# Patient- and Family-Centered Care in the Intensive Care;

## A Delphi Study to define important and feasible interventions

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# ABSTRACT

**Background:** ICU stays are stressful due to the technical environment, uncertainty of recovery, discomfort, sudden immobilization, and lack of autonomy. As a result, one may experience various physical and mental symptoms. Patient- and family-centered care (PFCC) is a recommended approach to reduce the burden of an ICU admission. Due to various barriers, PFCC is often lacking. Despite known advantages, most important and feasible PFCC interventions are still unknown. Exploration of these interventions can improve PFCC quality and reduce ICU admissions' impact on former ICU patients, their families, and healthcare professionals.

**RQ**: Which PFCC interventions are most important and feasible in Intensive Care, according to experts?

**Methods:** The RAND/UCLA Appropriateness Method(RAM), was used to develop a set of most important and feasible interventions for PFCC in intensive care according to experts, calculated by median scores and disagreement indexes. The RAM contains four rounds. In addition, a top-five ranking has been established for the most important interventions. The study population consisted of experts on PFCC: former intensive care patients/family, ICU nurses, ICU physicians.

**Results:** 60 interventions have been reduced in the first three rounds to 35 interventions in the final round. Consensus was reached on 31 Interventions that are considered important and feasible for PFCC at the ICU. The top five ranking includes two times the themes "Communication with the patient and family members", two times "Family presence and participation" and one time "Patient and family support".

**Conclusion and Implications of key findings**: Extensive communication and participation are key concepts in PFCC and should be eventually experienced as standard care. By further investigating which interventions are applied in practice, targeted implementation methods can be developed, resulting in a significant improvement in the quality of care and lowering the burden of ICU admissions.

**Keywords:** Intensive Care, Post-Intensive Care Syndrome, Patient-Centered Care, Family-Centered Care

## SAMENVATTING

**Achtergrond:** Een opname op de Intensive Care (IC) is stressvol, vanwege de technische omgeving, onzekerheden, ongemakken, plotselinge immobilisatie en gebrek aan autonomie. Als gevolg hiervan kunnen fysieke en mentale klachten ontstaan. Patiënt- en familiegerichte zorg (PFCC) is een benadering om de belasting van een IC-opname te verminderen. Echter wordt PFCC vaak belemmerd door verschillende barrières. Ondanks bekende voordelen zijn de belangrijkste en meest haalbare interventies voor PFCC nog steeds onbekend. Onderzoek naar deze interventies kan de kwaliteit van PFCC verbeteren en de impact van IC-opnames op voormalig IC-patiënten, hun families en zorgverleners verminderen.

**Onderzoeksvraag**: Welke PFCC interventies zijn het belangrijkst en meest haalbaar op de Intensive Care, volgens experts?

**Methode:** De RAND/UCLA Appropriateness Method (RAM) werd gebruikt om een set van belangrijke en haalbare interventies voor PFCC op de IC te ontwikkelen, berekend door Medianen en Disagreement Indexen. De RAM bestaat uit vier rondes. Hieraan is nog een top-5 ranking van meest belangrijke interventies toegevoegd. De onderzoekspopulatie bestond uit experts op het gebied van PFCC: voormalige IC-patiënten/familieleden, IC-verpleegkundigen, Intensivisten.

**Resultaten**: 60 interventies zijn in de eerste drie rondes, teruggebracht tot 35 interventies in de laatste ronde. Consensus is bereikt over 31 interventies, deze worden belangrijk en haalbaar beschouwd voor PFCC op de IC. De top vijf van deze interventies, omvat twee keer het thema "Communicatie met patiënt en familie", twee keer "Aanwezigheid en participatie van familie" en één keer "Ondersteuning van patiënt en familie".

**Conclusie en Implicaties**: Uitvoerige communicatie en participatie zijn hoofdthema's voor PFCC op de IC. PFCC zou uiteindelijk als standaardzorg moeten worden ervaren. Door verder onderzoek te doen naar toegepaste interventies in de praktijk, kunnen gerichte implementatiemethoden worden ontwikkeld. Met als gevolg een verbetering van kwaliteit van zorg en het verminderen van langetermijn klachten van IC-opnames.

**Trefwoorden:** Intensive Care, Post-Intensive Care Syndroom, Patiëntgerichte zorg, familiegerichte zorg

## INTRODUCTION

In the Netherlands, more than 65.000 patients are admitted to the Intensive Care Unit (ICU) each year and 80-90% of patients survive such an admission(2). An ICU stay is challenging and stressful for patients and families due to the technical environment, the uncertainty of recovery, discomfort and pain, sudden immobilization and lack of autonomy and decision-making(3). In the long-term, an ICU admission also has an enormous impact. After one year 50% of the patients and their family members still suffer from physical, cognitive or mental problems(4,3,5). Such problems, caused by an ICU admission, are defined as Post Intensive Care Syndrome (PICS). ICU-related complaints of family are defined as PICS family(f) whereby the term family represents ''individuals who provide support and with whom the patient has a significant relationship''(6). In addition to PICS, former ICU patients often experience a reduced quality of life; are unable to work again, and lack the vitality they did prior to their admission to the ICU(3,7).

A familiar concept to reduce the impact of an ICU admission is patient- and family-centered care (PFCC). PFCC is care "grounded in mutually beneficial partnerships among healthcare providers, patients and families". PFCC consists of four essential concepts; dignity and respect, information sharing, participation of patients and family in care, and collaboration(6). It indicates that healthcare professionals (HCP) actively involve patients and families in all aspects of care and well-being and daily care is tailored to their needs and wishes (8,9). These concepts align with the "Fundamentals of Care Framework" where safety, comfort, communication, dignity, privacy, respecting choice, and mobility, are seen as the essence and fundament of nursing care (10,11).

PFCC decreases the likelihood of developing PICS and may shorten the length of stay in the ICU (12,13). It also improves patient and family satisfaction (10,14,15). In addition to these patient and family-related benefits, PFCC is beneficial for HCP as well. HCP application of PFCC reduces job performance, sense of efficacy, well-being, and burnout levels(16). Despite these known advantages, it is challenging to apply PFCC in the technical environment of the ICU(17). Several barriers may contribute to this. For example disease severity, patients' sedation level, acute setting(18), HCP lack of time, skill-mix of staff and inadequate budget that limit feasibility (9).

The mutually beneficial partnerships among HCP, patients and families and the respect for the individual needs of patients and families can limit the short and long-term impact of an ICU admission. Although it is recommended to structurally provide PFCC(f) in the ICU (6), it is still unknown which interventions are most important and feasible according to former Intensive Care patients, their families and HCP(6,8).

## OBJECTIVE

Which PFCC interventions are important and feasible in Adult Intensive Care, according to Dutch former intensive care patients, their families and healthcare professionals?

## METHOD

### Design

To reach the objective, a four-round Delphi study was conducted between January 2023 and April 2023. The Delphi technique is an iterative multistage process designed to transform expert opinions into group consensus[19]. The study was executed according to the RAND/UCLA Appropriateness Method (RAM)[20]. The RAM contains four rounds: 1) extraction of the interventions 2) online questionnaire 3) expert panel consensus meeting 4) online questionnaire(figure 1). In addition to the consensus on important and feasible ICU PFCC interventions, a top-five ranking has been established on the most important interventions. The study population consisted of experts on PFCC namely: former intensive care patients, their families and HCP (ICU nurses and ICU physicians) working at an ICU in the Netherlands. The combination of these groups provides a comprehensive representation of healthcare, these practical experts are actively involved in the care of ICU patients on a daily basis.

### Extraction of the interventions (Delphi round 1)

The first round of the study aimed to develop a complete list of PFCC interventions for ICU care. A literature search and focus groups were conducted. For the focus groups, HCP (nurses and ICU physicians) were recruited at a Dutch university medical center. HCP had to have more than one year of working experience in the ICU. Former patients/families were approached through the patient organization 'IC-Connect'[21]. Former patients had to be 18 years or older at time of ICU admission and must have spent at least two nights in an ICU in the Netherlands in the past five years. Family had to be 18 years or older and related to a patient who spent at least two nights in the ICU in the last five years. Both needed sufficient knowledge of the Dutch language. Eligible participants received an email, information letter, and informed consent form.

Four focus groups were planned, two with former ICU patients/families, and two with HCP. During these focus groups, a post-doctoral researcher (BT) and nursing scientist (MdGr) discussed important interventions for PFCC in the ICU. In the focus groups, a semi-structured interview guide was used to structure the meeting. The conversations were recorded and

transcribed verbatim, two researchers (BT and CC) then coded the transcripts and grouped codes based on six main themes stated in the "Guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU"(22). Atlas.ti was used to analyze the data.

In addition to the focus groups, two researchers (BT, CC) conducted independently a literature search in PubMed on MESH terms associated with critical care, patient-centered care, holistic nursing, family-centered care, nursing and PFCC(appendix 1).

As a next step interventions from the focus groups and literature search were gathered in Microsoft Excel. The interventions underwent various iterative stages, involving extensive rewriting through splitting and merging processes. Subsequently, the interventions were discussed (BT, CC, MvdB) leading to adjustments and refinements. Finally, interventions were reformulated to be applicable to all target groups resulting in the final set of interventions.
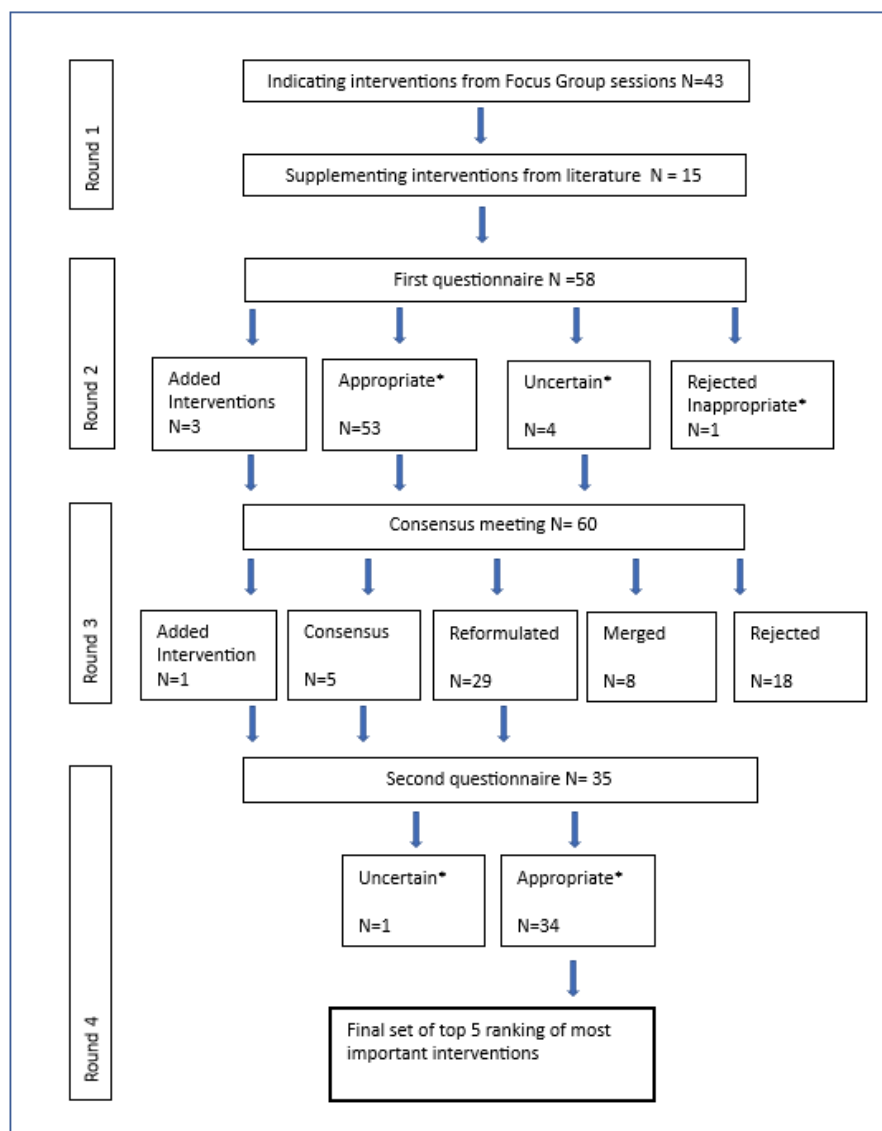


**Figure 1** *Development of the interventions, presented in four Delphi rounds*
*\* according to the operational Definitions of Levels of Appropriateness (20)*

**First questionnaire (Delphi round 2)**

The second round of the Delphi study aimed to assess the importance and feasibility of the PFCC interventions identified in the first round. HCP were approached through formal networks of the ICU "Nijmegen en omgeving". Former Patients were approached through the patient organization IC-Connect(21), an advertisement on the website of Family and Patient Centered Intensive Care(23), and social media. Eligible participants received an email with an information letter and were asked to participate in both online questionnaires(rounds 2 and 4). They also could sign up for the expert panel meeting(round 3). Former patients and their families had the opportunity to complete the questionnaire together. After indicating their willingness to participate, a link to the questionnaire in Castor EDC(23) was sent, which also included informed consent. The following inclusion criteria were used: 18 years or older, sufficient knowledge of the Dutch language and computer literacy. Former patients must have spent at least two nights in an ICU in the Netherlands in the past five years and HCP had to have one year of working experience at an ICU. To provide representative information, we aimed to include 45 participants: fifteen ICU nurses, fifteen ICU physicians, and fifteen former patients/family(17).

The questionnaire contained those interventions found in round 1. Participants were asked to rate each intervention on importance and feasibility using two, 9-point Likert scales (1: not important, 9: absolutely important; 1: not feasible, 9: absolutely feasible). They could also add comments and additional interventions. After one week, a reminder was sent to those who had not yet completed the questionnaire. Likert scale data were exported to Microsoft Excel and analyzed on levels of appropriateness on importance and feasibility. The levels of appropriateness for each intervention were analyzed using median ratings and disagreement index (DI)(table 1). The DI was calculated by the interpercentile range adjusted for symmetry (IPRAS) (20,24). A DI of >1.0 indicates a lack of consensus among participants on the importance and feasibility of an intervention for PFCC in the ICU(20)(appendix 2).

| Appropriateness | Panel median | Disagreement Index (DI) |
|---|---|---|
| Appropriate | median of 7-9 | without disagreement DI < 1.0 |
| Uncertain | median of 4-6 | OR any median with disagreement DI > 1.0 |
| Inappropriate | median of 1-3 | without disagreement DI< 1.0 |

*Table 1 Operational Definitions of Levels of Appropriateness* (20)

Interventions indicated as *appropriate* on importance and feasibility, without disagreement, were generally not further discussed in the consensus meeting but proceeded to the final

round. Interventions indicated *uncertain* on importance or feasibility, without disagreement, were included in the next round and discussed during the expert panel meeting. Interventions indicated as *inappropriate* on importance and feasibility were rejected.

**Expert panel meeting, reaching consensus (Delphi round 3)**

The aim of the third round was to reach consensus on interventions indicated as uncertain and interventions that had comments in the second round. The select group that registered for this round,  was contacted by email and could sign up for two meetings. Then, participants were evenly distributed per category and institution across the two meetings. Two consensus meetings were planned with half of the interventions to minimize burden. The interventions indicated as uncertain, added interventions and comments were discussed.

One week before the consensus meeting, participants received a document containing the interventions that had to be discussed. Both meetings were held online using Microsoft Teams and were recorded and moderated by the same researcher (BT). A second researcher (CC) observed, took notes and asked questions. At the start of the meeting, BT explained the aim and asked for informed consent. A list with remaining interventions, gathered comments and discussion points served as a guide.

Two researchers (BT and CC) independently analyzed recordings of both meetings. Interventions indicated as not relevant were removed, merged, rephrased and discussed by the panel members. A seventh theme 'discharge and aftercare' was added to the original six themes from the guideline.

**Second questionnaire round, ranking procedure (Delphi round 4)**

This round's objective was to determine the importance and feasibility of the *appropriate* interventions from the second round, added with the agreed-upon interventions from the third round, and to derive a top 5 ranking of the most important interventions.

A link to the questionnaire in Castor EDC(23) was sent to all participants of round two. The questionnaire contained those interventions found important and feasible by all panel members. Also, reformulated interventions and interventions that reached consensus after round 3 were added. Participants were again asked to indicate the importance and feasibility of each intervention using two, 9-point Likert scales. Additionally, participants were asked to indicate their 'top 5' of the most important interventions (most important: 5 points, less important: 4 points, etc.) A reminder was sent after two and three weeks.

Level of appropriateness, panel median, and DI were again calculated as described above. The top 5 rankings were calculated in Microsoft Excel through the accumulation of points obtained per intervention, five interventions emerged as possessing the highest scores.

**Ethical considerations**

Ethical clearance for this study was obtained from the hospital's ethical review board (number METC Oost-Nederland: 2022-16132) in agreement with the principles of the Declaration of Helsinki (version 64, October 2013). Research was conducted in accordance with the "Wet op de geneeskundige behandelovereenkomst" (WGBO).

**Handling and storage of data and documents**

Collected data will be handled in accordance with the General Data Protection Regulation (GDPR) and the Dutch Act on Implementation (AVG) and the FAIR principles(25). Castor EDC(23) was used for this survey, it is an application where securely online data can be selected and stored pseudonymized. The key file is stored on the hard disk of the research department of the Intensive Care of the Radboudumc. Data are only accessible to the researchers involved. All data are stored for 10 years and handled confidentially and anonymously.

## RESULTS

**Participants**

In the first Delphi round, thirty participants made contributions within the focus groups. The response rate of the questionnaires was 82% (round 2) and 71% (round 4). In these rounds (2 and 4), the experts had experience in at least seventeen different institutions. In the third round sixteen participants, divided into two groups (n= 9 and n=7) participated in the expert panel meeting. The additional demographics of the Delphi rounds can be found in accompanying tables (table 2, 3).

| | |
|---|---|
| Focus groups healthcare professionals, n | 16 |
| Nurses, n (%) | 12 (75) |
| ICU physicians, n (%) | 4 (25) |
| Age in years, mean (min-max) | 50.1 (34-65) |
| Female, n (%) | 13 (81) |
| Clinical experience in years, mean (min-max) | 14.5 (1-33) |
| Different institutions working, n | 1 |
| Focus groups former patients and family, n | 14 |
| Patients, n | 8 (57) |
| Caregivers, n | 6 (43) |
| Age in years, mean (min-max) | 46.6 (43-76) |
| Female, n (%) | 11 (69) |
| Admission days, mean (min-max) | 18.6 (3-35) |
| Different institutions admitted, n | 9 |

*Table 2 Baseline characteristics of participants of the first Delphi round, four focus groups*

| | Round 2 | Round 3 | Round 4 |
|---|---|---|---|
| Number of participants, n | 56 | 46 | 56 |
| Response rate, n (%) | 46 (82) | 16 (35) | 40 (71) |
| Female, n (%) | 33 (72) | 14 (88) | 31 (78) |
| Age in years, mean (min-max) | 45.7 (26-78) | 51.4(38-61) | 46.3 (26-61) |
| Former patients/family, n (%) | 16 (35) | 7 (44) | 16 (40) |
| Age in years, mean (min-max) | 50 (26-78) | 53 (41-61) | 49 (32-61) |
| Female, n (%) | 11 (69) | 5 (71) | 12 (75) |
| Admission days, mean (min-max) | 29.4 (2-115) | 23.9(7-72) | 21.4 (10-42) |
| Different institutions admitted, n | 13 | 5 | 12 |
| Nurses, n (%) | 15 (33) | 5 (31) | 13 (33) |
| Age in years, mean (min-max) | 45 (26-60) | 50 (38-56) | 45 (27-57) |
| Female, n (%) | 13 (87) | 5 (100) | 12 (92) |
| Clinical experience in years, mean (min-max) | 16.9 (1-37) | 21(15-29) | 16.5 (1-25) |
| Different institutions working, n | 10 | 4 | 7 |
| ICU physicians, n (%) | 15 (33) | 4 (25) | 11 (28) |
| Age in years, mean (min-max) | 45 (34-58) | 43 (35-50) | 44 (34-58) |
| Female, n (%) | 10 (67) | 4 (100) | 7 (64) |
| Clinical experience in years, mean (min-max) | 11.7 (2-25) | 12.8 (4-21) | 10.7 (1-25) |
| Different institutions working, n | 9 | 3 | 8 |

*Table 3 Baseline characteristics of participants of the second, third and fourth Delphi rounds*

## Delphi Round 1

Each of the four focus group sessions lasted for one and a half hours. After the analysis of the focus group conversations, a total of 43 interventions emerged. In the additional literature review a screening of 841 articles based on title and abstract was conducted. From this initial

screening, 160 articles were selected for full-text review, specifically focusing on interventions. As a result, fifteen novel interventions were identified and incorporated into the study(figure 1).

**Delphi Round 2**

In this round, 58 interventions were included in the questionnaire. Based on the levels of appropriateness(table 1), 53 interventions were rated as *appropriate* on importance and feasibility*.* Out of the remaining interventions, one intervention was rejected as *inappropriate*, and four interventions were rated as *uncertain*. Participants proposed three additional interventions in their comments. Furthermore, comments indicated that certain interventions were not specific to PFCC but represented standard care. Although appropriate interventions (Median 7-9, DI< 1.0) were not required to be discussed, they were included in the consensus round due to the remarks regarding standard care, resulting in sixty interventions for round 3(appendix 3).

**Delphi Round 3**

Per round, thirty interventions were one by one discussed over two hours. From the total of sixty interventions, eighteen interventions were rejected; eleven because they were labeled as 'standard care', six interventions were mentioned as not in line with the definition of PFCC (relating to ICU training and the facilitation of staff) and one intervention was mentioned to be still insufficiently developed for practical implementation. It was collectively determined that there was repetition among the interventions, leading to the merging of eight interventions(figure 1). Almost all interventions underwent minor adjustments. In the final set of interventions after round 3, five of them were related to discharge and aftercare. Therefore, an additional theme was added to the themes based on the guideline, resulting in a total of 35 interventions categorized into seven themes for round 4(appendix 4).

**Delphi Round 4**

One respondent (former patient) withdrew from the study citing the demanding nature of the experience in terms of re-experiencing and concentration. Two respondents did not complete the final question with the ranking procedure.

Based on the levels of appropriateness(table 1), 35 interventions have been identified, of which one ("participation during ICU rounds") scored *uncertain* on importance and feasibility (both mean 6). Additionally, three interventions scored uncertain, only on feasibility. There is consensus on this, as no DI above 1.0 was calculated. The lowest median was calculated regarding the "participation of patients" with a median of 5 on feasibility. Within the theme "Communication with the patient and family members" are eight interventions, of which five score a median of 9 on importance, three score a median of 8 on importance, and two

interventions had a DI of 0.0 on importance. Other interventions that score a median 9 on importance include interventions related to the option for an aftercare clinic, the use of diaries and posters, and the facilitation of family rooms(table 4).

Interventions that appeared in the top 5 rankings are presented in the table below(table 5). With a total of 43 points, the intervention on extensive communication with patients and families emerges as the most important.

At the end of the questionnaire, where participants could supplement one last comment, it was indicated that feasibility is difficult to estimate and it was mentioned that ICU patients are very diverse, from sedated to fully awake. Also, the importance of discharge and aftercare was explicitly mentioned in all rounds.

| 35 Interventions after Round 3 | Results round 4 | | | |
|---|---|---|---|---|
| | importance | | feasibility | |
| **Family presence and participation** | M | DI | M | DI |
| Nurses encourage the family to report the ICU admission and take pictures (diary), taking into account the patient's privacy. If there is a need, the nurse can supplement this report in consultation with the family (ranking 2). | 9 | 0,13 | 8 | 0,18 |
| Deviation from regular visiting hours is possible in consultation. Custom visiting hours are arranged, taking into account the possibilities of the ICU, the needs of the patient and family, and rest moments. | 8 | 0,13 | 8 | 0,29 |
| Healthcare professionals are aware of the family members waiting to visit the patient and ensure that the family can see the patient as soon as possible. | 8 | 0,13 | 7 | 0,06 |
| The patient is encouraged to participate as much as possible during care moments. | 8 | 0,16 | 5 | 0,52 |
| Family members can participate in care moments. The patient's privacy is taken into account during these moments. Nurses encourage the use of personal care products (e.g. body lotion, massage oil). | 8 | 0,16 | 7 | 0,05 |
| For continuity of care, first responsible ICU nurses and ICU doctors are assigned to each patient and their family. | 8 | 0,21 | 7 | 0,52 |
| In consultation with healthcare professionals, the patient and family, a daily schedule is made. This schedule is tailored to the patient's needs and abilities (ranking 4). | 8 | 0,21 | 7 | 0,27 |
| The family has the opportunity to be present during the patient's resuscitation, under the guidance of the nurse. | 8 | 0,22 | 7 | 0,65 |
| The family has the option to be present and participate during the medical rounds. Privacy is taken into account during these moments. | 6 | 0,37 | 6 | 0,63 |
| **Patient and family support** | | | | |
| The patient and family are offered psychological support from consultants (e.g. social worker, psychologist, pastoral worker) during the ICU admission, according to their needs (ranking 3). | 8 | 0,13 | 7 | 0,16 |
| Attention is given to activities for distraction and relaxation (live music, reading aloud, etc.). The family can also participate if they and the patient wish to do so. | 8 | 0,16 | 7 | 0,22 |
| If the patient's condition permits, efforts are made to find ways for the patient to go outside under the supervision of a healthcare professional. | 8 | 0,16 | 6 | 0,52 |
| Efforts are made to find ways to allow a pet to visit the ICU if desired by the patient. | 7 | 0,16 | 6 | 0,39 |
| **Communication with the patient and family members** | | | | |
| Communication with the patient and family takes place in understandable language and is tailored to the patient and family's background and culture. If necessary, apps or an interpreter are used. | 9 | 0 | 8 | 0,16 |
| The patient has a suitable alarm system that allows them to call a healthcare professional at all times. | 9 | 0 | 8 | 0,18 |
| A conversation is scheduled with the patient, family nurse and intensivist at least weekly. During these conversations, the patient's current condition, care, and policy are discussed. Care goals are set taking, into account the patient's and family's wishes and needs and explanations are given. Attention is also paid to the psychological and social well-being of the patient and family (ranking 1) | 9 | 0,13 | 8 | 0,09 |
| The patient's contact person is kept informed about the patient's condition as needed in consultation with the nurse. There is a shared responsibility between the nurse and the contact person in this regard (ranking 5). | 9 | 0,13 | 8 | 0,16 |
| If necessary, communication aids (letter board, iPad, eye computer) are used to promote communication with the patient. Healthcare professionals encourage the family to use these aids when they want to communicate with the patient. | 9 | 0,13 | 7 | 0,16 |
| (Digital) communication tools (such as telephone and video calls) are provided for contact between the patient and their family. | 8 | 0,04 | 7 | 0,22 |
| An anamnesis is taken with the patient and family, which focuses on the patient's physical, psychological, cognitive, and social functioning. | 8 | 0,13 | 7 | 0,16 |
| During a conversation about the admission, the patient and family are given information about the ICU environment. They are also directed to available information materials and technical aids (e.g. animations, VR glasses). | 8 | 0,16 | 7 | 0,37 |
| **Use of specific consultations and ICU team members** | | | | |
| Attention is paid to the pedagogical guidance of children (up to 17 years old). Pedagogical information material is also available. | 8 | 0,13 | 8 | 0,22 |
| There is a patient council that can provide advice to the ICU on improving care. | 7 | 0,22 | 7 | 0,52 |

| **Operational and environmental issues** | | | | |
|---|---|---|---|---|
| A "getting to know you" poster is used to display personal information, wishes, and needs of the patient. | 9 | 0,13 | 9 | 0,13 |
| There is a general visitors' room available where family members can stay during their visit to the ICU (for example, to have a cup of coffee). | 9 | 0,13 | 8 | 0,29 |
| A separate room is available for family members of a seriously ill ICU patient, where they can comfortably retreat and, if necessary, stay overnight. | 9 | 0,13 | 8 | 0,29 |
| ICU healthcare professionals encourage the family to bring personal belongings of the patient (such as photos, figurines, etc.) from home to place in the patient's room. | 8 | 0,13 | 8 | 0,13 |
| Stimuli (light, sound, etc.) are adjusted to the needs and conditions of the patient. If necessary and possible, the patient will be moved to another room for this purpose. | 8 | 0,13 | 7 | 0,22 |
| **Communication between healthcare professionals** | | | | |
| After an ICU admission, a medical handover takes place, with attention given to the patient's wishes and needs, and the physical, psychological, and social impact of an ICU admission. | 9 | 0,13 | 7 | 0,16 |
| Patient- and family-centered care is the norm. Healthcare professionals encourage each other to apply patient- and family-centered care and give each other feedback. | 8 | 0,13 | 7 | 0,37 |
| **Discharge and aftercare** | | | | |
| The patient and family have the option to use an ICU aftercare clinic and/or revisit the ICU after the admission when they are ready. | 9 | 0,13 | 8 | 0,13 |
| In the event of impending death, the patient and family's needs and options for dying at home are discussed. | 8 | 0,13 | 7 | 0,45 |
| During the aftercare trajectory, the patient and family are provided with information on how to get in touch with fellow patients (for example, through a patient association). | 8 | 0,13 | 8 | 0,18 |
| The patient is prepared as much as possible for discharge from the ICU. This includes attention to the transition from the ICU to the standard nursing ward and the period thereafter. Written information is also provided about the aftercare process. If possible, a discharge interview is held. | 8 | 0,13 | 7 | 0,22 |
| After discharge from the ICU, every ICU patient is visited by an ICU nurse or ICU doctor on the regular ward to answer any questions. | 8 | 0,29 | 7 | 0,16 |

*Table 4 Results after round 3 (35 interventions) presented in themes, accompanied by the results from round 4*
*Abbreviation: M = median, DI= disagreement index*

| Theme | Interventions | Ranking points | | | | | |
|---|---|---|---|---|---|---|---|
| | | 5 | 4 | 3 | 2 | 1 | Total |
| 1)Communication with the patient and family members | A conversation is scheduled with the patient, family nurse and intensivist at least weekly. During these conversations, the patient's current condition, care, and policy are discussed. Care goals are set taking, into account the patient's and family's wishes and needs and explanations are given. Attention is also paid to the psychological and social well-being of the patient and family. | 15 | 20 | 9 | 8 | 1 | 43 |
| 2)Family presence and participation | Nurses encourage the family to report the ICU admission and take pictures (diary), taking into account the patient's privacy. If there is a need, the nurse can supplement this report in consultation with the family. | 15 | 8 | 6 | 6 | x | 35 |
| 3)Patient and family support | The patient and family are offered psychological support from consultants (e.g. social worker, psychologist, pastoral worker) during the ICU admission, according to their needs. | 10 | 12 | 3 | 4 | 2 | 31 |
| 4)Family presence and participation | In consultation with healthcare professionals, the patient and family, a daily schedule is made. This schedule is tailored to the patient's needs and abilities. | 10 | 12 | x | 4 | 1 | 27 |
| 5)Communication with the patient and family members | The patient's contact person is kept informed about the patient's condition as needed in consultation with the nurse. There is a shared responsibility between the nurse and the contact person in this regard | 10 | 4 | 3 | 6 | 4 | 27 |

*Table 5 results round 4, top 5 rankings presented with theme*

## DISCUSSION

### Main findings

After four rounds of this Delphi method, 35 interventions have been identified by experts, for PFCC in ICU in the Netherlands. Including 31 interventions that are considered important *and* feasible by experts, one intervention that experts are uncertain about regarding its importance and feasibility, and three interventions that experts believe are important but have doubts about their feasibility for PFCC at the ICU. Of the five most important interventions, two are related to "Communication with the patient and family members", two focus on "Family presence and participation" and one addresses "Patient and family support".

Interventions related to 'communication' received high median scores and the intervention concerning extensive communication was at the top of the ranking. This is consistent with literature indicating that communication with clinicians is one of the most important needs for PFCC in the ICU (26,27) and ICU nurses consider communicating with families a vital part of their role (28). A difficulty in this matter is that decent communication is also complicated for the patient and their caregiver themselves. Patients and family indicate that they do not feel comfortable asking questions in the ICU and 50%–70% express hesitancy to voice concerns (29). Therefore, a safe atmosphere must be created in which questions can be asked. Interventions aimed at increasing communication (intervention aftercare) and improving accommodation (separate visitor rooms) for families also appear to have high median scores and can potentially be associated with this.

During the third round, the 'opportunity to be present at procedures' was rejected and in round 4 'participation in rounds' scored a median of 6 on importance. This is inconsistent with the literature. Much research has been done about the added value of having families present during procedures in the ICU, such as rounds, line placements, and even resuscitation(30) (31,32). Healthcare teams are often skeptical about the growing role of families in shared decision-making and their ability to represent patients' preferences(33). This was also highlighted in round three, where it was made clear that family members were allowed to be present, but only under certain conditions such as proper guidance. It was also mentioned that sterility might be compromised if family members were present, but this has never been proven in earlier research(31). Due to the inclusion of outcomes from all stakeholders in this study, it is not possible to determine the extent to which HCP and former patients/family differ in their perspectives.

The fact that 53 of the 58 (round 2) and 34 of the 35 (round 4) interventions score *appropriate* on importance, indicates how relevant it is for care, to be person- and family-centered and

corresponds with the vision that PFCC is fundamental to good care(10). However, the presence of four interventions (round 4) with *uncertain* feasibility suggests that implementation remains challenging, particularly in the current healthcare environment characterized by staff shortages and high work pressure(34,35). This could explain the lower median score on feasibility for the intervention about 'patients participating', as it can be time-consuming. The earlier mentioned barrier that sedated and intubated patients cannot easily participate in moments of care can further contributes to this challenge (2,17,18).

The experts in this Delphi study found many interventions initially categorized as PFCC to be standard care and mentioned that many environmental factors vary per ICU, such as the size of the ICU, the allocated budget, and the nursing arrangements (ward-based or single-room). This is consistent with the reporting of the World Federation of Societies of Intensive and Critical Care Medicine, which highlighted varying family-centered care practices with inconsistent implementation across different ICUs(30). Literature states that the understanding of PFCC in theory and in practice seems to pose a challenge (29,23).

**Strengths & Limitations**

By following the RAM method a robust approach is utilized to achieve consensus regarding PFCC in the ICU among stakeholders. A strength of this study was the high response rate from experts and the number of participants from different institutions in the several Delphi rounds, which positively impacts the validity of our findings(19). The study aimed to include a sample reflective of clinical ICU practice where PFCC occurs. Nurses, ICU physicians, and former patients/family were equally involved in the study, enhancing generalizability(19,36). By supporting quantitative with qualitative data, the results become more valid and practically feasible (19). The inclusion of the feasibility interventions, besides their importance, enhances the implication of the findings.

Acknowledging some limitations of the study is essential. The total sample was limited to one nation, potentially limiting the generalizability of the findings to other countries, but participants from ICUs located in both university and general hospitals across the entire country of the Netherlands were included. All participants were Native Dutch-speaking and reading, which may have biased the interventions on cultural aspects and the use of comprehensible language. The sample of the expert meeting was relatively small, taking into account the number of participants per category. This could have affected the validity of the results(15). Also, due to the fact that some of the experiences go back to ICU admissions five years ago, recall bias is plausible.

**Practical Implications**

There are 31 interventions that are important and feasible for PFCC at the ICU according to all stakeholders. These interventions should therefore be considered 'the golden standard' of care provided in every Dutch ICU. Regarding prioritization, this study provides direction, because care teams could start with the five most important ones. Stakeholders have to collaborate and decide which interventions work well within their specific team, and which ones need improvement (6,37,2). A prerequisite for successful implementation of these interventions is facilitation, support, and involvement of organizational leaders and individuals in charge of the ICUs who support PFCC (16,38).

In this study, the interventions related to 'training' were rejected in round 3. From this, one could conclude that there is not a demand for further training in the field of PFCC, but rather a need for awareness. To achieve this, a cultural change is necessary in the ICU. It is advised not only to focus on the most important interventions but have attention to behavioral change techniques during the implementation procedure(39).

Although guidelines for PFCC do not have a separate section for discharge and aftercare (4), it was consistently mentioned in all rounds that sufficient attention should be paid to this area. This is logical considering the long-term effects that an ICU admission can have and the high incidence of PICS(f) (7,3). So, it is interesting to investigate the extent to which intensive care can be improved in this aspect of care.

In essence, PFCC should be eventually experienced as standard care and it has to be noted that many of the recommended strategies can be implemented without substantial financial investments or special equipment. Further research has to be done to determine the current utilization of PFCC interventions in practice. By assessing the extent to which the five most important interventions are being applied, targeted implementation strategies can be developed and implemented.

In conclusion, 31 interventions were identified as important and feasible for promoting PFCC in the ICU according to experts. Including a top-five ranking of the most important interventions for PFCC at the ICU. The most important interventions concern communication and participation with patients and families. Also, the importance of discharge and aftercare was explicitly mentioned in all rounds.

Overall, PFCC is gaining increasing importance in healthcare. It needs to be integrated into daily care and eventually be perceived as standard care. Tailoring care to the individual is expected to enhance the quality of care and reduce the burden of an ICU admission for patients, families, and healthcare professionals.

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**APPENDIX 1** *Search string, 15 November 2022 (PubMed)*

(("critical care"[MeSH Terms] OR "care critical"[Title/Abstract] OR "critical care"[Title/Abstract] OR "care intensive"[Title/Abstract] OR "intensive care"[Title/Abstract] OR "care acute"[Title/Abstract] OR "acute care"[Title/Abstract] OR "ICU"[Title/Abstract] OR "surgical intensive care"[Title/Abstract] OR "care surgical intensive"[Title/Abstract] OR "intensive care surgical"[Title/Abstract]) AND ("patient centered care"[MeSH Terms] OR ("patient centered care"[Title/Abstract] OR "care patient centered"[Title/Abstract] OR "person centered care"[Title/Abstract] OR "care person centered"[Title/Abstract] OR "patient focused care"[Title/Abstract] OR "care patient focused"[Title/Abstract] OR "patient centered nursing"[Title/Abstract] OR "nursing patient centered"[Title/Abstract] OR "personalized care"[Title/Abstract] OR "care personalized"[Title/Abstract] OR "holistic nursing" [Title/Abstract] OR "nursing holistic" [Title/Abstract] OR "holistic care"[Title/Abstract] OR "care holistic" [Title/Abstract] OR "family centered care" [Title/Abstract] OR "care family centered" [Title/Abstract] OR "family focused care" [Title/Abstract] OR "care family focused" [Title/Abstract] OR "family centered nursing"[Title/Abstract] OR "nursing family centered"[Title/Abstract] OR "FCC"[Title/Abstract] OR "PFCC" [Title/Abstract]))) AND (y_10[Filter])

**APPENDIX 2** *Formulas for calculating the disagreement index*

| Measurements | Formulas |
|---|---|
| IPR 30th to 70th | [70th percentile]–[30th percentile] |
| Central point IPR | [70th percentile]+[30th percentile]/2 |
| Asymmetry index | 5-[central point IPR] |
| IPRAS | 2,35 + (1,5 *[Asymmetry index]) |
| Disagreement index | IPR/IPRAS |
| Disagreement | IPR > IPRAS |

*Abbreviations: IPR, inter percentile range;   IPRAS, interpercentile range adjusted for symmetry*

| 58 Interventions after Round 1 | Round 2 | | | |
|---|---|---|---|---|
| | importance | | feasibility | |
| **Family presence and participation** | M | DI | M | DI |
| Before or during an admission, the family is given a tour of the ICU. | 6 | 0,72 | 5 | 0,97 |
| Healthcare professionals invite the family to participate during care moments. | 7 | 0,26 | 7 | 0,52 |
| Family members are allowed to be present with the patient 24/7. | 8 | 0,29 | 7 | 0,42 |
| Cameras are installed in the patient's room, enabling family members to see the patient 24/7 (except during care moments). | 3 | 0,65 | 5 | 1,70 |
| The family is informed upon admission about the means of communication with the patient (such as a letter board) and patient care products (such as body lotion) and is invited to use them. | 7 | 0,37 | 8 | 0,33 |
| (Digital) communication tools (phone, video calls, etc.) are offered for contact between the patient and their family. | 8 | 0,13 | 7 | 0,29 |
| The family has the option to be present during all bedside procedures, such as line insertion and resuscitation. | 5 | 0,97 | 4 | 0,65 |
| The family is invited to attend doctors' visits/rounds on a voluntary basis. | 7 | 0,65 | 7 | 0,65 |
| Children (0-17) of ICU patients are guided during visits to the ICU. | 7 | 0,37 | 6 | 0,52 |
| **Patient and family support** | | | | |
| Attention is paid to the patient's and family's psychological and social well-being. | 8 | 0,16 | 7 | 0,37 |
| Technical innovations (films, animations, VR glasses) are used to prepare patients and families for ICU admission. | 9 | 0,13 | 9 | 0,13 |
| The patient and family are encouraged to keep a diary during the ICU stay. | 7 | 0,52 | 6 | 0,52 |
| A primary nurse is assigned to each patient and their family upon admission. | 9 | 0,00 | 8 | 0,16 |
| In case of impending death, the possibility of dying at home is discussed with the patient and family. | 9 | 0,13 | 9 | 0,13 |
| The patient and family have the opportunity to visit the ICU after discharge. | 7 | 0,37 | 6 | 0,97 |
| The patient and family have the option to attend an ICU aftercare clinic after discharge. | 8 | 0,29 | 7 | 0,65 |
| In case of impending death, the family is given the opportunity to say farewell to the patient. | 9 | 0,13 | 9 | 0,13 |
| The patient and family are prepared in a timely manner for discharge from the ICU and are remotely supported by ICU staff on the ward for several days after discharge. | 9 | 0,13 | 9 | 0,13 |
| Upon admission, the family receives a conversation about ICU admission and informational materials about the ICU. There is also room for the family to express their emotions during these conversations. | 9 | 0,00 | 9 | 0,13 |
| **Communication with the patient and family members** | | | | |
| The patient and family are communicated with in a calm and friendly manner. | 9 | 0,29 | 6 | 0,52 |
| Open and honest communication is maintained with the patient and family about the patient's current condition and treatment policy. | 9 | 0,29 | 7 | 0,75 |
| The patient and family are communicated with in understandable language. If necessary, a translator is called in. | 9 | 0,00 | 9 | 0,13 |
| Structured conversations are planned with the patient and family, during which the patient's current condition, care, and policy are discussed and evaluated. | 9 | 0,00 | 9 | 0,16 |
| During visits and care moments, healthcare professionals introduce themselves to the patient and family, and talk to, not about, the patient and family. | 9 | 0,00 | 8 | 0,29 |
| Patient information (such as medical history and medication use) is discussed and verified with the patient and family upon admission. | 9 | 0,13 | 8 | 0,13 |
| The patient and family are involved in decisions regarding the treatment policy. Care goals are set and explained, while healthcare professionals consider the wishes and needs of the patient and family. | 9 | 0,13 | 8 | 0,29 |

| Statement | | | | |
|---|---|---|---|---|
| At the start of ICU admission, an anamnesis (admission interview) is conducted with the patient and family. This focuses on the patient's physical, psychological, cognitive, social, and cultural functioning. | 9 | 0,13 | 8 | 0,16 |
| The family is kept informed daily about the patient's condition using (digital) communication tools such as phone, WhatsApp, and email. | 9 | 0,13 | 7 | 0,16 |
| A decision aid is used to support the patient and family in making decisions about medical treatment plans. | 6 | 0,59 | 5 | 0,59 |
| In palliative care, the patient and family's wishes and needs are discussed and taken into account in the decision-making process. | 8 | 0,29 | 7 | 0,49 |
| After a conflict or disagreement healthcare professionals try to restore trust with the patient and family through targeted interventions. | 9 | 0,00 | 8 | 0,13 |
| **Use of specific consultations and ICU team members** | | | | |
| If desired, the patient and family are offered psychological support by consultants (social worker, psychologist, pastoral care worker). | 9 | 0,13 | 7 | 0,20 |
| If desired, the patient and family are brought into contact with peers. | 8 | 0,13 | 8 | 0,13 |
| There is a patient/family council that provides advice to the ICU. | 8 | 0,29 | 8 | 0,29 |
| **Operational and environmental issues** | | | | |
| The patient's room is decorated with personal items of the patient (such as photos, their own pillow, etc.). | 7 | 0,37 | 6 | 0,52 |
| The location of the patient's room (central, with more stimuli, versus secluded, with fewer stimuli) is tailored to the patient's needs. | 8 | 0,29 | 8 | 0,29 |
| Attention is given to the use of glasses, hearing aids, and dentures of patients. | 8 | 0,29 | 5 | 0,97 |
| Attention is given to the patient's personal hygiene (washing hair, cutting nails, using perfume). The patient's family can participate if they and the patient want to. | 9 | 0,13 | 8 | 0,13 |
| Healthcare professionals try to care for the same patient as much as possible (continuity of care). | 8 | 0,13 | 7 | 0,16 |
| Attention is given to patients' sleep hygiene (reducing light and noise, etc.). | 8 | 0,23 | 6 | 0,32 |
| The patient and family are encouraged to actively participate during care and mobilization moments. | 9 | 0,13 | 7 | 0,37 |
| Structured activities are offered for distraction and relaxation (live music, reading, etc.). The family can also participate if they and the patient want to. | 9 | 0,13 | 7 | 0,37 |
| A daily schedule is made in consultation with the patient and family. Healthcare professionals adjust their own schedules (such as breaks) accordingly. | 8 | 0,16 | 6 | 0,27 |
| Communication aids (letter board, iPad, eye computer) are used by healthcare professionals to facilitate communication with the patient. | 7 | 0,26 | 6 | 0,97 |
| A "getting to know you" poster is used to display personal information, wishes, and needs of the patient. | 8 | 0,13 | 8 | 0,19 |
| The patient has a suitable alarm system with which he/she can use to call a healthcare professional at any time. | 9 | 0,13 | 9 | 0,13 |
| Healthcare professionals are trained in ways to apply patient- and family-centered care in practice. | 9 | 0,00 | 8 | 0,29 |
| Healthcare professionals are trained in the impact an ICU admission can have on the patient and family and what can be done to reduce that impact. | 8 | 0,21 | 7 | 0,20 |
| (Medical) protocols are adjusted to the individual wishes and needs of the patient and family as much as possible. | 9 | 0,13 | 8 | 0,33 |
| There is sufficient space (separate room) available where family can retreat. | 6 | 0,52 | 5 | 0,88 |
| Healthcare professionals are trained in patient and family-centered communication. | 9 | 0,13 | 8 | 0,49 |
| Family conversations can be held in a separate room if desired. | 9 | 0,06 | 9 | 0,16 |
| There is sufficient staff (nurses and intensivists) to provide PFCC. | 9 | 0,13 | 7 | 0,22 |
| It is possible to have a pet visit the ICU, but only when a strict protocol is followed. | 8 | 0,37 | 5 | 0,97 |
| The patient is comfortable and kept pain-free if possible. | 9 | 0,13 | 7 | 0,22 |
| **Communication between healthcare professionals** | | | | |
| All relevant patient data is shared both intra- and extramurally. | 8 | 0,13 | 7 | 0,37 |
| Healthcare professionals outside the ICU (both intra- and extramurally) are informed about the short and long-term impact of an ICU admission for the patient and family. | 8 | 0,21 | 7 | 0,37 |
| A patient and family-centered culture is the norm. Healthcare professionals encourage each other to apply patient and family-centered care and give each other feedback. | 8 | 0,13 | 7 | 0,37 |

*Note:  the underlined sections represented suggestions and points of discussion from the second round*

| | Step 1: 60 Interventions with underlined sections | Step 2: Actions during round 3 with reason | Step 3:35 Interventions after incorporating feedback from round 3 |
|---|---|---|---|
| 1 | Before or during admission, the family is given a tour of the ICU. | Reformulated | During an admission conversation, the patient and family are given an explanation about the ICU environment. They are also directed to available information materials and technical aids (e.g. animations, VR glasses). |
| 2 | Healthcare professionals invite the family and coordinate to help during care and mobilization moments. | Reformulated | Family members can participate in care moments. The patient's privacy is taken into account during these moments. Nurses encourage the use of personal care products (e.g. body lotion, massage oil). |
| 3 | The family has the opportunity to be present with the patient 24 hours a day. | Reformulated | Deviation from regular visiting hours is possible in consultation. Custom visiting hours are arranged, taking into account the possibilities of the ICU, the needs of the patient and family, and rest moments. |
| 4 | Upon admission, the family is informed of the location of patient care products (such as body lotion). The family is invited to use them in consultation with the nurse. | Merged | See intervention 2 |
| 5 | (Digital) communication tools (such as telephone and video calls) are provided for contact between the patient and their family. | No action | (Digital) communication tools (such as telephone and video calls) are provided for contact between the patient and their family. |
| 6 | The family has the opportunity to be present for all procedures at the patient's bedside (such as the insertion of infusion lines or intubation). | Rejected; no PFCC | |
| 7 | The family has the opportunity to be present during the patient's resuscitation, under the guidance of the nurse. | Consensus | The family has the opportunity to be present during the patient's resuscitation, under the guidance of the nurse. |
| 8 | The family has the opportunity to attend the doctors' rounds and actively participate if they wish. | Reformulated | The family has the option to be present during the medical rounds and participate in them in consultation with the ICU nurse and/or ICU doctor. Privacy is taken into account during these moments. |
| 9 | Children (up to 17 years old) are accompanied by a pedagogical consultant during a visit to the ICU by a doctor or nurse. | Reformulated | Attention is paid to the pedagogical guidance of children (up to 17 years old). Pedagogical information material is also available. |
| 10 | Upon admission, the family is given a conversation with information about ICU admission. Information material about the ICU is also offered. During these conversations, there is also room for emotions. | Merged | See intervention 1 |
| 11 | Technical innovations (such as animations and VR glasses) are used to support patients and families before, during, and after ICU admission. | Merged | See intervention 1 |

| 12 | During ICU admission, <u>the nurse and/or physician pays structural</u> attention to the psychological and social well-being of the patient and family. | Reformulated | A conversation is scheduled with the patient and family at least weekly. During these conversations, the patient's current condition, care, and policy are discussed. Care goals are set and explanations are given, taking into account the patient's and family's wishes and needs. Attention is also paid to the psychological and social well-being of the patient and family. |
|---|---|---|---|
| 13 | The patient, family, and<u>/or nurse</u> keep a diary and <u>may take photos</u> during ICU admission. | Reformulated | Nurses encourage the family to report the ICU admission and take pictures, taking the patient's privacy into account. If there is a need, the nurse can supplement this report in consultation with the family. |
| 14 | For each patient (<u>who is admitted for more than a week</u>) and their family, <u>several</u> primary responsible nurses and <u>a primary responsible physician</u> are assigned in the ICU. | Reformulated | For continuity of care, first responsible ICU nurses and ICU doctors are assigned to each patient and their family. |
| <u>15</u> | <u>The patient and family are prepared in a timely manner for discharge from the ICU</u>. They are also followed up and guided for several days after discharge on the ward by ICU personnel. | Reformulated | After discharge from the ICU, every ICU patient is visited by an ICU nurse or ICU doctor on the regular ward to answer any questions. |
| 16 | The patient and family are offered the opportunity to visit the ICU after discharge <u>when they are ready.</u> | Reformulated | The patient and family have the option to use an ICU aftercare clinic and/or revisit the ICU after the admission when they are ready. |
| 17 | The patient and family have the option to use an ICU aftercare clinic after discharge. | Merged | See intervention 16 |
| 18 | In the event of impending death, the family is given the opportunity to say goodbye to the patient. | Rejected; standard care | |
| 19 | In the event of impending death, the possibility of dying at home is discussed with the patient and family. | Reformulated | In the event of impending death, the patient and family's needs and options for dying at home are discussed. |
| 20 | At the beginning of ICU admission, an anamnesis (admission interview) is conducted with the patient and family. This anamnesis focuses on the patient's physical, psychological, cognitive, and social functioning. | Reformulated | An anamnesis is taken with the patient and family, which focuses on the patient's physical, psychological, cognitive, and social functioning. |
| 21 | The patient and family are communicated with calmly and kindly. | Rejected; standard care | |
| 22 | The current state of the patient and the policy are communicated to the patient and family in an open and honest manner. | Rejected; standard care | |
| 23 | Communication is in understandable language for the patient and family, and the <u>communication is tailored to their background and culture</u>. If necessary, apps or a translator are used. | Reformulated | Communication with the patient and family is done in understandable language and is tailored to the patient and family's background and culture. If necessary, apps or an interpreter are used. |
| 24 | During the doctors' rounds and care moments, healthcare professionals identify themselves to the patient and family. They introduce themselves and speak to, not about, the patient and family. | Rejected; standard care | |

| 25 | Patient data (such as medical history and medication use) are discussed and verified with the patient and family upon admission. | Rejected; standard care | |
|---|---|---|---|
| 26 | A conversation is scheduled with the patient and family at least once a week. During these conversations, the patient's current condition, care, and policy are discussed and evaluated. | Merged | See intervention 12 |
| 27 | Decisions regarding ICU policy are discussed with the patient and family. Care goals are set, and explanations are provided. Healthcare professionals consider the patient and family's wishes and preferences. | Merged | See intervention 12 |
| 28 | A decision-making tool/decision tree is used to support the patient and family in making decisions regarding (medical) policy. | Rejected; not developed | |
| 29 | The family is informed daily about the patient's condition. If it is not possible to be physically present, (digital) communication means are used (e.g. phone, WhatsApp, email). | Reformulated | The patient's contact person is kept in consultation with the nurse informed about the patient's condition as needed and. There is a shared responsibility between the nurse and the contact person in this regard. |
| 30 | If there is a palliative care policy (care during the final stage of life), the patient's and family's wishes and needs are discussed and taken into account in decision-making. | Merged | See intervention 12 and 27 |
| 31 | After an escalation with the patient and/or family, it is always discussed and an attempt is made to restore trust. | Rejected; standard care | |
| 32 | Psychological support is offered to the patient and family by consultants (social worker, psychologist, pastoral worker). | Reformulated | The patient and family are offered psychological support from consultants (e.g. social worker, psychologist, pastoral worker) during the ICU admission, according to everyone's needs. |
| 33 | If desired, during the aftercare process, the patient and family are put in touch with peers (e.g. via a patient association). | Reformulated | During the aftercare trajectory, the patient and family are provided information on how to get in touch with fellow patients (for example, through a patient association). |
| 34 | There is a patient/family council that can provide the ICU with advice on care improvements. | Reformulated | There is a patient council that can provide advice to the ICU on improving care. |
| 35 | Healthcare professionals encourage the family to bring personal items from home for the patient's room (such as photos, figurines, etc.). | Reformulated | ICU healthcare professionals encourage the family to bring personal belongings of the patient (such as photos, figurines, etc.) from home to place in the patient's room. |
| 36 | The location of the patient's room (central, more stimuli vs. remote, less stimuli) is tailored to the patient's needs. | Reformulated | Stimuli (light, sound, etc.) are adjusted to the needs and conditions of the patient. If necessary and possible, the patient will be moved to another room for this purpose. |
| 37 | There is attention paid to the use of glasses, hearing aids, and dentures for patients. | Rejected; standard care | |

| 38 | Nurses pay attention to the patient's personal care (washing hair, clipping nails, using perfume). | Rejected; standard care | |
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| 39 | Nurses take care of the same patient as much as possible (continuity of care). | Merged | See intervention 14 |
| 40 | There is attention paid to good sleep hygiene for the patient (limiting light and noise, etc.) | Rejected; standard care | |
| 41 | The patient is encouraged to assist during care and mobilization moments. | Reformulated | The patient is encouraged to participate as much as possible during care moments. |
| 42 | Structural activities are offered for distraction and relaxation (live music, reading, etc.). The family can also participate if they and the patient wish to. | Reformulated | Attention is given to offering activities for distraction and relaxation (live music, reading aloud, etc.). The family can also participate if they and the patient wish to do so. |
| 43 | A daily schedule is made in consultation with the patient and family. Healthcare professionals adjust their own schedule (such as breaks, etc.) accordingly. | Reformulated | In consultation with healthcare professionals, the patient and family, a daily schedule is made. This schedule is tailored to the patient's needs and abilities. |
| 44 | Communication tools (letter board, iPad, eye computer) are used to promote communication with the patient. The family is encouraged to do so as well. | Reformulated | If necessary, communication aids (letter board, iPad, eye computer) are used to promote communication with the patient. Healthcare professionals encourage the family to use these aids when they want to communicate with the patient. |
| 45 | A "getting to know you" poster is used to display personal information, wishes, and needs of the patient. | No action | A "getting to know you" poster is used to display personal information, wishes, and needs of the patient. |
| 46 | The patient has a suitable alarm system that allows them to call a healthcare professional at all times. | No action | The patient has a suitable alarm system that allows them to call a healthcare professional at all times. |
| 47 | Healthcare professionals learn to apply patient- and family-centered care in practice during ICU training and clinical lessons. | Rejected; no PFCC | |
| 48 | Healthcare professionals are trained during ICU training and clinical lessons on the impact an ICU admission can have on the patient and family and what can be done to reduce that impact. | Rejected; no PFCC | |
| 49 | (Medical) protocols are adjusted as much as possible to the individual wishes and needs of the patient and family. | Rejected; no PFCC | |
| 50 | A separate room is available where the family can retreat. | Reformulated and split up | There is a general visitors' room available where family members can stay during their visit to the ICU (for example, to have a cup of coffee). A separate room is available for family members of a seriously ill ICU patient, where they can comfortably retreat and, if necessary, stay overnight. |
| 51 | Family conversations can be held in a separate room if desired. | Rejected; standard care | |
| 52 | There are enough ICU professionals present to make patient- and family-centered care possible. | Rejected; no PFCC | |
| 53 | It is possible to have a patient's pet visit the ICU. A strict protocol is followed for this. | Reformulated | Efforts are made to find ways to allow a pet to visit if the patient desires it. |

| 54 | The patient is always comfortable and as pain-free as possible. | Rejected; standard care | |
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| 55 | Relevant patient data is shared both intra- and extramurally (within and outside the hospital). | Rejected; no PFCC | |
| 56 | Healthcare professionals outside the ICU (both inside and outside the hospital) are informed about the short- and long-term impact of an ICU admission. | Reformulated | After an ICU admission, a handover takes place, with attention given to the patient's wishes and needs, and the physical, psychological, and social impact of an ICU admission. |
| 57 | Patient- and family-centered care is the norm. Healthcare professionals encourage each other to apply patient- and family-centered care and give each other feedback. | No action | Patient- and family-centered care is the norm. Healthcare professionals encourage each other to apply patient- and family-centered care and give each other feedback. |
| 58 | If the patient's condition allows it, there is the possibility of going outside under the guidance of a healthcare professional. | Reformulated | If the patient's condition permits, efforts are made to find ways for the patient to go outside under the supervision of a healthcare professional. |
| 59 | Before each discharge, a discharge conversation is held. During this conversation, the transition to the nursing ward and the aftercare clinic are discussed. | Reformulated | The patient is prepared as much as possible for discharge from the ICU. This includes attention to the transition from the ICU to the standard nursing ward and the period thereafter. Written information is also provided about the aftercare process. If possible, a discharge interview is held. |
| 60 | If family members have to wait, an indication of the waiting time is given. If the wait is longer, this will be communicated. | Reformulated | Healthcare professionals are aware of the family members waiting to visit the patient and ensure that the family can see the patient as soon as possible. |