-3, sepsis (N, %) | 47 (36-59) |
| Sepsis-3, septic shock (N, %) | 4 (2–6) |
| APACHE IV (points) (median, IQR) | 41 (89%) |
| SOFA (points) (median, IQR) | 5 (11%) |
| **ICU therapy during ICU stay (N, %)** | 36 (78%) |
| Invasive mechanical ventilation | 4 (9%) |
| HFNO only | |
| Vasoconstrictive agents | 12 (6-22) |
| Renal replacement therapy | 21 (13–34) |
| **ICU outcome** | 46 (100%) |
| Duration of invasive mechanical ventilation (days) (median, IQR) | |
| ICU LOS (days) (median, IQR) | |
| Hospital LOS (days) (median, IQR) | |
| 28-day survival (N, %) | |

Legends: All continuous data are presented as the median (interquartile range), and all categorical data are presented as a number (percentage).
BMI: body mass index, COPD: chronic obstructive pulmonary disease, APACHE IV: Acute Physiology and Chronic Health Evaluation IV, SOFA: Sequential Organ Failure Assessment, HFNO: high-flow nasal oxygen, LOS: length of stay.

## Reported PICS Symptoms

Table 2 details the scored symptoms of PICS with the Post-ICU COVID-19 tool. We described each element of PICS and combined the quantitative data from the structured tool and the qualitative data extracted from the text of the consultation reports of the ICU nurse practitioners as quotes (R#). After the structured questioning with the tool, there was also room to discuss other symptoms or to question symptoms in more depth. This additional information was reported as loose text. From this text, we organized the additional symptoms and describe them in Table A1 (Appendix B). Table A2 (Appendix B) shows an inventory of the professionals involved in the individual care plans of the post-ICU patients included.

**Table 2.** Elements of post-intensive care syndrome (PICS)[9] scored by the STS Post-ICU COVID-19 tool.

| **Physical Function, N = 46**<br>**Reported Physical Symptoms (Median 7.0, IQR 5–8.75)** | | | | | |
|---|---|---|---|---|---|
| | **Not** | **Not Very much** | **Quite a Lot** | **Very Much** | **Not Assessable** |
| Loss of muscle strength | - | 17 (37%) | 25 (54%) | 3 (7%) | |
| Loss of condition | - | 11 (24%) | 27 (59%) | 6 (13%) | |
| Respiratory failure | 11 (24%) | 18 (39%) | 12 (26%) | 3 (7%) | |
| Fatigue | 5 (11%) | 10 (22%) | 19 (41%) | 10 (22%) | |
| Neuropathy | 27 (59%) | 11 (24%) | 4 (9%) | - | |
| Cognitive function (median 4.0, IQR 0–7.75) | | | | | |
| Inability to plan | 24 (52%) | 7 (15%) | 6 (13%) | - | 8 (17.4%) |
| Memory loss | 29 (63%) | 13 (28%) | 4 (9%) | - | - |
| Inability to concentrate | 29 (63%) | 10 (22%) | 5 (11%) | - | 1 (2%) |
| Inability to multitask | 22 (48%) | 9 (20%) | 7 (15%) | 1 (2%) | 7 (15%) |
| Overstimulation | 30 (65%) | 10 (22%) | 6 (13%) | - | - |
| Psychological burden (median 0.0, IQR 0.00–1.00) | | | | | |
| Feelings of anxiety | 33 (72%) | 10 (22%) | 2 (4%) | 1 (2%) | |
| Feelings of depression | 40 (87%) | 4 (9%) | - | 2 (4%) | |
| Symptoms of PTSD | 38 (83%) | | 8 (17%) | | |
| Caregivers’ reported burden | | 42 (91.3%) | 3 (6.5%) | | 1 (7.6%) |

Legends: All continuous data are presented as the median (interquartile range)
PTSD: Post Traumatic Stress Disorder.

### Physical Symptoms

All the patients experienced physical symptoms (n = 46). Over 60% of the patients experienced a loss of strength or condition. Fifty-four percent of patients reported the loss of muscle strength as “quite a lot”, and 59% reported the loss of condition as “quite a lot”. Dyspnea was scored as “very much” by 7% (n = 3) of the patients and as moderate by 26% (n = 12 patients). Fatigue was reported by 89% of patients (n = 39), and 22% (n = 10) of the patients reported this as intensely present.

The most frequent additional physical symptoms reported by the patients were dyspnea, poor condition, pain, and limited mobility. In particular, pain while breathing and fatigue were often mentioned as a limitation of daily function:

> *“In his own words, he sometimes ‘gasps for breath’”* (R#7).

Patients experienced additional physical symptoms such as oedema of the legs and sleeping problems. Sleeping problems were often mentioned, sometimes due to dyspnea, nocturnal urination, or psychological symptoms. If sleep problems were mentioned, a classification was lacking.

> *“I still have a lot of thoughts; I sleep an average of 2 to 3 h a night”* (R#15).

In addition, patients experienced weight loss and ICU-acquired weakness.

> *"Fine motor skills can still be improved, tingling in toes, colder hands are described"* (R#46).

**Cognitive Symptoms**

Cognitive symptoms were less frequently reported; the inability to plan (13%, n = 6), the inability to multitask (15%; n = 7), and overstimulation (13%; n = 6) were reported as "quite a lot". In addition, patients' symptoms regarding cognitive dysfunction were reported, especially memory loss (9% reported this as "very much") and concentration problems. Memory loss causes limitations in daily functioning and sometimes in the context of work.

> *"Patient cannot carry out his work as a lawyer because of fatigue and memory loss"* (R#3).

**Psychological Symptoms**

All patients experienced psychological symptoms; most of the symptoms were signs of Post-Traumatic Stress Disorder (PTSD) and were reported as "quite a lot" in 17% of cases (n = 8). The most mentioned symptoms of anxiety were excessive worry and irritability. Patients expressed their concerns about COVID-19 and feared a recurrence of illness.

> *"Patient expresses difficulties to deal with visitors because of fearing a recurrence of COVID-19"* (R#14).

During the telephone consultations, emotions were often still present. For some patients, the conversation was still too tiring or had too much of an impact. Some patients explained a state of avoidance around memories of the ICU and described flashbacks, including nightmares.

> *"Patient becomes emotional several times—nightmares, thoughts of the delirium he experienced. He mentioned, he was tied up, wanted to take out the ventilator. He understands that this was necessary, but now he has terrible thoughts about it that continue to haunt him"* (R# 15).

**Caregivers' Symptoms**

In nine cases, caregivers participated in the video or telephone call. In 91.3% (n = 42) of cases, caregivers reported experiencing "not very many" symptoms. In four cases, the caregivers did report psychological symptoms. Most symptoms concerned fatigue and sleeping problems: *"The caregiver is more tired lately, sleeps worse, since last days" (R#5).*

When caregivers participated in the phone calls, they could explain which symptoms were present; in other cases, the patients themselves described the symptoms of their relative or caregiver. Fatigue, anxiety, flashbacks, and nightmares were experienced as symptoms.

> *"Anxious son, doing better, very afraid [for] his father's health and the possibility of him getting a relapse of COVID"* (R# 24).
> *"Husband sleeps only one hour a night, because he dreams of time in ICU" (R# 36).*

In one case, relational problems were reported:

> *"Patient experiences stress from memories of the ICU admission, and this manifested itself in problems in communication with his family members (informal caregivers)"* (R#26).

**Patients' Needs**

Based on the reported symptoms, the nurse practitioners detected patients' needs based on their reported experience and symptoms. Patients especially mentioned the need for a continuity of care. This manifested itself primarily in the specific need for clear communication with their (primary) healthcare practitioners and clarity about follow-up at home. In addition, family caregivers expressed their need to be seen and heard in their role as informal caregivers. As a result, the ICU nurse specialist scheduled a follow-up meeting to listen to their experiences again as an aftercare measure. When healthcare practitioners were not involved, the ICU nurse specialist actively referred patients or caregivers to healthcare practitioners. In several cases, the ICU nurse specialist contacted the general practitioner or a medical specialist to improve the care plan—for instance, when symptoms had worsened or new symptoms had appeared. For some patients, the ICU nurse specialist could provide clarity about their admission into the ICU and provide information to meet their needs. Patients and family members always received an informal invitation to seek contact with the ICU nurse specialist in case of new problems. In some cases, the ICU nurse practitioners initiated extra follow-up calls for evaluating initiated advice and monitoring symptoms. Table A2, Appendix B shows an overview of the inventory of professionals already involved in the individual care plans of the post-ICU patients included.

# DISCUSSION

This study describes a quality improvement during the COVID-19 pandemic using the "STS Post-ICU COVID-19 tool". We offered structured telephone follow-up care to post-ICU patients who were discharged from the hospital to the home within four weeks after hospital discharge. Forty-six post-ICU patients experienced physical symptoms, whereas cognitive and psychological symptoms were reported less. Almost two-thirds of the participating patients mentioned a loss of strength and condition. Family caregivers expressed the need for a continuity of care and experienced fewer symptoms.

Recent studies focused on physical function, reported fatigue, and muscle weakness as the most common symptoms after ICU admission with COVID-19 pneumonia.[43] We compared our study with a recent Dutch multicenter study that included 246 patients who were alive one year following ICU treatment for COVID-19.[44] In this study, 74.3% reported physical symptoms, 26.2% reported mental symptoms, and 16.2% reported cognitive symptoms.[44] These findings are in line with our own. It is notable that our intervention was a self-report and was conducted shortly after hospital discharge (within 4 weeks). Another Dutch study including post-ICU patients without COVID-19 reported similar rates in terms of physical and cognitive symptoms. The rates of psychological symptoms were higher in this study.[45] Martillo et al. found a high prevalence (91%) of PICS elements in 45 COVID-19 post-ICU patients in a similar study with telephone follow-up after 1 month post-discharge. In this cohort, 87% reported physical impairments.[32] A study from Italy found reduced functional capacity in post-ICU patients with COVID-19 at 2 months post-hospital discharge.[46] The cardiopulmonary performance was presumably better in this study than in cohorts with other forms of ARDS. Carenzo et al. also highlighted the mildly reduced overall quality of life and a high proportion of PTSD symptoms at 6 months.[46] Halpin et al. (2020) implemented a similar rapid structured telephone tool, ordered by the International Classification of Functioning, Disability, and Health instead of the PICS classification we used.[47] Several studies reported physical symptoms such as fatigue, breathlessness, and psychological distress in COVID-19 survivors (n = 201) 14 and 20 days after hospital discharge.[47,48] In our study, we performed a follow-up at a median of 37 days (IQR 27-54), and our findings are in line with these aforementioned studies.[47,48]

A possible explanation for the high rate of physical symptoms is the higher proportion of ICU patients who received mechanical ventilation. A recent review showed that the number of ICU patients requiring mechanical ventilation during ICU admission increased from 20–40% in the period before COVID-19 to 63–87.3% during the COVID-19 pandemic.[49] Furthermore, the usual standards of care, such as the ABCDEF bundle, were not always practically feasible, which ideally would contribute to preventing PICS-F.[50–52] The symptoms of the family caregivers in our study were unexpectedly low. In nine cases, caregivers reported their concerns, and in the other cases, patients were asked to assess the symptoms of their caregiver; these assessments may have differed from the perceptions of the caregivers themselves. Nevertheless, the risk of suicide and self-harm has been associated with ICU admission when patients have pre-existent psychological conditions such as anxiety, depression, or PTSD.[53] This new insight supports the need for an individual assessment to determine the risk of developing symptoms of PICS and to initiate early interventions.

In our study, cognitive function scored low (“not”/“not often”), which is not in line with the current literature. The incidence of cognitive impairment after one year post-ICU was determined to be 43%.[54] In our study, patients were interviewed shortly after hospital discharge and were asked to self-assess their cognitive function. Early after discharge, the focus of most patients was on physical rehabilitation. Cognitive impairments may reveal themselves later; several studies have reported cognitive symptoms after a follow-up period of 2–156 months.[54–56] The self-assessment of cognitive function may be insufficient. Moreover, cognitive problems such as difficulty concentrating and multitasking often come to light when work and social obligations are resumed. However the early onset of symptoms and the need for extra help could be detected and could be helpful in reducing long-term PICS complaints.

The incidence of psychological symptoms was relatively low overall, except for the number of patients who reported PTSD symptoms (n = 8, 17%). A meta-analysis found that one-fifth of ICU survivors reported symptoms of PTSD after one year in the period before COVID-19. These numbers suggest that the psychological impact is high among survivors who have had “good” outcomes because they were discharged to home. We expect the numbers to be higher at a 6- or 12-month follow-up, as the impact on daily life becomes more apparent. However, recent studies report otherwise.[44] The caregivers in this study are underrepresented because they only participated in the consultations in a few cases. The few who reported their experience did describe psychological symptoms. Experts caution that the COVID-19 pandemic may have a greater impact on PICS-F numbers as family caregivers experience more awareness of the limitations of this crisis.[57] For family caregivers, a proactive follow-up call may have a positive impact in allowing them to share their experience and burden in order to access help early. Although several studies have described the burden on ICU patients with COVID-19 and their families after hospital discharge, there is less evidence of initiated interventions. Before the COVID-19 pandemic, there was little evidence of interventions that could prevent long-term symptoms such as those caused by PICS.[12]

This study describes a quality improvement in a single-center context and with a small sample size. Another limitation to mention is the fact that we only included patients discharged from the hospital to the home, which may not be representative of the whole population of ICU patients in this period. Almost one-third of COVID-19 patients admitted to Dutch ICUs died in the hospital.[58] The majority of the ICU patients admitted during this study period were transferred to a rehabilitation centre or nursing home and received a structured rehabilitation care plan. For patients discharged to home, a structured care plan was lacking. Secondly, not all eligible patients received interventions due to limited staff capacity during the COVID-19 pandemic, and not all calls from patients were answered. In addition, a substantial group of ICU patients were transferred to another ICU because of hospital bed capacity problems during the pandemic. This may have led to selection bias. In addition, we know that having a loved one admitted to the ICU can have a major impact on family caregivers, especially during the COVID-19 pandemic.

Nevertheless, family caregivers are underrepresented in this study, but they may have suffered more because the limited access to healthcare affected this group during the COVID-19 pandemic. This study substantiates that a structured, early inventory of PICS may potentially contribute to the proactive deployment of quality improvements. However, owing to a lack of time due to COVID-19, we did not perform an appropriate validation of the protocol. This tool may be beneficial for post-ICU patients and families in general in a non-pandemic setting. Further research is needed to validate and evaluate the effectiveness of structured tools to help professionals identify patients' needs. In addition, cognitive function was measured by self-assessment; this may have resulted in reporting bias. Lastly, the effect of the coordinating role of nurse practitioners remains underrepresented in this study. In further research, we recommend focusing on the process of individual care planning during complex transitions after ICU admission. Before COVID-19, Dutch ICU aftercare was not structured or structural.[8] Whether aftercare should be structured or more individually based is a topic of debate. Therefore, an early inventory may provide guidance for individual care plans during the transition period from the hospital to the home.

## CONCLUSIONS

To conclude, this quality improvement study shows that post-ICU patients and their family caregivers experienced symptoms of the PICS framework, identified at an early stage of post-discharge with the STS tool. Post-ICU patients diagnosed with COVID-19 pneumonia all reported symptoms in at least one of the three elements of the PICS framework. The most common symptom was physical burden in all patients, and symptoms of PTSD were also notable. We recommend individually planned early-onset rehabilitation and for more structured attention to be paid to family caregivers. Further research and follow-up are crucial, as COVID-19 is a new illness and post-discharge symptoms and long-term follow up are yet to be researched.

## Supplementary Materials

The following are available online at: https://www.mdpi.com/article/10.3390/ijerph19159689/s1. Table S1. Qualitative data quotes and categories ordered by PICSframework.

## Author Contributions

Conceptualization, S.A.J.J.o.‘t.H., A.M.E., H.V. and L.C.M.V.; methodology, S.A.J.J.o.‘t.H., A.M.E., H.V. and L.C.M.V.; software, S.A.J.J.o.‘t.H., M.W.J.C.P.-S., M.O. and J.A.H.v.O.; validation, S.A.J.J.o.‘t.H., J.L.B. and L.C.M.V.; formal analysis, S.A.J.J.o.‘t.H., J.L.B., M.O. and A.M.E.; investigation, S.A.J.J.o.’t.H.; resources, J.A.H.v.O., M.O. and J.A.H.v.O.; data curation, S.A.J.J.o.‘t.H.; writing—original draft preparation, S.A.J.J.o.‘t.H. and A.M.E.; writing—review and editing, S.A.J.J.o.‘t.H., H.V., J.G.v.d.H., L.C.M.V. and J.A.H.v.O.; visualization, S.A.J.J.o.‘t.H., H.V., J.G.v.d.H., L.C.M.V. and J.A.H.v.O.; supervision, H.V., J.G.v.d.H. and L.C.M.V. All authors have read and agreed to the published version of the manuscript.

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## Institutional Review Board Statement

The study was conducted in accordance with the Medical Research Ethics Committee Brabant, The Netherlands, and approved by the ETZ research board under the number NW2020-76, and the local hospital research protocol was provided with the research number L1079.2020.

## Informed Consent Statement

Not applicable.

## Data Availability Statement

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

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## Conflicts of Interest

The authors declare no conflict of interest.

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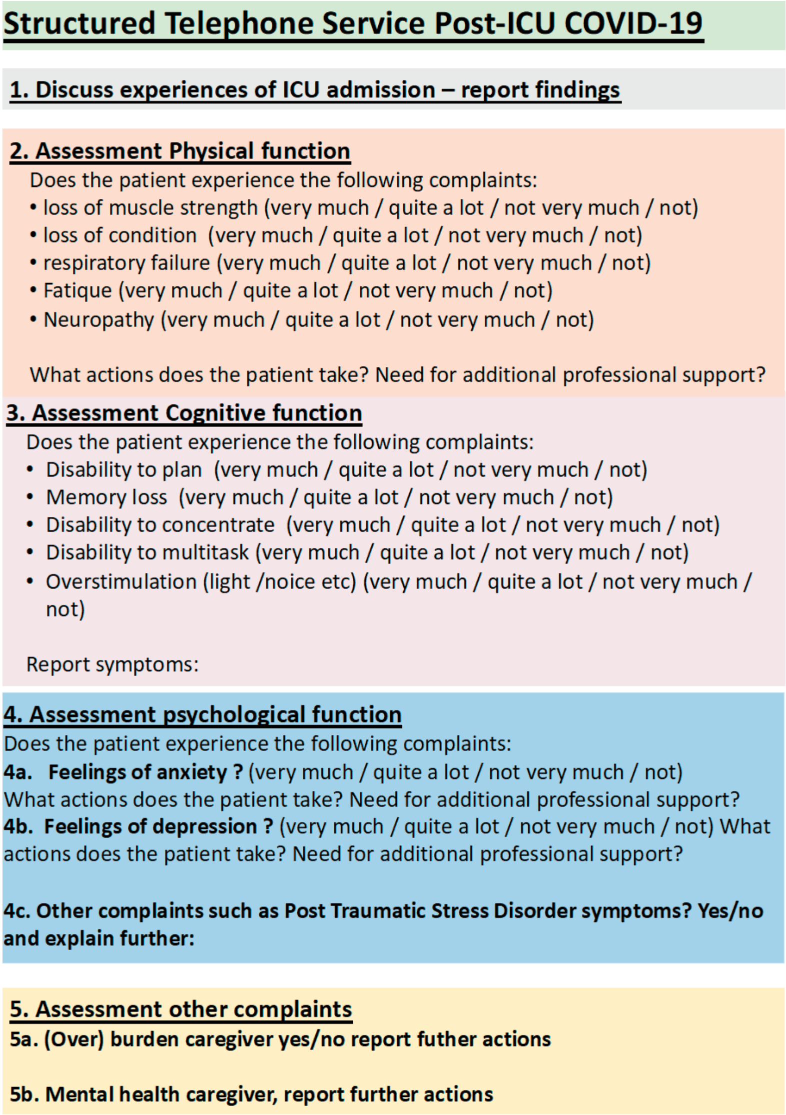
# APPENDIX A



**Structured Telephone Service Post-ICU COVID-19**

**1. Discuss experiences of ICU admission – report findings**

**2. Assessment Physical function**

Does the patient experience the following complaints:

- loss of muscle strength (very much / quite a lot / not very much / not)
- loss of condition (very much / quite a lot / not very much / not)
- respiratory failure (very much / quite a lot / not very much / not)
- Fatique (very much / quite a lot / not very much / not)
- Neuropathy (very much / quite a lot / not very much / not)

What actions does the patient take? Need for additional professional support?

**3. Assessment Cognitive function**

Does the patient experience the following complaints:

- Disability to plan (very much / quite a lot / not very much / not)
- Memory loss (very much / quite a lot / not very much / not)
- Disability to concentrate (very much / quite a lot / not very much / not)
- Disability to multitask (very much / quite a lot / not very much / not)
- Overstimulation (light /noice etc) (very much / quite a lot / not very much / not)

Report symptoms:

**4. Assessment psychological function**

Does the patient experience the following complaints:

**4a. Feelings of anxiety ?** (very much / quite a lot / not very much / not)

What actions does the patient take? Need for additional professional support?

**4b. Feelings of depression ?** (very much / quite a lot / not very much / not) What actions does the patient take? Need for additional professional support?

**4c. Other complaints such as Post Traumatic Stress Disorder symptoms? Yes/no and explain further:**

**5. Assessment other complaints**

**5a. (Over) burden caregiver yes/no report futher actions**

**5b. Mental health caregiver, report further actions**

**Figure A1.** Structured Telephone Service Post-ICU COVID-19.

# APPENDIX B

**Table A1.** Additional symptoms ordered by Post Intensive Care Syndrome (PICS).

| PICS Category N = 46 | Quote |
|---|---|
| **Physical Elements** | |
| Dyspnoea | *“In his own words, he sometimes ‘gasps for breath’” (r. 7)* |
| Poor condition | *“Showering and climbing stairs still consume a lot of energy” (r. 29)* |
| Poor mobility | *“Walking short distances in the house are still quite difficult” (r. 48)* |
| Sleeping problems | *“Still has a lot of thoughts, sleeps an average of 2 to 3 hours a night” (r. 15)* |
| Oedema in legs | *“Patient suffers from swollen feet, especially during the day” (r. 36)* |
| Weight loss | *“Patient lost weight, 18 kg in total. Now, gained another 2.5 kg” (r. 7)* |
| ICU-acquired weakness | *“Fine motor skills can still be improved, tingling in toes, colder hands are described” (r. 47)* |
| **Cognitive elements** | |
| Memory loss | *“Patient cannot carry out his work as a lawyer because of fatigue and memory loss” (r. 3)* |
| Attention/concentration problems | *“Slightly slower thinking ability, suited to the situation” (r. 26)* |
| **Psychological element** | |
| Anxiety, excessive worry | *“Patient expresses difficulties to deal with visitors because of fearing a recurrence of COVID-19” (r. 14)* |
| Anxiety, irritability | *“Patient states that sometimes he is a bit more/quicker irritated” (r. 33)* |
| Avoidance | *“Patient explains he experiences avoidance around the memories” (r. 37)* |
| Flashbacks, nightmares | *“Patient becomes emotional several times – nightmares, thoughts of the delirium he experienced. He was tied up and wanted to take out the ventilator. He understands that this was necessary, but now he has terrible thoughts about it that continue to haunt him” (r. 15)* |
| **Caregivers’ burden** | |
| Fatigue | *“Caregiver is a bit more tired” (r. 47)* |
| Anxiety | *“Anxious son, doing better, very afraid [for] his father’s health and the possibility of him getting a relapse of COVID” (r. 24)* |
| Relational, systemic problems | *“Patient experiences stress from memories of the ICU admission, and this manifested itself in problems in communication with his family members (informal caregivers)” (r. 26)* |
| Flashbacks, nightmares | *“Husband sleeps only one hour a night, because he dreams of time in ICU” (r. 36)* |

**Table A2.** Inventory of professionals involved in the individual care plans of the post-ICU patients included.

| **Type of Professional Involved** | ***n* = 46 (%)** |
|---|---|
| Physiotherapist | 33 (71.7) |
| Speech therapist | 4 (8.7) |
| Dietician | 11 (23.9) |
| Psychologist | 6 (13) |
| Ergotherapist | 2 (4.3) |
| Rehabilitation practitioner | 6 (13) |
| Social worker | 2 (4.3) |

# 7

# General discussion

# GENERAL DISCUSSION

For ICU patients and their relatives, appropriate care does not stop at the doors of an ICU. No matter at what point the patient and their relatives are in their recovery journey, they should always remain the center of our care (12, 13). In the ICU, we organize high-tech care around the patient to ensure survival with optimal outcomes. This has led to an upward trend in survival rates, but also leads to new challenges. During the last decade, multiple studies have shown that patients discharged from the ICU suffer from long-term physical, mental, and cognitive disturbances, the so-called Post-Intensive Care Syndrome (PICS) (2, 3). Also relatives suffer from mental disturbances (PICS-Family) (3). The wide range of variety in PICS and PICS-F problems requires a person- and family centered approach (14).

For patients and families, the multiple transitions through the healthcare system create ‘gaps’ in care. The challenge for health professionals is to ensure continuity of care across care domains (15, 16). To focus more on long-term survival and bridge the gaps in the fragmented care landscape, it requires transitional care interventions (17). Recalibrating this focus, raises the question, which outcomes are relevant to patients and their relatives? Therefore, an understanding of the experiences and needs of patients and their relatives is needed. Again, the impact in the long run is making it more relevant to start ICU treatment in the first place. Therefore, we see that next to the traditional wide range of medical outcomes (18), growing evidence shows ICU survivors have unmet needs, especially after the acute phase, in which relatives often play a role as caregivers (16, 19). Another question is, which outcomes are relevant to learn as an organization to organize the right care at the right place? (20, 21) If we agree that critical care includes care beyond the ICU or even beyond the hospital, a focus shift towards transitional care is needed to ensure continuity of care across the entire care continuum (12, 22).

As we outlined in the general introduction, a patient’s pathway to recovery is often unique, which precludes a one-size-fits-all strategy. However, a constant factor is that each patient and family goes through several transitions. Reducing the impact of these multiple transitions and optimizing continuity of care is a challenge in health care for both professionals and researchers, with up until now no golden standards (23, 24). Some experts suggest focusing more on context-based practice (22). In this thesis, we tried to expand the existing knowledge by investigating the following two research questions:

1. What are the experiences of relatives of ICU patients during the patient’s transition from the ICU to a general ward?
2. How can transitional care be improved to create a better continuity of care for ICU survivors and their relatives?

Furthermore, we aimed to evaluate if bottom-up nurse-led evidence-based projects in a local context can improve continuity of care. We evaluated this by properly mapping the process in a safety II approach. We will reflect on the content of this thesis based on our lessons learned and make recommendations for clinical practice and future research.

## Main findings

### *Part 1: the transition for ICU patients and relatives*

Hospitals have made tremendous progress in improving ICU care which is shown by the fact that 90% of admitted patients survive an ICU admission (25). Unfortunately, the flip side is seen as well: approximately 50 to 70% of the surviving ICU population including their relatives face physical, cognitive or psychological impairments (PICS) (3, 22). Therefore, it is important to understand how they experience the transition from ICU care to a general ward. Based on in-depth interviews (**Chapter 2**), we concluded that the relatives of ICU survivors experience a sense of relief (1) and uncertainty (2) during the transition from ICU to a general ward. They expressed their need to healthcare professionals to acknowledge relatives in their role of becoming a caregiver (3), to share expectations (4), and receive continuity in care (5) during this transition.

To improve the process of care transition, we systematically reviewed all available evidence on transitional care interventions for ICU patients and assessed the effectiveness of these interventions on symptoms of PICS and PICS-F **(chapter 3).** However, the results were disappointing. The five studies included in this review showed no evidence that transitional care interventions have an important effect on physical or psychological aspects of PICS or PICS-F with the exception for a nurse-led structured follow-up program, which showed a significant improvement in physical functioning at 3 months.

### *Part 2: nurse-led evidence-based quality improvements to improve transitional care*

Obviously, a high standard of care should be organized for the sickest and most expensive patient population, also during the transition from ICU to general wards. Unfortunately, the latter is not always the case (26). Australian colleagues developed a nurse-led transitional care intervention to smoothen the transfer for ICU patients to general wards (27, 28). This intervention appeared to be promising as it made the transition safer and less anxious for patients, relatives and nurses (29). Hence, we used this model as a basis to redefine a nurse-led intervention appropriate to the context of our local (Dutch) hospital setting. First, to learn from everyday practice in our context, we gained insight in how the intervention performed after implementation, the so-called, work-as-done (WAD) (10). We created a learning effect with the professionals involved by visualizing the process and analysing the differences in the process from the initial, conceived work-as-imagined (WAI). We used the Functional Resonance Analysis Method (FRAM) (10) to visualize the redefined nurse-led Critical Care Outreach Service (CCOS) as presented in **chapter 4**. With the insights of the process of both WAI and WAD, we assessed the effectiveness of the CCOS using an interrupted time series design (**chapter 5).** In this study, we showed that the CCOS did not significantly reduce ICU readmission rates after 24-, 48- or 72-hours and did not shorten ICU length of stay. We were unable to perform a formal statistical analysis on the 24-hour readmission rates, but we noticed an absolute reduction in re-admission rates of almost 50% in the intervention group (from 2.4% to 1.2%). However, readmission rates after 48, and 72 hours were comparable between groups.

Lastly, we undertook an initiative during the COVID-19 pandemic, to optimize transitional care for post-ICU COVID-19 patients, and their relatives (**chapter 6**). We rapidly designed and implemented a nurse-led structured telephone support (STS) to early identify PICS symptoms and to support post-intensive care patients and relatives in the transition from the hospital to home. This tool was used by ICU nurse practitioners who (video- called the patients and relatives to check if individual care plans were optimal and clear, and if indicated, initiated appropriate consultation from other disciplines to optimize further follow-up. All patients who received the STS intervention (n= 46) reported symptoms in at least one of the three domains of the PICS framework (3) Family caregivers reported fewer impairments but expressed a need for continuity of care. We concluded that also in a dramatically changed context, a STS tool might help healthcare professionals to provide guidance in an individualized care plan during transition from ICU to home.

## Lessons learned

### *The value of context- and practice based research*

In this rapidly changing healthcare landscape, there is a need to conduct socially relevant and practical research. It is key to engage patients and relatives in this research (30). This engagement requires more attention to determining what influences the context of our systems of care, organizations, and networks. In this thesis, we started from the perspective of the experiences and needs of patients and relatives, in order to determine which gaps in continuity of care require improvement (31). To improve care, evidence based interventions should be first of choice. However, we found little evidence on transitional care interventions to build a stronger pathway for patients and families. Despite an increasing amount of experience-based co-design research (30), the evidence is limited on how we should frame patient- and family-centered ICU care in the continuum of care (26, 32). Although several studies show that family engagement does no harm and is even beneficial, for example, for readmission rates (33). Still, active engagement of relatives during the whole continuum of care it is not the norm in everyday practice. To find more rationale for patient-and family centered care for the ICU population, it is essential to involve patients and family members in this research (24). Patient- and family engagement requires more attention to determining what influences the context of our healthcare systems, organizations and networks. The advantage is that we can learn as an organization and become more agile (34).

The Dutch Council for Public Health and Society is pleading the case for context-based practice rather than evidence-based practice: *"This is because of the importance of the specific context, the patient and the setting where the various sources of knowledge are used as the basis for the decisions that are taken. This goes beyond a more local implementation of external knowledge. It means a continuous process of learning and improving together. It also signifies a different approach to education, research, and supervisory practices"*(30) As a result, the current Dutch policy encourages a greater focus on practice-based research, as the Dutch Minister of Education, Culture and Science *(Minister Dijkgraaf)* states that knowledge infrastructure on practice-based research must be further developed. In the next 10 years, the ministry will invests 100 million euros for further development of practice-based research (35).

Learning from local practice can be done by combining quantitative and qualitative research methods (30). In this thesis, we used various practice-based research methods to attempt to uncover a complex local context. First, we presented Quality Improvements (QIs), which were designed and implemented by integrating the local context and health care professionals. Ideally, each QI should start from a perspective of the patient and their relatives (33). Although we started this thesis with the experiences of relatives of ICU patients (3) we were not able to integrate this perspective during the design of both QIs. We concluded that if we understand better what the patient' and relatives experiences are, this perspective in clinical practice will help us look, learn, and reconsider our existing processes. Therefore, we can underline that, for further research, patients and relatives should play an active role in designing, implementing, and evaluating interventions to value this perspective and evaluate the real impact: the answer to the needs of the patient and their relatives (33). We recommend giving relatives active roles to meet and redefine expectations and needs. This fits into the current paradigm, where we expect as a society that roles of patients and relatives act less as consumers and more as participants. With the growing scarcity of resources and professionals in healthcare systems, there is a growing urgency for families to take on caregiving responsibilities, which puts family engagement in a different light. At some point, family engagement may become a forced solution to keep healthcare available, especially in countries with lower income economies. Family engagement could improve care while also addressing the health worker shortage. We conclude from our work that pre-conditional relatives ask for guidance in this matter (21, 31, 36). Therefore, future research needs to focus on identifying facilitators and barriers to implementing patient- and family centered care. To learn what a family needs in a specific context, it is necessary to incorporate this perspective into every step of research.

Second, context- and practice based research is needed to customize appropriate care for ICU survivors and their relatives to reduce the short- and long-term impacts (22, 37). We learned that organizing care during transitions after ICU is not a one-size-fits-all solution, which is underlined in the newest published Dutch guideline: Aftercare and Rehabilitation of Intensive Care Patients, 2022 (24). This guideline recognizes the knowledge gap on effective interventions for preventing the long-term symptoms of PICS and PICS-Family (3). One of the key recommendations is to appoint an ICU aftercare coordinator (e.g., a nurse, nurse specialist) who is responsible for ensuring the continuity of aftercare. In this thesis, we present examples of nurse-led interventions that can contribute to continuity of care. We recommend that healthcare professionals, researchers, and policymakers explore how nurses and nurse practitioners can expand this coordinating role in their own context. Investing in coordinating roles is helpful in meeting the primary needs of relatives of ICU patients for guidance and continuity of care. Adapting this role to the local context can increase the adaptability of systems and potentially build a more agile organization (38, 39).

### Considerations for healthcare professionals, leaders, educators, and policymakers: If you do it, better do it well

Health is an important value for everyone. It is of value to every one of us to be able to count on good, accessible, and affordable care (20). To maintain these values, we need to change the way we organize health care. Ideally, decisions regarding life-prolonging treatments, such as treatment in an Intensive Care Unit (ICU), include careful consideration of the benefits and risks (40-42). ICU treatment requires a sincere and thoughtful, conversation between patients, relatives, and healthcare professionals. During this conversation, healthcare professionals should provide information on the potential impact of an ICU admission, including the long-term effects (43, 44). Especially, for vulnerable patients or relatives, enough insight is needed to re-think a high impact treatment in ICU, which most likely may change a human and family's life irreversibly.

If after careful consideration (Shared Decision Making, SDM), a decision is made for ICU treatment, it is essential to realize that these patients' need support throughout the entire care continuum. This includes giving guidance to patients and their relatives during the multiple transitions of the whole road towards a new life 'post-ICU'. To get there, networks in healthcare should seek collaboration to mark this population as 'complex' and provide individualized care, at every step of the chain (24). Although PICS is a recognized syndrome (3, 34) and there is consensus on the prediction and identification of long-term disability after critical illness (34), detection and follow-up care has not yet been established as standard care. We have attempted to set up the framework for identification and early guidance in care plans after discharge home using a structural telephone support system and integrated the PICS framework (35). This QI exemplified the role of a nurse practitioner, who can give guidance to patients and their relatives by taking an early inventory. A call to action to create a cross-domain perspective for professionals in clinical practice, policymakers, researchers, and educators to put more effort into expanding the coordinating function to organize 'care' after the 'cure'. With the expectation that by 2030 there will be an 18 million health care professionals' shortage worldwide, solutions with more professionals are out of the question (37). Doing the right thing requires a sharp focus on which ICU patients are at risk for complaints such as PICS and PICS-F and providing targeted, customized transition care. This issue reaches not only ICU patients and relatives, but also all vulnerable patient populations. With the right professional, early, proactive detection of complaints and needs helps address minor care issues before they become major issues. Patients and relatives ask for guidance to prevent the need to search for themselves in an overburdened healthcare system or 'wait for the wrong care'. Both tasks, early recognition and coordination of care, are vested in nurses and nurse practitioners; they have a unique relationship with patients and their relatives (38) because they literally stand beside the patient and their relatives. To target, we suggest using existing models such as the Transitional Care Model (30) to integrate and structure care plans through the chain (39). Across all systems and layers, we need to address these transitional care interventions by nurses and nurse practitioners to give them more coordinating roles.

The best ideas are born in everyday practice by professionals themselves. To offer more tailored care with the same volume of professionals requires organizing care smarter and differently. To appeal to the current group of professionals to start designing care systems differently, we need to start investing in this challenge among this group of professionals. We conclude that if we look closer at the process of a critical care outreach service, other outcomes remain underexposed, such as collaboration, knowledge transfer, and leadership empowerment. Earlier studies showed that outreach services facilitate educational support for ward nurses and for junior doctors on the ward (45). An easily accessible service such as outreach services helps to recognize and learn from clinical deterioration situations, which are still human factors addressed in nursing care (45, 46). Although the number of outreach services is growing, they are still not the norm worldwide (47).

In this thesis, we illustrate with two nurse-led quality improvement interventions how current ICU nursing teams are able to design nurse-led interventions With the same number of nurses, a new team was implemented as a complex intervention in everyday practice. Moreover, we show that nurse practitioners are able to combine both cure and care needs, and assume a coordinating role for ICU patients and families that can be cross-domain (48). We conclude that EHealth is promising to support transitions toward home, may be an accessible and practical tool. The studies of is thesis contributes to the body of knowledge about the experiences and needs of patients and their relatives during transitions in the road to recovery after intensive care. This thesis also gives practical examples of nurse-led interventions using the same existing teams that are agile enough to take on other tasks that cross borders. We hope that, by our examples, we may inspire healthcare professionals and healthcare organizations in their networks to invest in the development, implementation, and evaluation of nurse led transitional care interventions in their local contexts.

A constantly changing healthcare landscape requires agile professionals, and innovation must become a standard focus in education, research, and everyday practice. However, this shift will not happen by itself. Bringing the system, and thus healthcare professionals, into the movement is high on the agenda of healthcare executives. Major transition issues require changes in everyday practice to make an impact. We invite and encourage all professionals to search for inspiration to (re)design best practices in their own context.

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# 8

Summary
Nederlandse samenvatting (Dutch summary)
Data management plan
Curriculum Vitae
Curriculum Vitae in Dutch
List of publications
PhD portfolio
Dankwoord

# SUMMARY

Patients treated in intensive care units (ICU) undergo frequent health care transitions during their road to recovery. These transitions affect not only the patient but also their relatives. For healthcare professionals, it is challenging to ensure continuity of care across these transitions. To improve continuity of care, evidence-based transitional care interventions can be useful to implement in daily practice. These interventions should fit the preferences of patients and families and improve patient outcomes. Therefore, this thesis contributes to the body of knowledge on the experiences and needs of patients and their relatives during transitions in the pathway of intensive care. Second, this thesis presents examples of the development, implementation, and evaluation of nurse-led transitional care interventions for this patient group.

**Part 1: The transition for ICU patients and relatives**
To understand the needs of relatives, we described in **Chapter 2** that relatives of ICU patients experience a gap in the continuity of care during the transition from intensive care to a general ward. Relatives of ICU patients experience a sense of relief and, on the other hand, uncertainty. Relatives express the need to be recognized as family caregivers, and they want to share their expectations with professionals to experience better continuity of care. Relatives confirm that nurses can play an essential role in this process.

To explore how to address these needs and improve transitions after an ICU stay, we searched the literature for transitional care interventions that aim to smooth the transition from the ICU to wards and home. **Chapter 3** described the study, where we systematically reviewed all the relevant literature and assessed the effectiveness of these interventions on long-term impact, defined in terms of PICS and PICS-F. Of the five studies, including varied transitional care interventions, we found no evidence of the effects of transitional care interventions on the physical, cognitive or psychological aspects of PICS or PICS-F, except for a nurse-led structured follow-up program that showed a significant difference in physical function at 3 months.

**Part 2: nurse-led, evidence-based quality improvements to improve transitional care**
As relatives experienced gaps during the transition phase **(Chapter 2)**, and insufficient evidence of effective transitional care interventions is available **(Chapter 3)**, we systematically developed and implemented a new nurse-led intervention to improve continuity of care after ICU in a local Dutch hospital setting. In 2019, we implemented a nurse-led Critical Care Outreach Service (CCOS). Both the context of a hospital as a system and the intervention to smooth the continuity of care are complex. Therefore, we used safety II approach, which embraces both complexity theories and implementation science. In **Chapter 4**, we describe the implementation process of the CCOS using the

Functional Resonance Analysis Method (FRAM) to visualize the intervention in work as imagined (WAI) and work as done (WAD). Juxtaposing the WAI and WAD FRAM models showed the WAD contained more (additional) functions than the WAI and highlighted functions that were more complex than expected. FRAM revealed success factors of the interventions, such as the easy access to CCOS, the peer-to-peer coaching style, and friction between roles and expectations.

Evidently, we were also interested in whether CCOS improved patient outcomes. Therefore, in **Chapter 5**, we tested the effectiveness of the CCOS on ICU readmission, ICU length of stay, and mortality rates. We included over 3000 patients and compared patient outcomes using an interrupted time series design. We found no significant evidence that a CCOS reduces ICU readmission rates after 24-, 48- or 72-hour or the ICU length of stay, or the risk of dying during hospitalization.

In the year 2020, the outbreak of COVID-19 required drastic reorganization of ICU care. Intensive care admission during the COVID-19 pandemic was especially uncertain and stressful, both for patients and for their relatives. We anticipated an increase in PICS in the absence of structural aftercare for the patient and family shortly after discharge from the hospital. Therefore, in **Chapter 6**, we described another quality improvement project to identify PICS symptoms and to support post-intensive care patients and their relatives in the transition from the hospital to home. Within this project, we developed and implemented a tool to support post-ICU patients and their relatives. With the use of structured telephone calls to identify symptoms according to the PICS framework we organized individual support based on this information within four weeks after hospital discharge. In total, forty-six post ICU patients received structured telephone support, and all reported symptoms in at least one of the three domains of the PICS framework. For more than half of the patients, the main impairments were loss of strength or condition and fatigue. Cognitive and psychological impairments were reported less frequently. The caregivers reported fewer impairments concerning fatigue and sleeping problems and expressed a need for continuity of care. Based on the obtained information, the ICU nurse practitioners were able to check if individual care plans were optimal and clear and, if indicated, initiate disciplines to optimize further follow-up.

**Chapter 7** describes the main findings of this thesis, where we discussed the role of bottom-up, nurse-initiated, quality improvement initiatives (EBQI) and how they contribute to a continuum of care in the complex context of today's health care system. The methodological and study limitations were described for proper interpretation of our findings. We reflect on our lessons learned by describing the value of context- and practice based research. We conclude that the studies described in this thesis contribute to the body of knowledge about the experiences and needs of patients and their relatives during transitions on the road to recovery after intensive care. In a broader perspective, this thesis also gives practical examples of nurse-led interventions using the same existing teams that are agile enough to take on other tasks that cross borders.

# SAMENVATTING (DUTCH SUMMARY)

Patiënten die in een Intensive Care Unit (ICU) worden behandeld, ondergaan tijdens hun weg naar herstel vaak meerdere transities. Deze transities hebben niet alleen gevolgen voor de patiënt, maar ook voor diens naasten. Voor zorgprofessionals is het een uitdaging om de continuïteit van zorg tijdens deze transities te waarborgen. Evidence-based interventies kunnen bijdragen om de continuïteit van zorg in de dagelijkse praktijk te verbeteren, zoals tijdens de transitie van Intensive Care (IC) naar verpleegafdeling of naar huis. Idealiter sluiten deze interventies aan bij de ervaringen en behoeften van patiënten en familieleden, en leveren ze betere patiëntuitkomsten op. Dit proefschrift draagt bij aan de kennis over de ervaringen en behoeften van patiënten en hun naasten tijdens transities in hun hersteltraject na een ICU-opname. Ten tweede beschrijven we in dit proefschrift voorbeelden van de ontwikkeling, implementatie en evaluatie van verpleegkundig-geïnitieerde interventies voor deze patiënten en familieleden ter verbetering van de continuïteit van zorg.

**Deel 1: de overgang van IC naar verpleegafdeling voor IC-patiënten en familieleden**
Om de behoeften van familieleden te begrijpen hebben we in **hoofdstuk 2** beschreven dat naasten van IC-patiënten een hiaat in de continuïteit van zorg ervaren tijdens de transitie van Intensive Care (IC) naar verpleegafdeling. Tijdens deze transitie ervaren naasten van IC patiënten enerzijds een gevoel van opluchting en anderzijds onzekerheid. Naasten geven de behoefte aan om erkend te worden in hun rol als (toekomstige) mantelzorger. Ook hebben naasten de behoefte om verwachtingen in hun rol als mantelzorger af te stemmen met professionals. Hierin bevestigen deze naasten dat verpleegkundigen een essentiële rol spelen om naasten te betrekken bij het zorgproces en meer continuïteit te bieden. Om inzicht te krijgen in hoe gehoor te geven aan deze behoeften en transities na een IC-opname te kunnen verbeteren, is wetenschappelijk bewijs nodig. Wij hebben daarvoor in de literatuur gezocht naar de effectiviteit van interventies die erop gericht zijn de transitie van de IC naar de verpleegafdelingen en naar huis te verbeteren. **Hoofdstuk 3** beschrijft dit literatuuronderzoek waarbij we systematisch alle relevante literatuur analyseren op de effectiviteit van verschillende interventies gericht op de transitiemomenten na een IC opname, zowel tijdens een ziekenhuisopname als naar huis. We beoordeelden studies op het langetermijneffect, gedefinieerd in termen van Post Intensive Care Syndroom (PICS) en ook Post Intensive Care Syndroom - Familie (PICS-F). Van de vijf studies met verschillende transitie-interventies vonden wij geen bewijs voor transitie-interventies op lichamelijke, cognitieve of psychologische aspecten van PICS of PICS-F. Met uitzondering van één studie waarbij verpleegkundigen een gestructureerd follow-up programma aanbieden aan IC-patiënten, wat een significant verschil liet zien in het lichamelijk functioneren na 3 maanden na ontslag.

## Deel 2: Verpleegkundig- geïnitieerde kwaliteitsverbeteringen om de transitiezorg te verbeteren

Deel 1 laat zien dat naasten van IC-patiënten hiaten ervaren tijdens de transitie van IC naar verpleegafdeling **(hoofdstuk 2)**, en er onvoldoende bewijs is voor effectieve transitie-interventies **(hoofdstuk 3)**. Daarom hebben we systematisch een nieuwe verpleegkundig-geïnitieerde transitie-interventie ontwikkeld en geïmplementeerd in een Nederlandse ziekenhuissetting. Met als doel om de continuïteit van zorg voor IC-patiënten en hun naasten te verbeteren. In 2019 werd deze interventie geïmplementeerd, een zogeheten Nurse-led, Critical Care Outreach Service (CCOS). De interventie alsook de context van een ziekenhuis als zorgsysteem, zijn complex. Hiervoor gebruikten we een safety II-benadering die zowel complexiteitstheorieën als implementatiewetenschap omarmt.

In **hoofdstuk 4** beschrijven we het implementatieproces van de CCOS met behulp van de Functional Resonance Analysis Method (FRAM) om de interventie te visualiseren in work as imagined (WAI) en work as done (WAD). Door de FRAM-modellen WAI en WAD naast elkaar te zetten, werd duidelijk dat de WAD (extra) functies bevatte dan de WAI en dat de functies complexer waren dan verwacht. FRAM legde bloot wat de succesfactoren van de interventies waren, zoals de laagdrempelige benadering van de verpleegkundigen van de CCOS, alsook de coaching. Ook liet FRAM zien dat er een discrepantie was tussen rollen en verwachtingen. We concluderen dat FRAM-zorgprofessionals kan helpen om te reflecteren op hun eigen zorgprocessen in de dagelijkse praktijk en deze zo te kunnen verbeteren. Uiteraard waren we ook geïnteresseerd of CCOS als interventie, effect had op patiëntuitkomsten. Daarom onderzochten we in **hoofdstuk 5** de effectiviteit van de CCOS op IC-heropname, IC-opnameduur en mortaliteit. We includeerden meer dan 3000 patiënten en vergeleken de patiëntuitkomsten met behulp van interrupted time series. Wij vonden geen significant bewijs dat een CCOS het aantal IC-heropnames na 24, 48 of 72 uur, een kortere IC-opnameduur of het risico om tijdens de ziekenhuisopname te overlijden vermindert.

De uitbraak van COVID-19 in 2020 vereiste dat we de (IC-) zorg drastisch reorganiseerden. Voor zowel IC-patiënten als naasten waren IC opnames tijdens de COVID-19 pandemie extra onzeker en stressvol door geïsoleerde zorg. Bij gebrek aan structurele nazorg voor IC patiënten en hun naasten in de transitie van ziekenhuis naar huis, werd gevreesd voor een extra risico op het ontwikkelen van symptomen van PICS en PICS-F. Daarom beschreven wij in **hoofdstuk 6** een kwaliteitsverbeteringsproject om PICS-symptomen in kaart te brengen en post-intensive care patiënten en hun naasten te ondersteunen bij de transitie van ziekenhuis naar huis. Binnen dit project ontwikkelden en implementeerden wij een instrument om post-ICU patiënten en hun naasten te ondersteunen. Deze tool structureerde telefoongesprekken om symptomen te identificeren en te ordenen volgens het PICS-model en zo individuele ondersteuning te bieden op basis van deze informatie. Post-ICU-patiënten met de diagnose COVID-19 pneumonie en hun mantelzorgers werden binnen vier weken na ziekenhuisontslag benaderd via (video)bellen door een verpleegkundig specialist. In totaal kregen zesenveertig post-ICU patiënten gestructureerde telefonische ondersteuning en allen rapporteerden symptomen in ten minste één van de drie domeinen van het PICS-model. Voor meer dan de helft van de patiënten waren de belangrijkste beperkingen: verlies van kracht of conditie en vermoeidheid. Cognitieve en psychologische beperkingen werden minder vaak gemeld. De mantelzorgers meldden minder beperkingen met betrekking tot vermoeidheid en slaapproblemen en gaven aan behoefte te hebben aan continuïteit van zorg. Op basis van de verkregen informatie inventariseerden verpleegkundig specialisten de individuele zorgplannen en indien geïndiceerd, werden disciplines gevraagd om verdere follow-up te optimaliseren. **Hoofdstuk 7** beschrijft de belangrijkste bevindingen van dit proefschrift waarin we de rol van bottom-up, door verpleegkundigen geïnitieerde, interventies als kwaliteitsverbetering bespreken. We gaan in op de vraag hoe deze interventies kunnen bijdragen aan een continuüm van zorg in de complexe context van het huidige zorgstelsel. We beschreven de methodologische en studiebeperkingen voor een juiste interpretatie van onze bevindingen. Vervolgens reflecteren we op onze geleerde lessen door de waarde van context- en praktijkgericht onderzoek te beschrijven. We concluderen dat de studies van dit proefschrift bijdragen aan de wetenschappelijke kennis over de ervaringen en behoeften van patiënten en hun naasten tijdens transities in hun weg naar herstel na een IC-opname. In een breder perspectief geeft dit proefschrift ook praktische voorbeelden van verpleegkundig-geïnitieerde interventies waarin bestaande teams wendbaar genoeg zijn om andere taken op zich te nemen buiten hun oorspronkelijke domein.

# RESEARCH DATA MANAGEMENT

The data obtained during my PhD at the Radboud University Medical Center have been stored at the local secured drive: Research Data Management of the Elisabeth Tweesteden Hospital.

All folders are named in accordance with the chapters in this thesis. Every folder consists of at least the research proposal, the documents for the medical ethics committee, data analysis scripts, databases with raw and transformed research data, and the manuscript. The promotor of my PhD has access to this data. Access can be requested via the management of the Scientific Committee of the Elisabeth-Tweesteden Hospital, Tilburg, the Netherlands.

Data of the association study have been stored online in Data Research Manager, the electronic data capture system supported by the Elisabeth-Tweesteden Hospital. All databases are provided with the original scientific publications or are available from the first author at reasonable request. All studies were performed in accordance with the Good Clinical Practice principles and the Netherlands Code of Conduct for Research Integrity. We followed the International Committee of Medical Journal Editors (ICMJE) criteria for authorship. All studies involving human subjects were performed in accordance with the Declaration of Helsinki. The Medical Ethics committee for region Midden-Brabant,

gave approval to conduct these studies. No ethical consideration was requested for the systematic review in chapter 3. Full ethical consideration was waived by the Ethics Committee of Arnhem and Nijmegen for the study in chapter 4.

The data and informed consent forms will be stored for 15 years after termination of the particular study. Re-use of the data obtained in our studies is only possible with a renewed informed consent by the study participant as stated in the informed consent. Anonymous use of data or use for educational purposes are possible, if renewed informed consent is considered unreasonable. The datasets analyzed during these studies are available from the corresponding author on reasonable request.

# CURRICULUM VITAE

## Curriculum Vitae

Sabine (Adriana Johanna Josepha) op ‘t Hoog was born in Tilburg on the 16th of August 1988, the Netherlands. After finishing secondary school at 2college in Oisterwijk in 2000, she started studying nursing at the Koning Willem 1 College and later the Bachelor of Nursing at the HAN University of Applied Science in Nijmegen. She combined this scholarship with working as a nurse on surgical and non-surgical nursing departments. In 2013 she obtaining her intensive care nursing degree and worked as an ICU nurse in the Elisabeth-Tweesteden Hospital in Tilburg. After a few years, a deeper drive to improve transitional care for patients and their families was the motivation to start a Master Advance Nursing Practice at the HAN University of Applied Science. During this scholarship she visited 7 Australian hospitals to adapt new insights on critical care outreach services. This was the concept for the role of Nurse practitioner within the ICU in the Elisabeth-Tweesteden Hospital. During this period she started this PhD-trajectory which included design and implementing a nurse-led critical care outreach service, again based on the scientific evidence and best practices of Australian examples. Next to qualitative and quantitative studies she has studied to combine implementation science and complexity thinking, specific on safety II approaches to evaluate social innovations. In 2021 she focused more on palliative care and advance care planning as a nurse practitioner and in 2022 she started as a manager for the program nursing professional development and sustainable care in the Elisabeth-Tweesteden Hospital. Since 2019, she has been a board member of the nursing staff and board of nurse practitioners in the Elisabeth-Tweesteden Hospital. She also established a national network for intensive care nurse specialists in 2019. Since 2023, she has carried a role as a “young envoy” to highlight the nursing perspective in the context of appropriate care. In these various roles, the experiences and inspiration of this PhD trajectory will build on her continued work. The mission remains to encourage nurses, nurse practitioners, policy makers and board members to invest in bottom-up nurse-led innovations and evaluate it through multiple methodologies.

## Curriculum Vitae in Dutch

Sabine (Adriana Johanna Josepha) op ‘t Hoog is geboren in Tilburg op 16 augustus 1988. Na het afronden van de middelbare school aan het 2college in Oisterwijk in 2008 is zij verpleegkunde gaan studeren aan het Koning Willem 1 College en later de Bachelor of Nursing aan de HAN University of Applied Science in Nijmegen. Deze studie combineerde zij met het werken als verpleegkundige op chirurgische en niet-chirurgische verpleegafdelingen. In 2013 behaalde ze haar diploma intensive care verpleegkunde en werkte ze als IC-verpleegkundige in het Elisabeth Tweesteden ziekenhuis in Tilburg. Na enkele jaren was er een intrinsieke motivatie ontstaan om de transitiezorg voor patiënten en hun familie te verbeteren en een Master Advance Nursing Practice te starten aan de HAN university of applied science. Tijdens deze master bezocht zij 7 Australische ziekenhuizen om nieuwe inzichten over critical care outreach services te verkennen. Dit was het concept voor de rol van verpleegkundig specialist binnen de ICU in het Elisabeth-Tweesteden Ziekenhuis. Tijdens deze periode startte ze dit PhD-traject waarin focus lag op het ontwikkelen en implementeren van een verpleegkundige outreach service, gebaseerd op wetenschappelijk bewijs en best practices van Australische voorbeelden. Naast kwalitatieve en kwantitatieve studies heeft ze zich verdiept in het combineren van implementatiewetenschap en complexiteits-denken, specifiek gericht op safety II-benaderingen om sociale innovaties te evalueren. In 2021 richtte zij zich als verpleegkundig specialist meer op palliatieve zorg en advance care planning en in 2022 startte zij als manager voor het programma verpleegkundige professionele ontwikkeling en duurzame zorg in het Elisabeth Tweesteden ziekenhuis.

Sinds 2019 is ze bestuurslid van de verpleegkundige staf en het bestuur van verpleegkundig specialisten in het Elisabeth Tweesteden ziekenhuis. Ook zette zij in 2019 een landelijk netwerk op voor verpleegkundig specialisten voor intensive care. Sinds 2023 draagt zij een rol als ‘jong gezant’ om het verpleegkundig perspectief te belichten in het kader van passende zorg. In deze verschillende rollen zullen de ervaringen en inspiratie van dit PhD-traject voortbouwen in haar verdere werk. De missie blijft om verpleegkundigen, verpleegkundig specialisten, beleidsmakers en bestuursleden te stimuleren om te investeren in bottom-up verpleegkundig geleide innovaties en dit via meerdere methodieken te evalueren.

# LIST OF PUBLICATIONS

## This thesis

**Op‘t Hoog, S. A. J.J**., Dautzenberg, M., Eskes, A. M., Vermeulen, H., & Vloet, L. C. M. (2020). 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. Australian Critical Care, 33(6), 526-532.

**Op’t Hoog, S. A. J.J**, Eskes, A. M., van Mersbergen-de, M. P. J., Pelgrim, T., van der Hoeven, H., Vermeulen, H., & Vloet, L. C. M. (2022). The effects of intensive care unit-initiated transitional care interventions on elements of post-intensive care syndrome: A systematic review and meta-analysis. Australian Critical Care, 35(3), 309-320.

**Op ‘t Hoog, S. A.J.J.,** Eskes, A. M., van Oers, J. A., Boerrigter, J. L., Prins-Smulders, M. W., Oomen, M., ... & Vloet, L. C. (2022). A Quality Improvement Project to Support Post-Intensive Care Unit Patients with COVID-19: Structured Telephone Support. International Journal of Environmental Research and Public Health, 19(15), 9689.

**Op ‘t Hoog, S.A.J.J.,** A. M., van Mersbergen., Damen, N., Chaboyer, W., Weggelaar-Janssen, A.M., Vloet, L. C. & Vermeulen, H. Improving the quality of a nurse-led Critical Care Outreach Service using the Functional Resonance Analysis Method. Submitted to Journal of Patient Safety- April 2023

**Op ‘t Hoog, S.A.J.J.,** Vloet, L. C., A. M., van Mersbergen., Jongerling, J., van der Hoeven, H., Vermeulen, H., Eskes A.M. The impact of a nurse-led critical care outreach service to reduce ICU readmissions: an interrupted time series analysis. Submitted to Australian Critical Care- April 2023

## Other publications

**Op ‘t Hoog SAJJ.**, Lummel, E. Proactieve zorgplanning gesprek. Inspiratie, vakblad voor longverpleegkundigen. Juni 2023

**Op ‘t Hoog SAJJ.** TVZ uitgelicht: Ervaringen in de transitie van IC naar verpleegafdeling. TVZ- next. Maart 2023

**Op ‘t Hoog SAJJ.,** de Vos, AJBM. Lessons learned from Nursing Crisis Meetings: Qualitative study to evaluate nurses’ experiences and needs, accepted for publication - Nursing Open, 2022

**Op ‘t Hoog SAJJ**. 3 vragen over het verpleegkundig crisisoverleg in ETZ. Nursing. 14 Januari 2022. https://www.nursing.nl/3-vragen-over-hetverpleegkundig-crisis-overleg-in-etz

**Op ‘t Hoog SAJJ**., Mersbergen, M. De inzet van een consultatief IC-verpleegkundige als triage interventie tijdens de eerste COVID-19 golf. Venticare juni 2022

**Op ’t Hoog, SAJJ**. Verpleegkundig specialist als Liaison Nurse ICU? De verpleegkundig specialist 2017; 12(3): 26-27

**Research profiles**

**linkedIn** https://nl.linkedin.com/in/sabine-op-t-hoog-b9696666?trk=pub-pbmap
**ORCHiD** https://orcid.org/0000-0001-7537-3387
**Researschgate** https://www.researchgate.net/profile/Sabine-Op-T-Hoog
**Podcast** https://open.spotify.com/show/64Dmwk89kHHGLjBPCQ1q8j

# PHD PORTFOLIO

## PhD portfolio of Sabine op ‘t Hoog

Department: Radboud nstutute for Health Science
PhD period: **01/11/2018 – 01/011/2023**
PhD Supervisor(s): **Prof. dr. Hester Vermeulen, Prof. dr. Hans van der Hoeven**
PhD Co-supervisor(s): **Dr. Lilian Vloet, Dr. Anne Eskes .**

| Training activities | | Hours |
|---|---|---|
| **Courses** | | |
| - Perfect your academic writing skills | 2018 | 1.0 |
| - Qualitative research | 2019 | 0.3 |
| - Teach the teacher | 2019 | 0.8 |
| - Scientific Writing in English for Publication in Biomedical Journals | 2019 | 0.7 |
| - Conducting a Systematic review Cochrane E-learning | 2021 | 3.0 |
| - scientific Integrity course | 2022 | 1.0 |
| - RIHS- Introduction course for PhD candidates | 2022 | 0.25 |
| - Carend Course- palliative care | 2022 | 0.25 |
| - FAIR research data management E-Course | 2022 | |
| - E-course storydesign | 2022 | 0.25 |
| - E- BROK course | 2023 | 1.50 |
| - Workshop Agile- scrum method | 2023 | 0.25 |
| **Seminars** | | |
| - NVZ- Masterclass taakherschikking | 2022 | |
| **Conferences** | | |
| - 38th International Symposium on Intensive Care and Emergency Medicine- Brussel | 2018 | 0.9 |
| - ICN Nurse Practitioner / Advanced Practice Nursing Conference- Speaker oral presentation | 2018 | 1.0 |
| - IC Topics- speaker- oral presentation | 2018 | 0.3 |
| - STZ event- poster presentation | 2019 | 0.3 |
| - V&VNVS jaarcongres- oral presentation passende zorg, zinnige zorg? | 2022 | 0.8 |
| - Masterclass palliatieve zorg | 2022 | 0.6 |
| - European Nursing Congress 22- Nursing Proof | 2022 | 0.9 |

| **Training activities** | | **Hours** |
|---|---|---|
| **Other** | | |
| - Leergang Strategie en Positionering V&VNVS | 2021-2022 | 3.0 |
| - stage Nederlandse Zorg Autoriteit | 2022 | 2.0 |
| **Teaching activities** | | |
| **Lecturing** | | |
| - CIV project coaching outreach team | 2019-2020 | 2.0 |
| **Supervision of internships / other** | | |
| - Supervision of 2 master students (MANP) | 2017-2020 | 10 |
| **Total** | | **86.30** |

# DANKWOORD

Deze thesis is ontstaan vanuit intrinsieke motivatie om in beweging te komen, impact te maken voor betere zorg. Met veel bewondering en respect heb ik heel dichtbij mogen staan bij verschillende families. Ik heb ervaren hoe kronkelig de weg naar herstel kan zijn en verdere betekenis heeft als mens en familie na een ICU opname. Meerdere namen en gezichten vergeet ik nooit, daarvoor respect en dank.

Dank aan mijn collega's op de intensive care, verpleegkundigen, intensivisten en ieder die met mij mee wilden denken en doen. In beweging komen doe je samen. In het bijzonder, Gerarda van der Nat. Als collega en mens heb ik veel geleerd van je, nogmaals dank. Ook Marc Beerens, voormalig hoofd, je gaf me de kans en de ruimte. Dank aan alle collega's die nu de naam 'CIV' dragen of Verpleegkundig Specialist ICU, jullie zijn de verandering, jullie maken de impact! Tijdens COVID-19 heb ik in de frontlinie gestaan met het ICU-team en ik heb enorm respect voor het werk wat hier dagelijks geleverd wordt. Ik kijk met trots terug dat de verpleegkundige outreach rol, CIV, tijdens COVID-19 een prominente rol speelde in de zorg voor patiënten met COVID-19 en in tijden van beddenkrapte een belangrijk triage middel bleek.

Dr. Wendy Chaboyer, in 2016 belde ik je vanuit de nieuwsgierigheid voor de Australische outreach rol, de liaison nurse, dank voor je inspiratie en empowerment. Ik kreeg de kans om deze rol te schaduwen in zeven Australische ziekenhuizen, hiervan te leren en dit mee te nemen naar Nederland. Hierin bedank ik ook speciaal de Liaison nurse van het Box Hill Hospital in Melbourne, Renata Mistarz voor je ervaringen te delen, in hetzelfde jaar, 2017 heb je de Tilburgse IC gezien en ik denk daar met veel plezier aan terug.

Een innovatie zet je in voor impact in de praktijk. Om dit zichtbaar te maken, is praktijkgericht, wetenschappelijk onderzoek passend. Speciale dank Lilian Vloet dat je zag dat er potentie lag in dit idee. Als copromotor gaf je me coaching en leerde ik zoveel meer dan alleen onderzoeker worden. Vervolgens bleek de wereld klein, Dr. Wendy Chaboyer vanuit Australië stuurde me door naar Amsterdam, Anne Eskes. Anne, dank voor je waardevolle bijdrage. Het perspectief van de familie bleef steeds terugkomen. Daarnaast was je altijd positief kritisch en door jou heb ik de lat en mijn eigen grenzen kunnen verleggen.

Dr. prof. Hester Vermeulen en Dr. prof. Hans van der Hoeven, als promotoren ben ik jullie veel dank verschuldigd, begeleiding, geduld en vertrouwen om dit onderzoek tot een proefschrift te brengen. Maar ook om mee te denken toen COVID-19, de context veranderde.

Persoonlijk ben ik erg dankbaar dat de thema's van deze onderzoeksgroep; ICU-geneeskunde en ICU (na)zorg, familieparticipatie en verpleegkundige innovaties, een mooi samenspel kregen in dit proefschrift. Dit is te danken aan dit team, ik had het niet anders kunnen wensen.

Een aantal onderzoeksmaatjes heb je nodig, ook in tijden van COVID-19 is het fijn dat je ruggenspraak kan vinden. Boukje Dijkstra, dank voor onze middagen in Nijmegen en daarna online. Marielle van Mersbergen, je bent mijn maatje in het ETZ en we hebben veel geleerd en veel gelachen, dank voor wie je bent. Ik ben blij dat je mijn paranimf wil zijn.

Tot slot, maar zeker niet in de laatste plaats, dank aan mijn familie en vrienden. Een maatje van de MANP, die weet wat mijn journey is vanaf dag 1, lieve Heidi je bent een parel in mijn leven. De mensen die dicht bij me staan, die weten dat deze jaren van onderzoek doen, gepaard ging met een aantal persoonlijke life-events. Dat goede zorg uitmaakt, heeft dit alles mij nogmaals bevestigd. Mijn familie, we zijn samen met elkaar er altijd voor elkaar. Mijn lieve ouders, broer en zus, wil ik bedanken voor wie jullie zijn voor mij. Lieve Laura, samen met Robin zijn jullie mijn alles, van onschatbare waarde, en zoals met knipoog beloofd gaat mijn laatste dank uit naar jullie.

# Improving patients’ and families’ journeys during ICU pathways

With nurse-led interventions

## Why?

**Almost 90%** of ICU patients survive. Of these survivors, **50-70%** experience new physical, cognitive or psychological impairments, the so-called Post Intensive Care Syndrome (PICS). **25-50%** of the relatives of ICU patients experience a range of psychological symptoms (PICS-Family) The **PICS-syndrome** includes:

1. Physical symptoms
2. Cognitive symptoms
3. Psychological symptoms

**The road towards recovery** for ICU patients and their relatives:

- Each patient face a unique pathway
- Each pathway includes several transitions
- ICU patients and relatives experience a gap in continuity of care during these transitions.

## What do patients and their relatives experience?

Relatives of ICU patients experience a "gap" in the transition from ICU to ward, themes such as;

1. Relief
2. Uncertainty
3. the need to be acknowledged as a caregiver
4. share expectations
5. continuity of care

Relatives of ICU patients express the need in more continuity of care and see that nurses can play an essential role in improving continuity of care.

## What is the evidence?

In a review of all relevant literature, we assessed the effectiveness of these interventions on long-term impact, defined in terms of PICS and PICS-F.

Of the five studies, including varied transitional care interventions, we found no evidence of the effects of transitional care interventions on the physical or psychological aspects of PICS or PICS-F. Except for a nurse-led structured follow-up program that showed a significant difference in physical function at 3 months.

## Our work

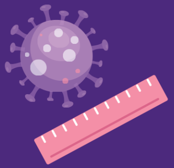
We developed and implemented a new nurse-led intervention in co-creation with professionals to improve continuity of care after ICU in a local Dutch hospital setting. In which a new nurse-led team followed up standard ICU patients and relatives in the transition of the first 24 hours from ICU to nursing ward. In the process, this team provided coaching to nurses on the nursing ward.

**We learned** this had no significant effect on "patient" outcome measures such as ICU readmissions after 24, 48 or 72 hours, ICU length of stay or mortality.
**We learned** by making a work-as-imagine (WAI) and work-as-done (WAD) with professionals in co-creation that we can learn from the complexity of the process and revealed unexpected success factors of the interventions , such as the easy access to CCOS, the peer-to-peer coaching style using the Functional Resonance Analysis Method (FRAM) as a safety II tool contributes to engage healthcare professionals in the reflecting and learning cycle during the process of a quality improvement and adds value in this to become a more learning organization together. This study exemplified how professionals can be resilient and agile in improving everyday practice.

## Our work

We initiated 1 nursing intervention using eHealth after ICU admission during the COVID-19 pandemic. By offering ICU patients diagnosed with COVID-19 and their loved ones structured telephone support (STS) by a nurse specialist.

**We learned** by structuring by the PICS elements, the nurse practitioner was able to offer, person-centered, support and advice. We observed that out of 46 patients, all patients experienced at least on 1 element of PICS symptoms



## Lessons learned

1. Engage relatives of ICU patients in care processes, proactively and give them an active role during quality improvement processes.
2. If you do it, better do it well. Appropriate ICU care, requires continuity of care after ICU admission. Herein, it is important to provide person-and family-centered care, with an eye on long-term quality of survival for ICU patients and their relatives.
3. With the same number of nurses, new teams can improve everyday, care processes. Nurses and nurse practitioners show that they are able to combine both cure and care needs, and assume a coordinating role for ICU patients and families that can be cross-domain.
4. Value context- and practice based research in the local context. The closer to everyday practice, the better professionals can learn to improve together the every practice of complex (health) systems.

# Meer continuïteit van zorg voor IC-patiënt en zijn naasten

### Hoe dragen verpleegkundige bottom-up interventies bij?

## Waarom?

Meer dan **90% van de patiënten** overleeft een Intensive Care opname. Hiervan ervaart **50-70%** klachten van het Post Intensive Care Syndroom (PICS) **25-50% van de naasten** ervaren psychische klachten (PICS-Familie)

Het **PICS-syndroom** bestaat uit:

1. Lichamelijke beperkingen
2. Cognitieve beperkingen
3. Psychische beperkingen.

Het **hersteltraject** van IC patiënten en naasten:

- is een eigen unieke weg naar herstel
- iedere weg kent meerdere transitiemomenten
- hierin ervaren patiënten en naasten een 'gat' in continuïteit van zorg.

## Wat ervaren naasten?

Naasten van ic-patiënten ervaren een 'gat' in de overgang van IC naar afdeling, er spelen thema's als;

1. Opluchting
2. Onzekerheid
3. Erkend worden als mantelzorger
4. Verwachtingen delen en
5. Continuïteit van zorg.

Naasten spreken de behoefte uit in meer continuïteit van zorg. Naasten zien dat verpleegkundigen een essentiële zorg kunnen spelen in het verbeteren van de continuïteit van zorg.

## Wat is het bewijs?

Er zijn weinig studies gericht op verbeteren van continuïteit van zorg door interventies in te zetten tijdens transitiemomenten na IC-opname.

Van de vijf studies liet 1 studie met een verpleegkundige interventie een significante verbetering zien op elementen van PICS, na follow-up 3 maanden na IC-ontslag.

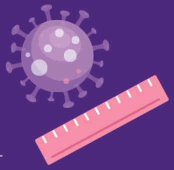
## Wat wij deden:

We initieerden 1 verpleegkundige interventie in de lokale context waarbij een nieuw verpleegkundig team standaard IC patienten en naasten opvolgden in de transitie van de eerste 24 uur van IC naar verpleegafdeling. Daarbij gaf dit team coaching aan verpleegkundigen op de verpleegafdeling.

**We leerden dat** dit geen significant effect had op 'harde' uitkomstmaten zoals ICU heropnames na 24, 48 of 72 uur, IC ligduur of mortaliteit.

**We leerden dat** door samen met professionals in co-creatie een work-as-imagine (WAI) en work-as-done (WAD) te maken dat we kunnen leren van de complexiteit van het proces en waar ruimte is ter verbetering. Het Functional Resonance Analysis Method (FRAM) als safety II tool gebruiken in een implementatieproces kan hierin van meerwaarde zijn om samen een meer lerende organisatie te worden tijdens dit proces. Deze wijze van zorg verbeteren laat zien dat professionals veerkrachtig en wendbaar kunnen zijn in het verbeteren van de dagelijkse praktijk.

## Wat wij deden:



We initieerden 1 verpleegkundige interventie met inzet van eHealth na een IC-opname tijdens de COVID-19 pandemie. Door IC-patiënten, gediagnosticeerd met COVID-19, en hun naasten gestructureerde telefonische ondersteuning (STS) aan te bieden door een verpleegkundig specialist.
**We leerden dat** door te structuren op de PICS-elementen kon de verpleegkundig specialist, persoonsgerichte, ondersteuning en adviezen aanbieden. We zagen dat van de 46 patiënten, alle patiënten tenminste op 1 element van PICS-symptomen ervaarde.

## Wat geven we mee:

1. Betrek familieleden van IC-patiënten proactief bij zorgprocessen en geef hen een actieve rol tijdens kwaliteitsverbeteringsprocessen.
2. Als je het doet, doe het dan goed. Passende (IC) zorg, vereist continuïteit van zorg na IC opname. Hierin is het belangrijk om persoons- en familiegerichte zorg te bieden, met het oog op lange termijn kwaliteit van overleving voor IC-patiënten en hun naasten.
3. Met hetzelfde aantal verpleegkundigen, kunnen teams de dagelijkse zorgprocessen verbeteren. Verpleegkundigen en verpleegkundig specialisten laten zien dat zij in staat zijn zowel 'cure' als 'care' zorgbehoeften te combineren. Beide rollen kunnen een meer coördinerende rol voor ic-patiënten en families op zich nemen die domein-overstijgend kan zijn.
4. Waardeer context- en praktijkgericht onderzoek in de lokale context. Hoe dichter bij de dagelijkse praktijk, hoe beter professionals kunnen leren om samen de elke praktijk van complexe (gezondheids)systemen te verbeteren.

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