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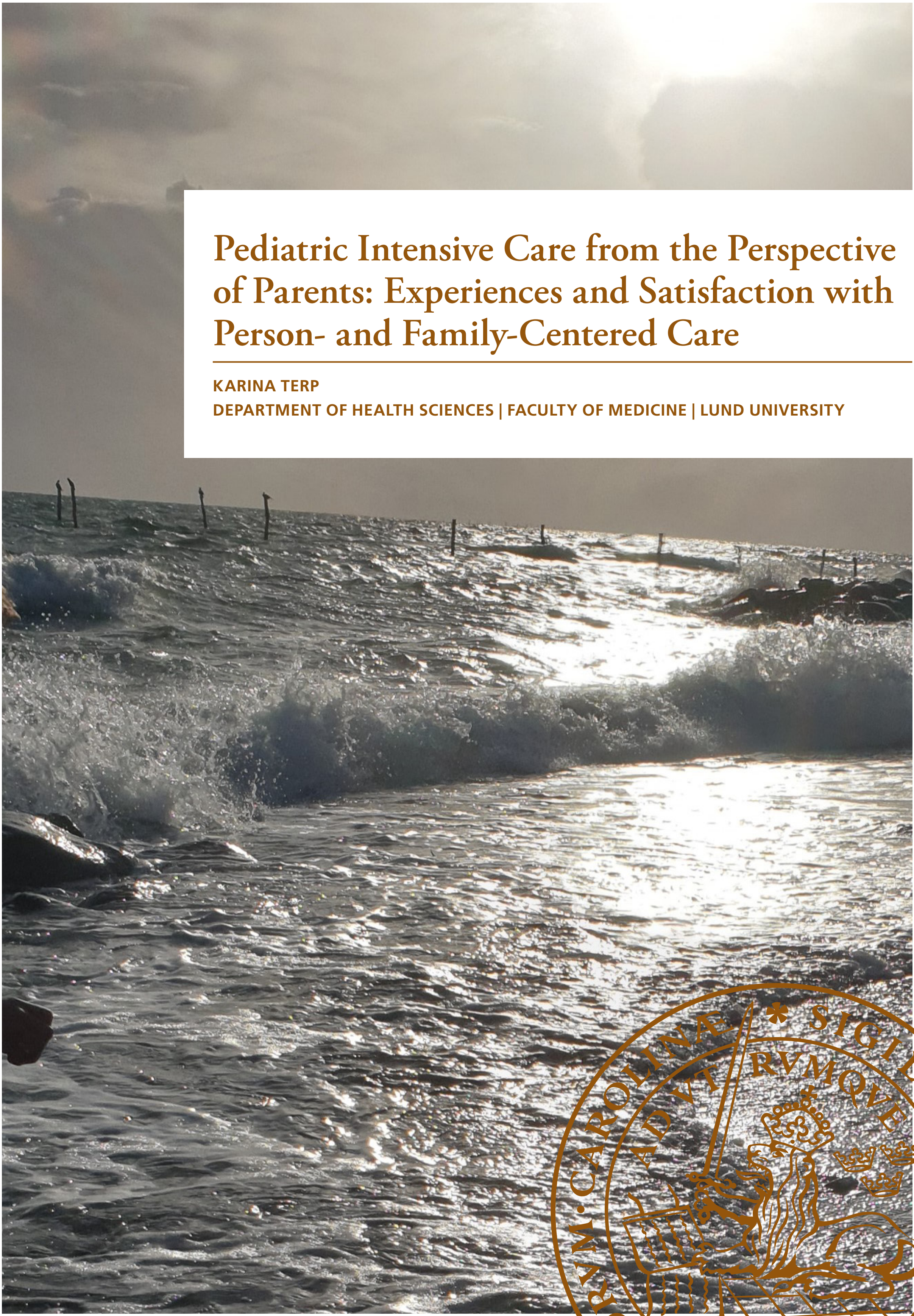

Pediatric Intensive Care from the Perspective of Parents: Experiences and Satisfaction with Person- and Family-Centered Care

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Pediatric Intensive Care from the Perspective of Parents: Experiences and Satisfaction with Person- and Family-Centered Care

Karina Terp

DOCTORAL DISSERTATION

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Abstract:

The overall aim of this thesis was to investigate parents' experiences and satisfaction with family-centered care (FCC) when their child was cared for at a pediatric intensive care unit (PICU). To obtain a deeper understanding of parents' experiences and satisfaction, two qualitative studies were conducted (Papers I and III). For Paper I, 10 individual interviews were conducted two years after their child was cared for at a PICU. The interviews were analyzed using content analysis. In Paper III spontaneous statements (n=70) obtained from the open questions in the questionnaire Empathic-30 were analyzed (deductive and inductive) based on a thematic method. In order to further investigate parents' satisfaction with care from a family-centered perspective, the questionnaire Empathic-30, which is based on family-centered care, was translated and initially validated into Swedish (Paper II, n=97). Data from Paper II were also used to present the outcome of Empathic-30 (Paper IV). For Paper I data were collected from one out of four PICUs in Sweden and for Paper II, III and IV at two of the four PICUs in Sweden.

Papers I and III focus on parents' experiences and satisfaction when the child was cared for in the PICU. The findings showed that parents of children in need of care at a pediatric intensive care unit experienced an emotional strain due to, e.g. their child's different appearance, the medical equipment that reduced their participation in their child's care and the unfamiliar environment. Although the parents experienced the environment as frightening, they felt safe at the PICU and had high confidence in the healthcare professionals taking good care of their child. The experiences remained in the memory of the parents and were easily recollected. There were occasions when the experiences resulted in ill mental health. The parents were satisfied with the care their children received at the PICU (Paper IV) and they felt they were treated with dignity and respect by the healthcare professionals (HCPs) (Paper I, II and IV). Although parents were highly satisfied with the care their child received, suggestions for improvements emerged. This was mainly evident in the FCC concepts of information sharing particularly in connection with the child's discharge and participation in decisions about the child's care.

Keywords: Experiences**,** Family-centered care, Parents, Pediatric intensive care, Satisfaction

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Spirit lead me where my trust is without borders
Let me walk upon the waters
Wherever You would call me
Take me deeper than my feet could ever wander
And my faith will be made stronger …

Oceans (Where Feet May Fail)
Hillsong United

Table of Contents

Abstract

The overall aim of this thesis was to investigate parents' experiences and satisfaction with family-centered care (FCC) when their child was cared for at a pediatric intensive care unit (PICU). To obtain a deeper understanding of parents' experiences and satisfaction, two qualitative studies were conducted (Papers I and III). For Paper I, ten individual interviews were conducted two years after their child was cared for at a PICU. The interviews were analyzed using content analysis. In Paper III spontaneous statements (n=70) obtained from the open questions in the questionnaire Empathic-30 were analyzed (deductive and inductive) based on a thematic method. In order to further investigate parents' satisfaction with care from a family-centered perspective, the questionnaire Empathic-30, which is based on family-centered care, was translated and initially validated into Swedish (Paper II, n=97). Data from Paper II were also used to present the outcome of Empathic-30 (Paper IV). For Paper I data were collected from one out of four PICUs in Sweden and for Paper II, III and IV at two of the four PICUs in Sweden.

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Populärvetenskaplig sammanfattning

Pediatrisk intensivvård fokuserar vård av barn och ungdomar med livshotande sjukdomar och skador. I Sverige finns idag fyra barnintensivvårdsavdelningar (BIVA) vilka är centraliserade till regionsjukhusen i Göteborg, Lund, Stockholm och Umeå. Avdelningarna vårdar barn från sina egna upptagningsområden men även barn som remitteras från andra sjukhus i Sverige och ibland från utlandet. Det är väl känt att föräldrar till barn i behov av pediatrisk intensivvård upplever en känslomässig påfrestning. Oro för om barnet skall överleva, utfallet av vård och behandling och att vara åtskild från syskon och andra familjemedlemmar är faktorer som kan påverka föräldrar negativt och orsaka olika stressreaktioner som kan resultera i psykisk ohälsa. När vården genomförs utifrån ett familjecentrerat perspektiv har det visat sig positivt för föräldrars och barns välmående. Familjecentrerad vård (FCV) kan också leda till en ökad tillfredställelse med vård. Det finns ett samband mellan tillfredsställelse med vård och kvalitet, en högre tillfredställelse kan innebära en god vårdkvalitet. Från en svensk kontext är kunskap avseende föräldrars upplevelser i samband med deras barns vård på BIVA samt deras tillfredsställelse med vården begränsad. Syftet med avhandlingen var därför att undersöka föräldrars upplevelser och tillfredsställelse med svensk pediatrisk intensivvård med utgångspunkt i principerna för FCV.

Avhandlingen omfattar fyra delstudier, två kvalitativa studier (delstudie I och III) vilka ger en förståelse för föräldrarnas upplevelser och tillfredställelse med vård samt två kvantitativa studier (delstudie II och IV). För delstudie I genomfördes tio individuella intervjuer med föräldrar två år efter att deras barn vårdats på en BIVA i Sverige. Intervjuerna analyserades med en kvalitativ innehållsanalys. För att få kunskap om föräldrars tillfredsställelse med vård ur ett familjecentrerat perspektiv översattes och validerades frågeformuläret Empathic-30 (delstudie II) till svenska. Frågeformuläret är uppbyggt utifrån principerna för FCV. De 30 frågorna är uppdelade i fem domäner, *information*, *vård och behandling*, *organisation*, *föräldrarnas delaktighet* och *professionella attityder* vilka besvaras på 6-gradig ”Likert”-skala som sträcker sig från ett "håller inte med" till sex "instämmer helt". Frågeformuläret påvisade goda psykometriska egenskaper vilket innebär att det kan användas i klinisk praxis för att utvärdera föräldrars tillfredsställelse med vård. Föräldrarna hade möjlighet att i Empathic-30 besvara fem öppna frågor som fokuserade deras upplevelser under vårdtiden på BIVA (delstudie III). Deras svar analyserades tematiskt, deduktivt och induktivt. Slutligen i delstudie IV analyserades utfallet av de 30 frågorna i Empathic-30 med deskriptiv och analytisk statistik.

I resultatet framkom att efter två år hade föräldrarna fortfarande tydliga minnen av deras barns vårdtid på BIVA. När de tittade på foto/bilder eller tänkte tillbaka på vårdtiden kunde de känna ångest och oro (delstudie I). De beskrev rädsla relaterat till båda barnets tillstånd samt den främmande miljön. En del föräldrar beskrev att de bara sett en intensivvårdsavdelning på film tidigare (delstudie I). Medicinskteknisk utrustning och att se barnet intuberat ledde till oro och stress hos föräldrarna (delstudie I). Föräldrarna kände sig osäkra att röra och hantera sitt barn, då de var rädda att koppla bort utrustning av misstag och förvärra barnets tillstånd, vilket försvårade deras deltagande i barnets vård (delstudie I och III). Föräldrarna ville delta i sitt barns vård men behövde stöd och hjälp av personal att delta. Det fanns tillfälle när de inte upplevde sig inbjudna att delta, framför allt då personalen gjorde uppgifter per rutin och glömde bjuda in dem (delstudie III). Miljön på BIVA upplevdes som skrämmande och främmande trots det ansåg föräldrarna att det var en säker och trygg plats för barnet att vara på, då de hade en stor tilltro till personalens kompetens (delstudie I och III). Föräldrarna ansåg att de möttes med respekt och värdighet av personalen, vilket gjorde att de kände stöd och förtroende för dem (delstudie I och III). Föräldrarna var tillfredsställda med vården deras barn fick samt med bemötandet (delstudie I, III och IV).

Även om det i delstudie III och IV visade att föräldrarnas tillfredsställelse med vården var hög så framkom förbättringsförslag i de kvalitativa studierna (delstudie I och III), framför allt vad gäller kommunikation mellan föräldrarna och vårdpersonalen samt deras delaktighet i vården och beslut kring barnets vård. Föräldrarna upplevde att kommunikationen emellanåt inte skedde i dialog. Vad gäller delaktigheter upplevde föräldrarna att de inte deltog i planering av barnets vård.

List of Papers

Paper I

Terp, K., & Sjöström-Strand, A. (2017). Parents' experiences and the effect on the family two years after their child was admitted to a PICU - An interview study. Intensive and Critical Care Nursing. Doi: https://doi.org/10.1016/j.iccn.2017.06.003

Paper II

Terp, K., Jakobsson, U., Weis, J., & Lundqvist, P. (2023). The Swedish version of EMPATHIC-30 translation and initial psychometric evaluation. Scandinavian Journal of Caring Sciences 2023 Vol. n/a Issue n/a. DOI: https://doi.org/10.1111/scs.13166

Paper III

Terp, K., Weis, J., & Lundqvist, P. (2021). Parents' Views of Family-Centered Care at a Pediatric Intensive Care Unit-A Qualitative Study. Frontiers in Pediatrics
2021 Vol. 9 Pages 725040. DOI:10.3389/fped.2021.725040
https://www.frontiersin.org/articles/10.3389/fped.2021.725040/full

Paper IV

Terp, K., Jakobsson, U., Weis, J., & Lundqvist, P. (2023). Satisfaction with family-centered care in pediatric intensive care: Parents' Perceptions. (Submitted)

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Abbreviations

ASD	Acute Stress Disorder
CHD	Congenital Heart Defect
FCC	Family-Centered Care
FCR	Family-Centered multidisciplinary rounds
HCP	Health Care Professionals
ICU	Intensive Care Unit
LOS	Length of Stay
PCC	Person-Centered Care
PFCC	Person- and Family-Centered Care
PICU	Pediatric Intensive Care
PTSD	Posttraumatic Stress Disorder
TA	Thematic Analysis
WHO	World Health Organization

Introduction

Medical and technical development, as well as improved nursing care, have resulted in increased survival rates for children in need of pediatric intensive care. Consequently, a greater number of children and their families must deal with the challenges associated with such care. In Sweden, pediatric intensive care is centralized within four regional hospitals, and children with threatening or manifest organ failure are eligible for care at one of these high-technological units. The units treat children within their admission area but children in need of pediatric intensive care can also be referred from hospitals outside the pediatric intensive care units (PICUs) catchment area. Between 2010 and 2019, the number of admissions to the four PICUs in Sweden increased by 14%. The PICUs in Sweden have a family-centered approach with no restrictions on the presence of parents (Swedish Intensive Care Register, 2020).

It is well known that parents of children in need of pediatric intensive care experience an emotional strain. Concerns about e.g. the child's diagnosis, care, and treatment as well as being separated from siblings and other family members are factors that might negatively affect parents and cause different stress reactions (Debelić et al., 2022; Bloxham, et al., 2023; Whyte-Nesfield et al., 2023). Furthermore, they can also be distressed by seeing their child being connected to medical equipment (Board & Ryan-Wenger, 2002; Colville et al., 2009; Rodríguez-Rey & Alonso-Tapia, 2016). Equipment that, together with their child's vulnerability, contributes to their experience of difficulties approaching their child and performing daily care. Earlier research has demonstrated that parents can develop both acute stress disorder (ASD) and post-traumatic stress disorder (PTSD) (Colville & Pierce, 2012; Nelson & Gold, 2012; Ward-Begnoche, 2007). Post-traumatic stress does not only affect the parent; it could also negatively affect the family as a whole (Erçin-Swearinger et al., 2022; Nelson et al., 2019).

Satisfaction with care has been shown to improve parents', as well as children's well-being, both during and after the child´s intensive care period. Satisfaction with care can be affected by various factors and, among other things, it has emerged that positive communication and collaboration with healthcare professionals are important for ensuring a higher level of satisfaction (Abuqamar, Arabiat, & Holmes, 2016; Bastani, Abadi, & Haghani, 2015). One way to increase parental satisfaction with care is to practice family-centered care (FCC) where communication and collaboration are included as concepts (Abuqamar, Arabiat, & Holmes, 2016; Latour, van Goudoever, Schuurman, et al., 2011; Mortensen et al., 2015). The Institute for Patient and Family-centered Care (IPFCC, 2017) describes FCC as "*an approach to the planning, delivery, and evaluation of health care*". The care should be based on a "*mutually beneficial partnership*" among the patient/person, the family, and the health care professional.

There is a lack of knowledge regarding the parents' experiences and satisfaction with care when their child is being treated in a highly technological environment such as Swedish pediatric intensive care. Acquiring such knowledge could benefit future parents and families. Therefore, the focus of this thesis was to investigate parents' experiences and satisfaction with pediatric intensive care based on the principles of FCC.

Background

Pediatric intensive care

Pediatric intensive care is a specialized medical discipline focusing on the critical care of infants and children with life-threatening illnesses and injuries. This specialized field covers a diverse range of healthcare professionals, including intensive care physicians, nurses, and pharmacists among others. When the polio epidemic increased in the 1930s-50s, the need for respiratory care escalated and this can be seen as a starting point for the formation of PICUs. The first PICU in the world was established in Gothenburg, Sweden at the Children's Hospital, by Göran Haglund in 1955. Ten years after the first intensive care unit, several units were initiated around the world (Epstein & Brill, 2005).

The reasons for admission to a PICU are diverse and can vary depending on factors such as age, underlying medical conditions, and geographical location. Some of the most common causes of admissions to pediatric intensive care units include respiratory conditions, such as severe asthma exacerbations, respiratory distress syndrome, and pneumonia. Other common reasons for admission include sepsis, trauma, neurologic emergencies, and post-operative care following complex surgeries (Guzman-Cottrill & Kirby, 2014; Ibiebele et al., 2018; Seifu et al., 2022). The care provided in the PICU requires advanced monitoring and life support as well as advanced competence among the healthcare team working at the PICU. The multidisciplinary team, along with improvements in technology, care and treatment based on advancing research, continues to increase patient outcomes (Slusher et al., 2018). Mortality of children treated in PICUs has decreased significantly over the years. One reason could be that the treatment of more advanced conditions has progressed (Agra-Tuñas et al., 2020; Kashyap et al., 2020).

Length of stay (LOS) varies depending on the child's condition. A majority of the children, over 50%, are hospitalized for two days or less, or a period of less than seven days. However, a minority of children require hospitalization for more than seven days, extending to multiple weeks, within the PICU. It is most common for children of younger ages and those children who need mechanical ventilation to require care for longer periods (Marcin et al., 2001; Pollack et al., 2018).

Swedish Pediatric Intensive Care

In Sweden, there are four pediatric intensive care units, located in Gothenburg, Lund, Uppsala, and Stockholm. The units provide care to children with severe medical and surgical conditions. The focus is on diagnostics, monitoring, treatment, and nursing care. Since the 1950s open heart surgery for children has been developed and performed in Sweden. As a result of this development, advanced postoperative care was required. The increased need for postoperative care started a growth of PICUs in Sweden (Nilsson et al., 2015).

The PICUs primarily care for children within their catchment area, but they are also referral centers for children from other areas in Sweden or other countries who require advanced treatment and care. The units have specially trained nurses, anesthetists, and other healthcare professionals. In pediatric intensive care, as well as in general pediatric care, the care philosophy is based on family-centered care (Oude Maatman et al., 2020), which means that the parents are encouraged to participate in their child's treatment (Svenska Intensivvårdsregistret SIR, 2023).

Due to limited admission capacity in the four PICUs in Sweden, children who require intensive care could also be hospitalized in a general intensive care unit (ICU). According to Swedish recommendations, all general ICUs should have the capability to stabilize children who are critically ill. Furthermore, if required, offer intensive care for up to 48 hours. Children 12 years of age or older with a weight over 40 kg can be cared for in a general ICU. That is, if there are no other reasons such as a need for special care that only can be provided at a PICU or if the expertise required for the child’s condition is not available in the general ICU. During a 10-year period (2012 to 2022) the distribution of children between PICUs and general ICUs was evenly distributed (Table 1). Looking at the total PICU admissions, 72% were unplanned (Svenska Intensivvårdsregistret SIR, 2023).

Table 1. Child hospitalized in Swedish intensive care from 2012 to 2022.

Children, n=35449	**PICUs (n)**	**General ICU (n)**
Admissions	19030	16419
Age 0–1 month-old	3770	641
Age 1–5 months-old	3964	1077
Age 6-12 months-old	1682	1031
Age 1-7 years old	5999	5927
Age 8-15 years old	3615	7743

There is a variation regarding LOS for children cared for in intensive care (PICUs and general ICUs) in Sweden. Between the years 2012 to 2022, it varied from less than 1 day to more than 30 days (Table 2).

Table 2. Children's LOS in PICUs and general ICUs in Sweden (2012-2022, Svenska Intensivvårdsregistret SIR, 2023).

LOS children n=35449	**n (%)**
1 h to < 24 h	19169 (54)
24 h to < 4 days	10879 (31)
4 days to < 11 days	3793 10)
11 days to < 30 days	1333 (4)
≥ 30 days	275 (≈ 1)

Younger children and children with severe medical conditions are prioritized for admission to PICUs. Conversely, older children and those with less critical illnesses are more frequently cared for in the general ICU (Gullberg et al., 2008).

Parents' experiences and needs in Pediatric Intensive Care

Becoming a parent is in many ways an overwhelming and life-changing experience. The parental role involves the responsibility of nurturing a child from infancy to adulthood. A parent's role, among others, is to love, care for, guide, and support the child along the way to adulthood (Frosch et al., 2021). When a child becomes seriously ill, parents often take on the role of advocate for their child (Brady et al., 2020). It is common for parents to discover signs of their child's deteriorating health before even the most experienced medical professional does (Brady et al., 2020; Lundqvist et al., 2021). The presence of a seriously ill child raises significant levels of stress and fear among parents (Alzawad et al., 2020; Debelić et al., 2022). Parents of children receiving treatment in the PICU face a significant risk of developing psychological disorders such as ASD and PTSD (Nelson & Gold, 2012; Nelson et al., 2019). Stress results from the uncertainty of the child's condition, treatment procedures, and potential complications (Grandjean et al., 2021; Bloxham et al., 2023). The fear of the child's risk of not surviving is another psychological burden on parents, resulting in intensified stress levels and an increased risk of mental health problems (Balluffi et al., 2004; Mowery, 2011; Ward-Begnoche, 2007).

The unfamiliar PICU environment further intensifies parental distress, as they face overwhelming emotions while witnessing their child in a critical state in a high-technological setting. The stress symptoms can, in some cases, remain for several months up to years after the child's discharge from the PICU (Balluffi et al., 2004; Colville & Pierce, 2012). The constant presence of medical equipment, alarms, and healthcare professionals can be overwhelming for parents. Likewise, observing their child undergoing traumatizing procedures, being in pain or discomfort and even perhaps, in addition, be sedated is also painful to witness for parents. It evokes feelings of powerlessness and guilt among the parents as they cannot protect their child from harm (Grandjean et al., 2021). These emotions further intensify parental distress and can lead to psychological consequences (Colville & Gracey, 2006; Lisanti et al., 2017).

Parents' stress levels can be reduced if they are acknowledged by the healthcare team, and if they are invited to be a part of their child's care. Both in decision-making according to the care, as well as being invited to participate in direct nursing care (Argent et al., 2022; Debelić et al., 2022). It is important to allow parents to have private space. Parents have described a need for, e.g. a kitchenette at the unit, so that they can make coffee or heat food without leaving their child. A comfortable chair to rest in has also been considered significant for parents (Vasli et al., 2015).

The relationship with the healthcare team is important for parents and they want to be shown compassion and gain support from the healthcare team, as well as having someone to talk with about their situation (Majdalani et al., 2014; Mortensen et al., 2015). It is also important that the parents have their cultural needs and beliefs respected, (Meert et al., 2009). Furthermore, it is central for them that their child is treated as a person and called by their name.

Guidance and encouragement from the healthcare team are essential for parents to participate in their child's care, due to the advanced equipment (Hill et al., 2018). Parents need ongoing comprehensive information as well as information in time before e.g. discharge and/or transfer to another care facility (Azoulay et al., 2002; Majdalani et al., 2014).

Satisfaction within Healthcare

Satisfaction as a concept within healthcare has been defined in various ways over the years, however, the main meaning is associated with the person's/patient's response to a service experience (Crow et al., 2002). The meaning of Satisfaction is described as "*a pleasant feeling that you get when you receive something you wanted, or when you have done something you wanted to do*" (Cambridge Dictionary, 2023).

The concept of patient satisfaction was stated as early as the 1970s and was associated with patients' attitudes toward physicians and health care (Hulka et al., 1970; Zyzanski et al., 1974). Ware et al. (1978) undertook a comprehensive literature review to elucidate the conceptualization of satisfaction in the context of healthcare. The review highlighted dimensions that influenced patient satisfaction. Notably, the dimensions encompassed the quality of care delivered, containing both technical competence and personal expertise, as well as the attitudes exhibited by healthcare professionals. Additionally, the review emphasized the significance of factors such as accessibility and convenience, economic considerations, the physical environment, continuity of care, efficiency, and the outcome of the care received. Hall and Dornan (1988) revealed indicators for overall satisfaction and highlighted, among other things, adequate information, organizational aspects, and the attention given to psychological concerns. This was further compiled by Cleary and McNeil (1988) to the patient's *characteristics, structure, process,* and *outcome*. Consequently, a person's expectations and social demographic characteristics, together with physical status, were all factors impacting the experienced satisfaction. Linder-Pelz (1982) defined patient satisfaction as "*an individual's positive evaluation of distinct dimensions of health care*". She explained that a measurement of satisfaction in health care services is a person's subjective experiences of different aspects. Fitzpatrick and Hopkins (1983) highlighted the aspects of the personal meeting that influence satisfaction and the overall experience as well as the patient's previous experiences together with expectations of the healthcare (Fitzpatrick & Hopkins, 1983).

One of the key dimensions of satisfaction with care is the technical competence of healthcare providers. Patients expect healthcare professionals to possess the necessary knowledge and skills to diagnose and treat their medical conditions effectively. When patients perceive healthcare providers as competent, it enhances their overall satisfaction with the care they have received (Lochman, 1983). Moreover, the effectiveness of treatments plays a significant role in determining patient satisfaction (Chen et al., 2017; Li et al., 2017). This was further summarized by Donabedian (1988) who stated that satisfaction is based on the personal relationship in the meeting between the patient and the healthcare professionals, as well as the patient's previous experiences and values. According to Crow et al. (2002), the dominant predictor of high satisfaction is the relationship between patients and healthcare professionals. Graham (2016) enlightened the importance of the patients' expectations. If patient expectations were not met, they tended to be less satisfied. However, several studies (Cheng et al., 2003; Fenton et al., 2012; Hekkert et al., 2009; Nguyen Thi et al., 2002) have shown a connection regarding the correlation between patient satisfaction and various demographic factors, namely age, sex, education, and health status. Several studies (Dubina et al., 2009; Hung et al., 2015; Kane et al., 1997) have also demonstrated a positive relationship between satisfaction with care and higher health outcomes.

Measuring satisfaction with care

There are different forms to measure satisfaction with care, e.g. the Patient Satisfaction Questionnaire Short Form (PSQ-18) (Marshall & Hays, 1994), the Pediatric Family Satisfaction in the Intensive Care Unit 24 (pFS-ICU 24) (Epstein et al., 2013), the Pediatric Inpatient Experience Survey (PIES) (Ziniel et al., 2016), and the EMpowerment of PArents in THe Intensive Care 30 (Empathic-30) (Latour et al., 2013), see Table 3. In Nordic countries, satisfaction is widely investigated, however, different forms are often used for similar patient groups, which makes it difficult to make comparisons between larger groups and between countries (Friedel et al., 2023). When patient satisfaction is measured, it is important to choose the right survey for the purpose and target group to get a reliable result (Al-Abri & Al-Balushi, 2014; Crow et al., 2002).

Measuring satisfaction with care can provide knowledge for more efficient and higher quality of care, as well as improved psychological well-being of the patient, enhanced healthcare service and feedback for improvement potentials of the care provided. Satisfaction is important for the quality of care although the quality of care is a separate concept (Ilioudi et al., 2013; Lescher & Sirven, 2019)

Table 3. Examples of instruments measuring satisfaction with care

Author(s)	Instrument Number of Items	Description	Measure Scale/Scoring	Administration
Marshall and Hays (1994)	PSQ-18 18 items	Questionnaire focusing on satisfaction with pediatric medical care	Patient Satisfaction Likert scale	Self-administrated
Epstein et al. (2013)	pFS-ICU 24 24 items	Questionnaire focusing on parents' satisfaction with overall care and decision-making at PIUCs	Parents satisfaction Likert scale	Self-administered
Ziniel et al. (2016)	PIES 61 items	Questionnaire focusing on parents' experience of pediatric care from family-centered concepts	Parents experiences and satisfaction Likert scale	Self-administrated
Latour et al. (2013)	Empathic-30 30 items	Questionnaire focusing on parents' satisfaction with pediatric intensive care from a FCC perspective	Parents satisfaction Likert scale	Self-administrated

Quality of Care

Quality of care is described by achieved quality defined indicators, and several organizations have identified quality indicators for quality of care. The World Health Organization (WHO) (2023, October) identified the following indicators for quality of care, *effective* as supplying needed care to people, *safe* as preventing harm in healthcare, *people-centered* as giving care out of individual preferences and values, *timely* as reducing time to care, *integrated* as coordinated care at all levels and *efficient* as use of appropriate resources. In addition, the Organization for Economic Co-operation and Development (OECD) established a conceptual framework where dimensions for quality in healthcare were summarized. Besides the above-mentioned indicators, they also highlight *responsiveness,* which is described as meeting the person's expectations. Another dimension that they included in their framework is *accessibility*, which is described as easily available healthcare. The element of *equity* was also brought to light, which is described as fair and equally distributed healthcare among people (Kelly & Hurst, 2006). The Institute of Medicine Committee on Quality of Health Care (2001) defines the quality of care as *safe, effective, patient-centered, timely*, *efficient,* and *equitable*. Donabedian (1966) created a model that is widely accepted to measure quality of care, he divided the indicators into three main categories, *structure, process,* and *outcome*. The model is explained as follows; the *structure* stands for the physical or organizational part where the healthcare is provided. While the *process* is the part that focuses on given care such as diagnosis and treatment. The *outcome* in the model aims to the effect of the care provided (Donabedian, 2003). The model describes that all three main categories are related to each other, to achieve good quality both structure, process and outcome need to have been achieved (Donabedian, 1988, 2005). Quality of care can be measured with various instruments, for example; *The Quality-of-Care Questionnaire* (Katarina et al., 2018), *Quality evaluation questionnaires – nursing homes* (Triemstra et al., 2021) and *Development and validation of the quality care questionnaire – palliative care* (Yun et al., 2018). However, when measuring the quality of care, it is important to use the right instrument for the purpose (Beattie et al., 2015).

> *"Quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with evidence-based professional knowledge"* (World Health Organization, January 2024, second paragraph What is quality?).

Relationship between Satisfaction and Quality of Care

The relationship between satisfaction and quality of care is a complex and multifaceted phenomenon that has been extensively studied in the scientific literature. Various studies have been conducted to investigate this connection (Choi et al., 2004; Cleary & McNeil, 1988; Lescher & Sirven, 2019; Mercado-Rey, 2020). A strong positive correlation between patient satisfaction and quality of care is widely acknowledged by researchers and healthcare providers, stating that high levels of satisfaction together with clinical results are associated with quality of care (Choi et al., 2004; Hudak &

Wright, 2000). Thereto, it is important to note that many of the indicators used to measure satisfaction are closely related to the indicators used to measure quality of care (Cleary & McNeil, 1988).

According to Donabedian (1988), the primary aspect of quality lies in achieving optimal health outcomes and overall patient satisfaction. In a study conducted by Mercado-Rey (2020), a connection between satisfaction and care quality was found, particularly in terms of safety and treatment, with a focus on the physician-patient relationship. Cleary and McNeil (1988) argue that higher patient satisfaction is indicative of better communication and patient relationships, which in turn contribute to higher quality of care. Similar results were reported in a study conducted by Tasso et al. (2002), where patients reported higher satisfaction when interpersonal high-quality care was provided. In their recent study, Lee et al. (2021) demonstrated a significant association between organizational culture and patient satisfaction as well as the quality of care (Lee et al., 2021). In a comprehensive study examining the association between hospital quality and patient satisfaction, a strong positive correlation was observed across various indicators encompassing safety, efficiency, treatment outcomes, pain management, providing of information, and the overall hospital environment, among others (Lescher & Sirven, 2019). Comparable findings were exhibited between quality of care and satisfaction both in terms of information, relationships and attitudes from professionals, and the treatment administered to patients (Zarei et al., 2015). When measuring satisfaction, the focus lies on an individual's subjective encounter (Crow et al., 2002; Linder-Pelz, 1982). Conversely, when evaluating the quality of care, it implies evaluating the objective outcomes such as successful surgical procedures, survival rates, duration of treatment, and number of care days, among others (Donabedian, 2005). To distinguish a subjective and objective fact Bernoulli (2006) stated the following;

> *"The certainty of anything is considered either objectively and in itself or subjectively and in relation to us. Objectively, certainty means nothing else than the truth of the present or future existence of the thing. Subjectively, certainty is the measure of our knowledge concerning this truth."* (Bernoulli, 2006 p. 315).

Theoretical Framework

Family-Centered Care

The development of FCC started during the second half of the 20th century (Shields et al., 2007). One important starting point was the Platt report “Welfare of Sick Children in Hospital” (1959), a report that was written on behalf of the Ministry of Health in the United Kingdom of England. The Platt report focused, among other things, on children’s needs during hospitalization and avoidance of hospital admission. During the evaluation of pediatric care in hospital settings, several inaccurate factors were brought to light. One aspect that was emphasized concerned the restricted access for parents to freely visit their children beyond designated visiting hours. Furthermore, in some cases, the separation from the parents was identified as a potentially more distressing experience than the illness itself. Additionally, a child in a hospital was not permitted to engage in playful activities - the child was often subjected as a small adult. The report initiated a need for collaboration between the hospitals that care for children and the parents to increase the child's welfare during hospitalization (Davies, 2010; Platt, 1959).

After the Second World War attention was paid to the trauma children suffered when they had been separated from their parents, this knowledge increased the importance of not separating children from their parents when they were hospitalized (Jolley & Shields, 2009). This was further studied by James Robertson who had a significant role in the development of children's healthcare. As a result of Robertson (1959) research and his undertaking to spread information via the film “*A Two-Year-Old Goes to Hospital* “, a shift took place where parents were granted the opportunity to accompany their child during hospitalization (Robertson, 1959). From there, the FCC developed, first involving the parents, and then initiating a partnership between the family and the healthcare professionals (Jolley & Shields, 2009). The importance of partnership was enlightened as an important principle of FCC (Coyne, 1995; Kay Hutchfield, 1999).

FCC has been further developed and the nurse's role in cooperation with the family has been presented as an important part of the implementation of FCC (Hill, 1996; Ziniel et al., 2016). Recognizing FCC is seen as important by nurses. They also expressed that parents know their child best. On the other hand, the nurses believe that it could be emotionally difficult for parents to participate in their child's care. As well as the fact that it takes longer time to carry out tasks when parents participate, as they also need to be supported during the care procedure (Boztepe & Kerimoglu Yildiz, 2017). Nurses also recognize the benefits of cooperating with parents, especially in association with building a relationship between parents and healthcare professionals. Other benefits of having parents' at their child's bedside are that several single rooms are established in the pediatric units which reduce patient intake and thereby also the burden on staff. On the other hand, the nurses felt that patient safety could be compromised as children are isolated in single rooms (Coats et al., 2018). In order to be able to successfully implement FCC, it is required that the healthcare staff has a positive attitude towards the care model, have communication training and that the environment is suitable for FCC (Oude Maatman et al., 2020).

Different descriptions of FCC have been presented over the years, The American Academy of Pediatrics states that the family serves as the primary source of strength and support for the child, and the collaboration between family and healthcare is essential in clinical decisions (AAP, 2012). Shields et al. (2006) defined FCC as *"…a way of caring for children and their families…which ensures that care is planned around the whole family…*", (Shields et al. 2006, p. 1318). Mikkelsen and Frederiksen (2011, p. 1155) highlighted the following areas in the concept of FCC, *"shared responsibility, parent autonomy and control, negotiation and family support shared responsibility*". They argue that FCC has benefits for parents and supports the normal parental role (Mikkelsen & Frederiksen, 2011). Although the principles that illuminate FCC have been summarized by many, there is still not a consensus on definition but most often the following areas are highlighted, partnership, participation, respect for the family's autonomy, support and cooperation between healthcare and parents both regarding care and the development of care such as e.g. policy documents (K. Hutchfield, 1999; Mikkelsen & Frederiksen, 2011; Shelton, 1994).

Person- and Family-Centered Care

A patient is recognized as a person when person-centered care (PCC) is utilized. All individuals have a story, and the person arises out of this story. Personal identity comes from the story of who you are and not from the description of what you are (Ekman, 2014). A human's *person value* is, independent of the value others assign the person, or what he/she can achieve, enjoy, or desire. Instead, it is based on a person's intrinsic value. PCC does not evaluate human life according to its utility but to its intrinsic person value equal for all human beings. This person's value can further be described by indicators to clarify the meaning and content which need to be safeguarded (Carlberg, 1998). The person first becomes a patient when they encounter healthcare services (Ekman, 2014; Oben, 2020). The person in the patient remains even though he/she needs healthcare services (Oben, 2020).

When person-centered care is practiced a transition from viewing the patient as a passive recipient to an active participant in their care is performed (Edberg, 2021). A person's rights and dignity must be respected in the PCC (McCance et al., 2009). The PCC involves the competence of the nurse and her/his values and beliefs, the context where the care is delivered, from organizational to environmental. Another important aspect of PCC is to work together with the patient and respect his/her beliefs and values. In addition, involving the patient in decision-making regarding his/her care is a goal in PCC (McCormack, 2003; McCormack & McCance, 2006). For PCC to be realized, the relationship between the patient and the professionals is an important part (McCance et al., 2009; McCormack, 2003).

Another concept that has been developed during the last decades is child-centered care (CCC) (Franck & Callery, 2004). The core of CCC is described as the child being at the center of care. The child is the key person in the partnership, has his/her rights and must therefore be the one who decides upon his/her care supported by an adult in his/her decisions (Coyne et al., 2016). It is argued that the child should be allowed to take a greater role in their care and his/her views should be taken into account to a greater extent. The focus should not be on the family but on the child being cared for and when he/she can bring their case, they must be heard (Ford et al., 2018). The parent's objective interpretation of the child's subjective needs may differ, especially for children who undergo treatment for a longer period (Franck & Callery, 2004).

In this thesis, the model *"Patient- and Family-Centered Care"* (PFCC), according to the definition by the Institute for Patient- and Family-Centered Care (IPFCC) will be used (IPFCC, 2017). In patient- and family-centered care, as well as in other definitions of FCC, it is the patient and family who define their family. The family decides their level of participation in care and decision-making. The patient and family are viewed as essential allies in a mutually respectful partnership (IPFCC, 2017; Kaufman, 2008). When PFCC is accomplished, care is planned, delivered, and evaluated in partnership between the health care provider, patient, and family. The four main core concepts in the framework by IPFCC are 1. *Dignity and Respect,* which highlights the importance for the professional team to respect and listen to the patient and family desires and respect their values and cultural background. 2. *Information Sharing* refers to the collaboration in information sharing between the patient, family, and professionals. The importance of continuous, honest, and accurate information is emphasized to be able to involve patients and families in decision-making. 3. *Participation* and *4. Collaboration,* where participation refers to the professionals' capacity to encourage and support the patient and family to participate in decisions as well as in care based on their ability and desires. From a wider perspective, collaboration includes the alliance between patients, families, professional healthcare teams, and healthcare leaders e.g., policy and program development, research activities, and delivery of care. When collaboration between the patient, family, and professional team is on equal terms in the core concepts of the framework, the *partnership* is achieved (IPFCC, 2017).

As the perspective in this thesis was parents to children cared for at a PICU, the framework of PFCC was most in alignment. Children in Paper I-IV were predominantly very young (0=6 years old) and, in addition, acutely ill. They were often sedated and thereby needed their family to form a partnership with the HCPs. In Table 4 the different concepts of FCC, PCC, PFCC and CCC are summarized.

Table 4. Overview of the four concepts Family-Centered Care, Person-Centered care, Patient- and Family-Centered Care and Child-Centered Care.

Family-Centered Care[1]	**Person-Centered Care**[2]	**Patient- and Family-Centered Care**[3]	**Child-Centered Care**[4]
The family and the child are in focus.	The person is in focus	The person and the family are in focus	The child is in focus
A Partnership between the family and the HCPs	A partnership between the person and the HCPs	A partnership between the person, the family, and the HCPs	A partnership with the child and the HCPs, the family is seen as an important part of the child's life.
The family is active in care and care planning and in decision making. They share responsibility with HCPs	The person is active in care planning and decision making	The person and the family are active in care planning and decision making. They share responsibility with HCPs	The care and decision making is based on the perspective of the child. The child is supported by adults (e.g. the family)

[1] K. Hutchfield, 1999; Mikkelsen & Frederiksen, 2011; Shelton, 1994; Shields et al., 2006

[2] Edberg, 2021; Ekman, 2014; McCance et al., 2009; McCormack, 2003

[3] IPFCC, 2017)

[4] Coyne et al., 2016; Ford et al., 2018; Franck & Callery, 2004.

Rationale

Parents of children cared for at a PICU are in a vulnerable situation. They must deal with many different stressors that can affect their well-being both during the child's hospitalization and in a longer-term perspective. In earlier research, care based on an FCC approach has revealed a positive effect on parents´ as well as the child's well-being.

To the best of my knowledge, there is a lack of research from a Swedish pediatric intensive care context focusing on parents' experiences and satisfaction with care from an FCC perspective. As the care is organized in different ways in different countries, it is important to increase knowledge from a Swedish perspective as it can increase the conditions for possible future interventions to be sustainable.

To be able to develop interventions aiming to assist parents, and thereby the family as a whole when a child is cared for at a PICU it is important to gain a deeper understanding of parents' experiences and which variables that influence their satisfaction with care. These research questions will be focused on in this thesis.

The results may provide an understanding that can form the basis for further development of person- and family-centered care within a high-technological context such as pediatric intensive care.

Aim

The overall aim of this thesis was to investigate parents' experiences and satisfaction with family-centered care when their child was cared for at a pediatric intensive care unit.

The thesis is based on four individual papers, each with its specific aim:

I. To describe parents' experiences and the effect on the family two years after their child was admitted to a PICU.

II. To translate Empathic-30 and conduct an initial psychometric evaluation of the Swedish version in a pediatric intensive care context.

III. To describe parents' views of family-centered care in a pediatric intensive care unit.

IV. To explore parental satisfaction with pediatric intensive care.

Material and methods

Design

This thesis involves both qualitative (Papers I and III) and quantitative (Papers II and IV) study designs. A qualitative design with an inductive approach was applied in Paper I. In Paper III a qualitative design with a deductive and inductive approach was used. Paper II had a psychometric design while Paper IV had a comparative cross-sectional design. Qualitative and quantitative methods can complement each other and give a deeper understanding of the phenomenon being investigated. An overview of the sample, data collection and analysis are presented in Table 5.

Table 5. Sample, data collection and analysis in Papers I-IV

Paper	Sample	Data collection	Analysis
I	Parents to children being cared for at a PICU (n=10)	Individual semi-structured interviews	Inductive content analysis
II	Parents to children being cared for at a PICU (n=97)	The questionnaire Empathic-30	Translation procedure Psychometric evaluation Descriptive statistics
III	Parents to children being cared for at a PICU (n=70)	Spontaneous responses to open questions in the questionnaire Empathic-30	Deductive and inductive thematic analysis
IV	Parents to children being cared for at a PICU (n=97)	The questionnaire Emphatic-30	Descriptive statistics Analytical statistics

The context of the studies

The studies were carried out at two out of four PICUs in Sweden. The two PICUs cared for children aged 0 (full-term) to 18 years. Each unit cares for approximately 400 children per year (Svenska Intensivvårdsregistret SIR, 2023). The children admitted to the units are primarily from their catchment area, but could also be from other parts of Sweden, or from abroad. The units have both single and multi-bedrooms. They usually have unlimited presence for parents, siblings and next of kin. However, during the COVID-19 pandemic, when part of the data collection took place, only one visitor at a time was allowed.

The units provide accommodation options for parents and siblings at a Ronald McDonald House. Parents are usually not attending the daily rounds but are informed afterward by the physician. In the intensive care room, there is no space for the parents to have a bed next to their child, but there is an option for an armchair. The parents are invited to participate in the child´s daily care. They may also be present in resuscitation situations.

Sample

Paper I

Paper I includes a total of 10 parents, whose children were admitted to one of the PICUs from November 2012 to December 2013. The inclusion criteria were that the child should have been admitted to the PICU for a minimum of one week. Additionally, the parents had to be fluent in speaking and understanding Swedish. Parents of children who had passed away following discharge were excluded from the study due to ethical reasons.

Out of the 10 interviewed parents, eight parents were parental couples and two represented different families. The children in the study were between the ages of 0 and 5 years. All the children had a congenital heart defect (CHD). The LOS varied, ranging from seven days to 18 days with a median of 10 days. Demographic data for the parents were not collected.

Paper II-IV

The sample in Papers II and IV was collected through the questionnaire Empathic-30 (Latour et al., 2013). A total of 234 questionnaires were distributed to parents at two PICUs in Sweden, between February 2018 and September 2020. Parents of children under the age of 18, who had been cared for in one of the two PICUs for a minimum of 48 hours and were proficient in the Swedish language, were invited to participate. Parents whose child passed away during their stay at the PICU were excluded from the study due to ethical reasons. A total of 100 questionnaires out of 234 (42.7%) were returned. Three questionnaires were excluded due to not meeting the inclusion criteria (n=2) or being returned blank (n=1) which meant that the final sample was 97 questionnaires. Parents' and children's characteristics are presented in Table 6 and Table 7. The most common origin among the parents was Swedish, 88%, European origin represented 10% and 2% had non-European origin.

Table 6. Parents' characteristics n=97 (Paper II and IV)

Parents (n=97)	**Mother n=50 (52%)**	**Father n=47 (48%)**
Age years		
Mean (SD)	37 (6)	38 (8)
Min-max	23-52	25-61
Education *, (n, %)		
Elementary school	3 (6)	2 (4)
Upper secondary school	14 (29)	18 (39)
University	31 63)	25 (55)
Other Education	1 (2)	1 (2)

*Internal missing mother n=1; father n=1

Table 7. Children's characteristics n=55 (Paper II and IV)

Length of stay, days	
Mean	11.9
Median	7
Man-max	2-84
Children, n=55 (n, %)	
Prior experience of PICU care	12 (22)
Planned admission	23 (42)
Treated on ventilator	53 (96)
Siblings in the family	41 (75)
Children's Age	
Range	3 days – 15 years
Mean (SD)	2.4 years (4.2 years)
Median	78 days
Admission cause (n, %)	
Heart diseases	34 (62)
Lung diseases	2 (3.5
Sepsis	1 (2)
Infection	6 (11)
Tumor diseases	2 (3.5
Undetermined	10 (18)

In Paper III the sample consists of the parents' spontaneous responses to the five open-ended questions of the Swedish version of the questionnaire Empathic-30 (Appendix 1). In total 70 (72%) of the final included 97 parents were included. Due to no answers or brief answers to the open questions such as e.g. "good" 27 questionnaires were excluded. The participants were parents (mothers n=40; fathers n=30) of 47 hospitalized children aged 0 to 15 years. The parents were mainly Swedish by origin, n=63 (90%) or European n=6 (9%), and two parents (3%) had a non-European origin. Of the children, 43 (91%) were between 0-6 years, and the remaining proportion were between the age of 7-18 years. Characteristics of the parents and children in Paper III are presented in Table 8.

Table 8. Parents' and children's characteristics (Paper III)

Parents, n=70	
Age years (mean, range)	37 (23-55)
Education, n=68 (n, %)	
Primary school	2 (3)
High School	23 (34)
University/Collage	41 (59)
Other education	2 (3)
Childs' (n=47) LOS days (n, %)	
2	7 (10)
3-7	32 (46)
8-10	5 (7)
>10	26 (37)
Children in mechanical ventilation	44 (93)

Data collection

Individual interviews (Paper I)

In Paper I qualitative individual semi-structured interviews were conducted with parents 2 to 2.5 years after their child was discharged from the PICU. A contact nurse verbally informed the parents in connection with a follow-up visit at the PICU and asked if they wanted to participate in the study. The interested parents were first contacted by phone or email by the author of this thesis. The parents who agreed to be interviewed were sent written information about the study including a form for written consent and a prepaid return envelope. The place and time for the interviews were decided in agreement with the parents. Written consent was obtained from the parents prior to the interviews.

In total 12 interviews were conducted, two pilot interviews and 10 interviews that were included in the analysis. The two pilot interviews were conducted (by telephone) prior to the 10 included interviews following the semi-structured interview guide (Appendix 2). The pilot interviews were not included in the final sample as the inclusion criteria were not met (LOS was not fulfilled). The purpose of the pilot interviews was to ensure whether the interview guide responded to the purpose of the study. Subsequently, minor changes were made to the interview guide**.**

Follow-up questions and questions for clarification were posed during the interviews when necessary. Of the 10 included interviews the author of this thesis conducted and transcribed nine of them. One interview was conducted and transcribed by the co-author of Paper I. Of the 10 interviewed parents eight chose to be interviewed by telephone and two chose to be interviewed in their own homes.

Questionnaire (Paper II-IV)

In Papers II-IV data collection took place from February 2018 to September 2020. The data were collected using the Empathic-30 questionnaire (Appendix 1). Parents were invited to participate in connection with their child's discharge from the PICU. The study was explained to the parents verbally by a member of the healthcare team, either a nurse or an assistant nurse, at the time of the child's discharge from the PICU. Both parents were given the opportunity to participate, and if any of them agreed, they were provided one envelope each. The envelope contained a questionnaire, written information about the study, a consent form, and a prepaid return envelope. The parents could also return the completed questionnaire in an assigned box at the PICU. Parents who had not been approached in connection with their child's discharge were sent an invitation letter by the unit's secretary to their home address, along with all the necessary materials mentioned above. The invitation letter replaced the verbal information that was otherwise given at the PICU.

Instrument

Empathic-30

The Empathic-30 questionnaire was originally developed in the Netherlands by Latour et al. (2013), it is self-administered and grounded in the principles of family-centered care. The original Dutch version had acceptable psychometric properties, Cronbach's alpha for total scale 0.93, and for the domains 0.73 to 0.81. The questionnaire aims to measure parental satisfaction with family-centered pediatric intensive care. Consequently, it enables the evaluation of the overall quality of care provided, while also identifying specific areas of family-centered care that require to be improved (Latour et al., 2013). The questionnaire has been translated into various languages, e.g. English (Gill et al., 2017), German (Girch et al., 2022), Brazilian Portuguese (Lessa et al., 2021) and Spanish (Pilar Orive et al., 2018) among others and is used worldwide. However, no Swedish version was available.

Empathic-30 contains five domains; *information* (five items), *care and cure* (eight items), *organization* (five items), *parental participation* (six items) and *professional attitudes* (six items) (Latour et al., 2013).

Participants provided their answers using a 6-graded Likert scale, which ranges from one (indicating "strongly disagree") to six (indicating "strongly agree"). If the parents had no opinion or experience of the item described, they were able to choose "not applicable" (NA). A response of a value of three is interpreted as "neutral". The scores are presented with mean values both for single items and domains. Besides the 30 items included in Empathic-30, there is one question focusing if the parents would recommend the unit to others and one question asking them - if they find themselves in the same situation again - would they want to return to the same PICU? Furthermore, there are two questions regarding the experience of the nurses/assistant nurses and the physicians, those two questions are answered on a ten-graded Likert scale ranging from one “very poor” to 10 “excellent”. At the end of the questionnaire, there are five open-ended questions (five in the Swedish version and four in the original version) that parents can answer in free text about their experiences (Appendix 1).

Translation procedure

Before translating the questionnaire, consent was obtained from the original author. In the first step, the questionnaire was translated from Dutch to Swedish by an authorized translator, resulting in two versions; one certified translation and one adapted to Swedish culture. The translation was reviewed by three of the authors (Paper III) and minor adjustments were made to align with the concepts of family-centered care. The original author was consulted to clarify questions related to the translation. Thereafter feedback was obtained from 12 clinically active HCPs at a PICU on two different occasions (in total n=24). They were asked to review the questionnaire based on the Swedish PICU context. This led to adaptations such as also including assistant nurses in the questionnaire in accordance with Swedish staffing at a PICU. In the next step an expert group of nurses (n=4), with pediatric intensive care experiences, one with a PhD in nursing reviewed the questionnaire and made suggestions for cultural and contextual adaptations. The questionnaire was adjusted based on their feedback. Thereafter eight parents with PICU experience gave feedback on the questionnaire, they were asked to, in particular, review word choice in some questions such as e.g. treatment or intervention and efficiency effect. They could also give comments in free text about the items comprehensively. For translation process see Figure 1.

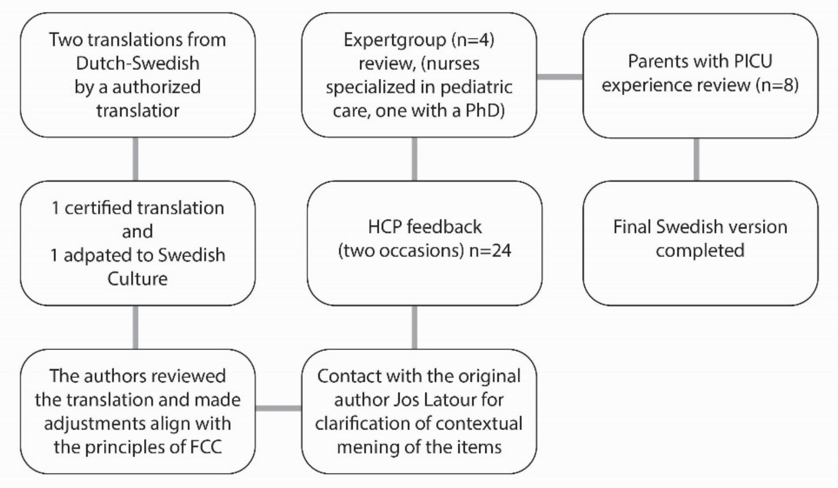

Figure 1. Translation process of Empathic-30

Data analysis

Qualitative content analysis (Paper I)

Qualitative content analysis is a method used frequently as it is suitable for various disciplines, including healthcare research. Content analysis can be conducted on a manifest and/or latent level (Krippendorff, 2004). Both manifest and latent analysis are somewhat interpretable, the difference is the depth of interpretation (Graneheim & Lundman, 2004). The manifest analysis focuses on the obvious in the data while the latent is more complex in both coding and interpretation of the meaning of the data (Hsieh & Shannon, 2005; Kondracki et al., 2002). The latent analysis can also include interpretation of the participant's body language, the silence, the laughter etc. (Elo & Kyngas, 2008). Content analysis can have an inductive and/or deductive approach. The inductive approach has no predefined themes, categories, or guides while the deductive method starts with a predefined theory, model, theme or category (Krippendorff, 2004).

The interviews in Paper I were analyzed using qualitative inductive content analysis according to Graneheim and Lundman (2004) to get a deeper understanding of the parents' experiences, and the effects on the family two years after their child was hospitalized at the PICU. Prior to the analysis, all interviews were transcribed verbatim. Initially, the transcriptions were read several times and discussed by the two authors to obtain an overall meaning of the content. Based on the aim meaning units were identified. The meaning units were then condensed and thereafter coded. Codes with similar content were then merged into subcategories and categories (Graneheim & Lundman, 2004). Finally, an overall latent theme covering the overall experiences was formed. The authors had an ongoing discussion during the whole analysis process until a consensus was reached. Quotes from the interviews were used to illuminate the findings.

Thematic analysis (Paper III)

Thematic analysis (TA) is a widely used flexible and analytic method (Braun & Clarke, 2012). TA has been a common methodology in the social sciences for years (Roulston, 2001). It is commonly applied as an analytic method within a qualitative approach (Boyatzis, 1998). Qualitative analysis is complex to carry out, however, TA is a method that is distinct and easy to follow (Holloway & Todres, 2003). The TA can be utilized both inductive and deductive or as a combination of both (Ayre & McCaffery, 2022; Castleberry & Nolen, 2018). An inductive method for coding and analyzing data is characterized by that the codes and themes emerge progressively from the data's content itself. Consequently, the researcher's mapping during analysis closely aligns with the actual content of the data. On the opposite, the deductive approach to data coding and analysis, in which the researcher employs a predetermined concept, ideas, or theories which the data is coded and interpret from. Consequently, the codes and themes primarily arise from the concepts and ideas that the researcher incorporates into the analysis of the data (Braun & Clarke, 2012).

In Paper III the data were analyzed both deductively and inductively according to TA, (Braun & Clarke, 2006) guided by the core concepts of the model PFCC (IPFCC, 2017). To gain familiarity with the data, the author read and reread the text several times. In the next step all data were compiled into one document and a comprehensive review was carried out, resulting in a separate document that provided an overview of the entire dataset. Thereafter, the author of this thesis conducted deductive sorting and coding whereas the core concepts of the PFCC model constituted the themes: Dignity and respect, Information sharing, Participation, and Collaboration (IPFCC, 2017). Thereafter, an inductive analysis of the text in each theme took place. Codes with similar content were grouped into subthemes. During the analysis, nothing emerged except the deductive categories according to PFCC. All authors were engaged in discussions toward achieving consensus (Braun & Clarke, 2006).

Statistics (Paper II and IV)

In Paper II demographic data were displayed as percentages (%), mean, SD and range. The Empathic-30 results were reported for both total scale and domains. Furthermore, an acceptable value below 15% was calculated for floor and ceiling effect (Streiner et al., 2014). To analyze the internal consistency of the Empathic-30 instrument, Cronbach's alpha coefficient was applied with an acceptable value ≥ 0.70 for reliability. Additionally, corrected item-total between items and total scale were examined. Construct validity, specifically convergent and discriminant validity of the Empathic-30 instrument, was assessed using Spearman's rank-order correlation. This assessment involved the analysis of inter-correlations between the sub-scales and the correlation between the sub-scales and the total score.

In Paper IV demographic information was presented as frequencies (n), percentages (%), mean value with standard deviation (SD), median, and minimum-maximum values. Group comparisons were conducted with the Mann-Whitney U-test due to the non-normal distribution of the data. The statistical significance was set to $p<0.05$.

All data in both Papers II and IV were analyzed using IBM SPSS Statistics Version 27 (IBM Corp, 2017).

Ethical considerations

Before an application for ethical approval took place there were ethical considerations that needed to be discussed. Ethical considerations that were raised from the parent's vulnerable situation of having a child in need of intensive care. A situation that probably is life-changing as the child is part of a family composition that is affected in its entirety by the child's illness (Golics et al., 2013; Yagiela & Hartman, 2021). The experiences the parents bring with them after such an life-changing event might bring new values in life (Abela et al., 2020). The studies were approved by the Ethics Committee at Lund University (Paper I, DNR.2013/739, Paper II-IV, DNR.2018/547, DNR. 2019-04602) and conducted in accordance with the Declaration of Helsinki ("World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects," 2014), and regarding to the principles of autonomy, beneficence, non-maleficence and justice (Beauchamp & Childress, 2009).

According to the principle of autonomy, the participants' (Paper I-IV) received both oral and written information about the studies, that their participation was voluntary and their right to withdraw their consent without giving any reason. Furthermore, all data were handled confidentially, no personal characteristics would be presented, and the results would be presented at a group level (Beauchamp & Childress, 2009). Informed consent was obtained from all participants (Paper I-IV) before their participation. In Paper I dates and places for the interviews were planned in accordance with the parents´ wishes, which correspond to the principle of autonomy (Beauchamp & Childress, 2009).

According to the principle of beneficence and non-maleficence, the benefits from the research should outweigh any risk of harm (Beauchamp & Childress, 2009). The authors in Paper I were aware that the parents could react with discomfort as the interview could bring stressful memories to life. However, there is no other way to gain knowledge about a specific phenomenon than to ask those who have experienced it, i.e. parents. The results could benefit future parents in the same situation and therefore the benefits were judged to outweigh the risk of harm. If a parent seemed to be affected negatively by the interview there was a plan for offering support through a counsellor or psychologist.

The principle of justice refers, according to Beauchamp and Childress (2009), to that participants should be invited to participate in a non-discriminatory way. In Paper I, the parents had to speak and understand Swedish and in Papers II-IV only parents fluent in Swedish were included as the questionnaire used was tested for a Swedish context. Those parents who lacked proficiency in Swedish were therefore excluded from participation. Those parents might have other experiences that could affect their satisfaction with care.

In Papers II-IV, the parents were asked to participate in connection with their child's discharge from the PICU. This may have been experienced as stressful for the parents. It is to be noted that about 70% of those who participated also wrote statements in free text, with detailed comments, which may indicate that they believed that their answers were important.

Results

The results from Papers I, III and IV are interpreted, integrated, and presented in two sections *Parents' Experiences of care* and *Parents´ Satisfaction with care*.

The section *"Parents' experiences of care"* consists of qualitative data presented in three headings, *"Handling the child's illness"*, "*The unfamiliar PICU environment"* and "*The impact on the parents and the family*".

The section "*Parents Satisfaction with care"* is merged out of Papers I, III and IV, and both qualitative and quantitative data are presented according to the core concepts of PFCC, with the headings, *Dignity and Respect, Information Sharing*, *Participation* and *Collaboration*. In addition, the "*Validation of the Swedish instrument Empathic -30"* (Paper II) measuring parents' satisfaction when the child is cared for in PICU, is also presented in this section, see Figure 2.

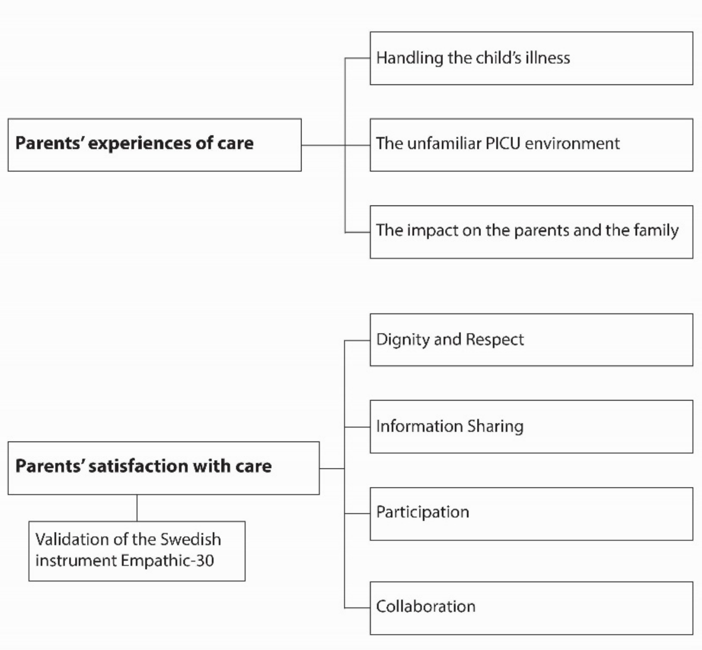

Figure 2. The results of Papers I-IV are presented under two sections with selected headings.

Parents' experiences of the care

To gain a deeper understanding of the parents' experiences when their child had been cared for in a PICU, two qualitative studies were performed (Papers I and III). Interpreted and integrated findings from the studies are presented in the following section.

Handling the child's illness

The parents described they were in shock when their child was hospitalized in the PICU. They felt worried and carried a constant fear within them that the child would not survive (Paper I). Seeing their child attached to medical equipment was terrifying (Papers I and III) as were the times they could not recognize their child because of e.g. edema swelling. The parents were afraid to touch, and handle their child, because of the risk of accidentally disconnecting important equipment. They needed guidance and help from the HCPs to care for their child and be able to be close to their child (Paper I). However, they were not always invited to participate by the HCPs, sometimes the HCPs forgot to invite them and sometimes they seemed to be too stressed to invite them. This created a feeling of being left out (Paper III). The parents interpreted it as the care procedure was carried out faster if the HCPs managed it themselves because their participation required guidance that the parents interpreted the HCPs did not have time to do (Papers I and III).

It was difficult for the parents to see their child in such a vulnerable situation and in a serious condition and not be able to help them. There were times when they felt they just had to wait and see how the child's situation developed. They described themselves as being in a bubble or being outside reality. Some parents did not have the strength to stay with the child for a longer period, as they could not bear to see their child suffer. The parents who felt that they were supported and respected by the HCPs for their choice of not staying at the PICU for longer periods of time could accept their choice afterward. While those who felt that they did not receive support in their choice struggled afterward with a feeling of not being enough supportive of their child (Paper I).

Two years after the child's hospitalization at the PICU, the parents had vivid memories of the trauma. Some parents were treated for post-traumatic stress, and others received psychiatric help, either during their child's hospitalization or directly afterward. Parents described feeling palpitations, nausea, dizziness, and anxiety both when they later visited the hospital or when they thought about the time when the child was admitted to the PICU (Paper I).

The unfamiliar PICU environment

Most parents could only relate to the environment at the PICU from movies or television (Paper I) as they had no prior experience with pediatric intensive care (Papers I and III). They found different ways to deal with the environment, e.g. when the alarms from technical equipment sounded, they dealt with it by being sensitive to HCPs' behavior and body language and interpreting if their behavior seemed to depict uncertainty or not. Their anxiety could re-appear when two years later they looked at pictures from their time in the PICU (Paper I).

Conversely, although parents described the environment in the PICU as frightening, they felt that the PICU was the safest place for their child due to their child's need for advanced care. The parents considered that the highly specialized care their child obtained in the PICU could not be received elsewhere. This made the parents feel safe to let the HCPs take care of their child (Paper I and III). They also became familiar with the environment as time passed by and could at times see past all the equipment and fear, as it was not possible to stay in a mood of fear all the time (Paper I).

The impact on the parents and the family

During the child´s admission, the family members were separated which caused distress. Parents felt it was hard for them to hold their family together. This was particularly evident when there were siblings in the family. The parent who was together with the child at the PICU expressed a feeling of being abandoned by their partner, especially if the condition of the hospitalized child deteriorated. Conversely, the parent, who was at home taking care of siblings or had to go to work, felt anxious and guilty for not being present with their child and partner at the hospital. In addition, there was also a financial impact, especially in relation to longer admissions. Altogether, this was distressing for the parents. Despite the strain, parents experienced during their child´s PICU admission they found their relationship to be strengthened. They felt that their partner was the only one who could understand what they were going through and with whom they could talk openly about the situation (Paper I).

During the child's hospitalization, everything else in life was put on hold, such as friends and acquaintances. The parents also felt that everyone else had trivial problems compared to themselves, which resulted in not having the energy to meet acquaintances (Paper I).

Another source of distress for parents was when it was time to transfer to another unit. They did not feel prepared and did not always agree with the HCPs that their child was stable enough to be discharged from the PICU. They did not feel safe handing over the care of their child to someone else than the HCPs at the PICU (Papers I and III).

The child's care period at the PICU could sometimes also affect siblings. Parents reported that siblings could respond by becoming overprotective of the brother/sister who had been hospitalized. Even the child who had been hospitalized showed anxiety when revisiting the hospital. Some children had night terrors and bedwetting in connection with discharge (Paper I).

Parents' satisfaction with care

In this section, the findings will be presented according to the four core concepts of PFCC, *dignity and respect, information sharing, participation,* and *collaboration*. Both qualitative and quantitative data are presented in this section (Papers I, III and IV). The parents showed an overall high level of satisfaction with care (total scale 5.53, domains 5.42-5.77 and for items 4.44-5.99) (Paper IV). However, despite this, a variation in the level of satisfaction emerged in the qualitative data in Papers I and III.

Dignity and Respect

The concepts of *dignity and respect* embrace meeting the person and his/her family with dignity and respect, plan and give care in partnership based on the person/family's values, and requirements. Partnership develops through a relationship out of mutual respect between HCPs and the family. In addition, the culture of the person and the family must be considered.

During their child´s PICU admission, parents felt that they were treated with dignity and respect. The domain *professional attitude* measured by Empathic-30 had a high satisfaction score with a mean of 5.77 (Paper IV). The parents felt that the HCPs did their utmost for the child and the family, by showing understanding and empathy for both the child and themselves (Paper III). Parents also felt satisfied by being shown compassion by the HCPs (Paper I). They also respected the HCP's expertise (Papers I and III). Although the parents could see that the HCPs had a heavy workload, they felt that they set aside time for them and their child (Paper III). The HCPs were empathetic, and the parents felt they were sensitive to their need to rest.

The parents were highly satisfied with both empathy and respect shown to them by the HCPs. The items, "*The health care team showed us and our child respect*" and the "*… child's well-being was always taken into consideration*" demonstrated high satisfaction among parents with scores ≥5.90. Although empathy and respect were shown toward parents (Papers I, III and IV), they did not consider that they regularly were asked about their feelings. The item "*staff regularly asked us how we felt*" had a lower satisfaction rate (5.00) in comparison with other items in the questionnaire (Paper IV).

Parents expressed a need for support and comprehension from HCPs. When the parents felt that the HCPs could fulfill their needs, their satisfaction increased, and the relationship was strengthened between parents and HCPs (Paper III). The parents who had received support from the HCPs during the admission could process their child's illness and hospitalization more easily (Paper I). Partnership was built through reliable relationships between families and HCPs, however, to be able to establish a relationship parents needed continuity of HCPs caring for their child. When frequent staff changes were made, parents found it difficult, they felt they had to start over and build a new relationship (Paper III). This also appeared in the item *"We knew every day who was responsible for our child by physicians*". This item had the lowest satisfaction value of all items with a score of 4.44 (Paper IV). The parents experienced the relationship as important so that the HCPs would get to know them and their child and thereby gain knowledge about the child's needs. Especially if the child had special needs e.g. a disability.

Information Sharing

According to the concept of "*information sharing*" information shall take place in dialogues between HCPs, the person and the family, so they actively can participate in decisions concerning care and treatment.

The parents considered that they received information continuously about the child's care and treatment. Likewise, they felt that the information they received was given clearly and was adapted to their level of knowledge. Furthermore, the parents expressed that they were comfortable asking questions (Papers I and III). When critical situations occurred, the parents described that the HCPs tried to give ongoing information. If it was not possible, they gave the information afterward. Likewise, the parents received information about situations in which they could not participate (Paper III). Although the parents sometimes were afraid to be informed about the child's prognosis, they wanted to know the truth about their child's condition. In some cases, parents experienced that HCPs withheld information as they believed that the parents could not handle the truth (Paper I).

When parents evaluated their satisfaction with information in the Empathic-30 the item *"We had daily conversations about our child's care and treatment with the physician"* revealed a satisfaction level of 5.09, which is a high satisfaction level but slightly lower compared to other items in general. On the other hand, parents felt more satisfied regarding information from nurses and assistant nurses (5.86) and about examinations and treatments (5.75). In comparison with other items in the domain *information*, parents considered that they received less information about the effects of the medicines (5.25) (Paper IV). Occasionally parents got contradictory treatment strategies around their child's illness which confused them and made them unsure (Paper III).

When it was time for the child's discharge from the PICU the parents did not feel well informed about the transition, in some cases, they did not believe that their child was well enough to be transferred to another unit (Paper I and III). This was also demonstrated in two items that had a lower satisfaction value "*We were prepared in good time before our child's transfer/discharge by …*" physicians (4.93) and nurse/assistant nurse (5.19) (Paper IV). Parents who were informed in advance of the child's transition, more often accepted it, and understood that it was the right time for their child to be discharged from the PICU (Paper III).

Participation

The concept of *participation* addresses that HCPs actively promote and assist the involvement of the individuals and the families partaking in care and the decision-making process. This is based on their own choice and ability to participate.

The second lowest mean value of satisfaction among parents in the Empathic-30 questionnaire was found in the domain of *parental participation* 5.44 (Paper IV). Parents described that they were invited to participate. However, when a child had a disability and needed to be approached differently, the HCPs sometimes forgot to use parents' knowledge, which made the parents feel that the HCPs had difficulty responding to the child's needs. Parents expressed a wish to plan the child's care together with the HCPs in those situations (Paper III).

Parents were afraid of accidentally disconnecting mechanical equipment and thereby worsening the child's condition, which made them afraid to participate in their child's care. This created a feeling of being physically separated from the child, which disrupted the attachment between the child and the parents (Paper I). There were occasions when the HCPs failed to invite them to participate in the child's care, most often this happened when the HCPs were stressed and worked based on routines (Paper III). On the other hand, the parents felt that the HCPs invited them and supported them so that they could participate in the child's care and stay close to their child. They were also encouraged to stay with their child, even during emergencies (Paper IV).

Sometimes the parents felt they did not want to participate because they were too tired. On those occasions, they felt safe handing over the care of their child to the HCPs, as the parents recognized them as highly skilled. Some parents felt that it was the only time they could feel completely relaxed when someone other than themselves was taking care of their child (Papers I and III). This was also found in the items of feeling trust for HCPs (nurses, assistant nurses, and physicians) which scored high (5.78 and 5.86) (Paper IV). The HCPs were described as calm and organized even in situations of emergencies and acted professionally (Paper I and III).

In terms of decision-making regarding the child's care, opposing opinions were demonstrated among the parents. Some parents felt excluded in decision-making regarding the child's care (Papers I and III). Other parents even experienced it as self-evident not to participate in decisions as they considered that the care the child received was so advanced that they could not contribute at all (Paper III). Conversely, parents felt that in some cases the HCPs made decisions against their will, which had happened in connection with the child’s discharge from the PICU (Paper I). Those situations created a feeling in the parents not being a part of decision-making in their child’s care (Papers III and IV). Also, the result from the Emphatic-30 demonstrated a lower satisfaction value (5.06) for the item *“We were involved in the decision-making process of our child's care and treatment”* (Paper IV).

Collaboration

The concept of collaboration includes an active collaboration between the person and family, along with HCPs and leaders beyond the child’s actual hospital admission. The cooperation can, among other things, include the development of documents, facilities, education, and care.

Parents presented suggestions that could be incorporated into practice. They stated a need for private space, which was mainly evident when their child shared a room with another child, but also on occasions when their child needed to always have an HCP present in the room (Paper I). The parents requested e.g. a guided tour of the unit to be informed that there was access to coffee-making facilities, as they found out that several days after the child’s admission. Parents indicated that they spent many hours at the unit and that an ergonomic armchair, duvet and pillow would have eased their situation (Paper III). They also found the space around the bed less satisfactory with a mean value of 5.19 (Paper IV). Based on the aspect of developing and improving both the facility and the working method in collaboration, the parents considered that the HCPs had satisfactory collaboration (5.75) and worked hygienically (5.90) and efficiently (5.87). They also felt that the department was easy to reach by phone. The parents considered the noise level on the unit *"as reduced as possible"* (Paper IV). Nevertheless, parents had written in their statements that the disturbances during the night, by the tasks that took place at nighttime gave the child disturbed sleep (Paper III).

Validation of the Swedish instrument Empathic-30 (Paper II)

The Swedish version of Empathic-30 is a valid and reliable instrument. The result revealed a Cronbach's alpha of 0.925 for total scale and varied for the domains between 0.548 to 0.792 (Table 9). The results are based on 97 questionnaires answered by parents of 55 children with an even distribution between mothers (n=50) and fathers (n=47). Parents' and children's characteristics are presented in Table 6 and 7.

Item characteristics

The internal missing was low, two out of the 97 questionnaires were returned with missing values. Not applicable (NA) is an option in the questionnaire the two items with the most frequency of NA were the items "*We were actively involved in decision-making in the child's care*" and " *The unit was easy to reach the by telephone* ". The results showed a ceiling effect in all five domains. The ceiling effect ranged from 27.6% (domain *care and cure*) to 63.5% (domain *professional attitudes*). Mean values for the domains were high 5.42 to 5.77 as well as for total score 5.53 (Table 9).

Internal consistency

The internal consistency of the Swedish version of Empathic-30 was acceptable with a Cronbach's alpha coefficient of 0.925 for the total scale, see Table 9. One question *"The unit was easy to reach the by telephone"* increased Cronbach's alpha coefficient (0.928) when conducting Cronbach's alpha if the item was deleted.

Table 9. Domain statistics and internal consistency (n=97)

Domains	**Mean (SD)**	**Cronbach's alpha**	**Cronbach's alpha if the item deleted**	**Corrected item-total correlation**
Information	5.56 (0.67)	0.774	0.693 - 0.772	0.449 - 0.69
Care and cure	5.42 (0.65)	0.792	0.731 - 0.796	0.331 - 0.705
Organization	5.66 (0.46)	0.548	0.344 - 0.628	–0.028 - 0.509
Parental participation	5.44 (0.64)	0.719	0.669 - 0.704	0.468 - 0.633
Professional attitude	5.77 (0.42)	0.763	0.648 - 0.799	0.350 - 0.784
Total Scale	5.53 (0.51)	0.925	0.920 - 0.928	–0.350 - 0.765

Construct validity

The five domains showed a satisfactory correlation to the total scale (0.623-0.805). The inter-scale correlation between the domains varied from 0.440 to 0.743. The domain *organization* had a lower correlation to two domains, *information* and *care and cure,* but an acceptable correlation to the total scale. The domain *organization* had a negative value in the corrected item-total correlation -0.28, this value was correlated to the item *"The unit was easy to reach the by telephone"* (Table 9).

Discussion

Methodological considerations

In this thesis, both qualitative and quantitative methods were used. The qualitative methods (Papers I and III) will be discussed based on the concepts of trustworthiness, *credibility*, *dependability*, *confirmability* and *transferability* (Lincoln & Guba, 1985). The methods in Papers II and IV will be discussed according to validity and reliability (Polit & Beck, 2020).

Credibility refers to the believability of the findings. In order to achieve credibility accurate data must be used, and a relevant interpretation of the data be conducted (Lincoln & Guba, 1985). A threat to credibility in Paper I was that all interviewed parents were parents of children with CHD. This was a coincidence, but it might have affected the findings. Furthermore, in both Papers I and III, parents of children who passed away during the hospital stay or afterward were excluded due to ethical reasons. Parents of children with other diagnoses or whose child passed away during or after hospitalization might have other experiences than those presented in Papers I and III. However, several studies show that parents of children, cared for in a PICU, regardless of diagnosis, have similar experiences to those reported in Paper I (Balluffi et al., 2004; Dahav & Sjostrom-Strand, 2018; Debelić et al., 2022). Conversely, a strength of Paper I was that one of the authors had professional PICU experience and was familiar with the context which facilitates the interpretation of the data and thereby the credibility (Lincoln & Guba, 1985). On the other hand, the risk of pre-understanding (Polit & Beck, 2021) increases when the author is familiar with the context. This was counteracted by the other author who had no professional PICU experience. As for Paper III, none of the authors had professional PICU experience, but all authors had professional experience in working with acutely ill children in other contexts, e.g. neonatal intensive care, anesthesia, and pre-hospital care.

Another limitation of Paper I was that no demographic data were collected and thus the variation of the sample could not be presented. A heterogeneous sample supports the credibility (Graneheim & Lundman, 2004). However, this was an active choice in order not to reveal the confidentiality of the parents and children. The sample size was small and as all children had CHD it might have been a risk that the HCPs at the PICU could identify them through their demographic data.

A small sample size might be a threat to credibility though the variation of the sample might be limited (Polit & Beck, 2020). However, in terms of information power (Malteru, Siersma, Guassora) a smaller sample size might be acceptable as the parents were experts on the phenomenon that was being investigated. Further, the interviews were rich in content and responded to the research question, which increased the credibility (Lincoln & Guba, 1985). The larger sample size (n=70) in Paper III is a strength but as the data emanates from parents' written spontaneous statements there was no opportunity to ask probing questions for clarification, which might be seen as a limitation. On the other hand, there is a variation in the children's diagnoses, as well as planned and unplanned admissions, and LOS which ranged from 2-84 days. This increases the possibility of capturing a variety of experiences related to the care and thus also increases credibility (Lincoln & Guba, 1985).

Another limitation that shall be brought to light is that some of the parents were parenteral couples (Paper I-IV). When we made comparisons between mothers and fathers in Paper IV, there was no significant difference between them. This can raise thoughts about whether the parents influenced each other when answering the questions, however, we have no knowledge about this. On the other hand, Foldager Jeppesen et al. (2024) conducted a study in Swedish pediatric care about parents' satisfaction and demonstrated a significant difference between mothers' and fathers' satisfaction, indicating that they did not influence each other regarding their answers. Mothers were more satisfied than fathers in the study, both in terms of communication with HCPs and being included in the child's care (Foldager Jeppesen et al., 2024). However, all parents have their own experiences and perspectives, which is important to obtain regardless of whether it has been influenced by someone or not.

To increase credibility in Paper I an interview guide was constructed and two pilot interviews were conducted to ensure that the guide aligned with the aim of the study (Elo & Kyngas, 2008). A further limitation that should be addressed in Paper I is that the majority of the interviews were conducted via telephone. Irvine et al. (2013) argued that interviews not conducted face-to-face tend to be shorter and less extensive. This is not in line with the interview time in Paper I. The parents talked extensively and the interviews lasted between 55-105 minutes. However, there is a risk that a part of the communication is left out, as body language is not possible to observe. In addition, it can be difficult for the interviewer to interpret emotions expressed through body language (Smith, 2005). Conversely, there are also beneficial aspects of conducting the interviews via telephone. The person being interviewed can feel more anonymous, thereby it can be easier to talk more openly (Cachia & Millward, 2011). Trier-Bieniek (2012) stated that it is easier for a participant to leave an ongoing interview conducted via telephone than if it is face-to-face, which gives a feeling of greater control and freedom to the person who is being interviewed (Trier-Bieniek, 2012).

Dependability cannot be achieved without credibility. It refers to the ability to replicate findings. This can be done if there is a clear transparent described research process. Dependability also deals with consistency (Lincoln & Guba, 1985). According to Graneheim and Lundman (2004), authors should be aware of and discuss that longer periods of data collection may affect dependability. The time period for data collection in Paper III was carried out over a longer duration (32 months). This might have affected the outcome of experiences due to e.g. changing routines at the PICUs and/or internal education of staff. To our knowledge, this did not occur during the inclusion period.

Confirmability refers to transparency in the analysis and interpretation of data. An important aspect to ensure confirmability is that the interpretation of the data is objective and not based on the researcher's assumptions and imaginations, in other words, the researcher’s preunderstanding (Lincoln & Guba, 1985). According to Gadamer (2013), it is not possible for a researcher to avoid her/his pre-understanding completely, as pre-understanding is based on, among other things, earlier preferences and perspectives, as well as personal preferences of habits etc. (Gadamer, 2013). As preunderstanding cannot be ignored it is important to be aware of it in qualitative research (Aspers & Corte, 2019; Maxwell, 2012). With this knowledge in mind and an awareness during the interpretation of the material, pre-understanding has been taken into account both in Papers I and III. Furthermore, the findings have been discussed at research seminars where nurses with pediatric and intensive care confirmed the findings (Lincoln & Guba, 1985).

In Papers I and III the analysis process is described as clearly as possible and quotes from the interviews are presented to make the interpretation visible and confirm the findings (Graneheim & Lundman, 2004). As meaning units (Paper I) are an important part of the analysis procedure in content analysis, these were carefully processed and discussed between both authors to strengthen the confirmability. In Paper III both a deductive and inductive analysis was conducted and during the inductive analysis, an ongoing discussion among the authors took place until agreement was reached to ensure confirmability (Lincoln & Guba, 1985).

Transferability refers to the degree to which the findings can be generalized to other contexts (Lincoln & Guba, 1985). In order to enhance transferability, the context and the participants are described as clearly as possible in Papers I and III. Parents' experiences that appeared in Papers I and III may be comparable to parents in a similar situation with a child in need of high-technological care in another context. However, when discussing transferability, it must be taken into consideration that PICUs are organized differently and have different resources and policies for parental presence in different parts of the world as well as in Sweden. Other factors also play a role in how parents experience the PICU, such as the child's age, diagnosis, the parents' education level etc. (Debelić et al., 2022). This must be taken into consideration when discussing transferability.

Validity

Internal validity refers to the truth of the conclusions drawn in a study and whether the study examines what was intended to be examined and whether the observed changes or differences are not coincidences (Kazdin, 2010). Important points of view to address regarding threats of bias are selection, history, maturation and mortality (Polit & Beck, 2021). In this thesis, selection and history will be considered.

Selection bias implies if the included data are significant for the population (Kazdin, 2010; Polit & Beck, 2020). When the participants for Papers II and IV were selected, parents who had a child who passed away during admission were excluded. It is known that the outcome of the care has an impact on parents' satisfaction of care, thereby the results may have been affected by the exclusion (Abidova et al., 2020; Batbaatar et al., 2017). These parents were excluded due to ethical reasons. As parents according to Alcón Nájera and González-Gil (2023) are emotionally affected by the loss of their child. Another risk of selection bias in Papers II and IV was the exclusion of parents who did not understand and speak Swedish. Abuqamar et al. (2016) confirmed that persons who had communication difficulties were also less satisfied with the care, which means that the parents who were excluded in Papers III and IV might have other experiences regarding satisfaction. It is to be noted that these parents were excluded as one aim was to validate the translated Swedish version of Empathic-30. In future research, it is important to include these parents as their experiences may contribute to additional knowledge.

As for threats to history, it includes changes that may occur over time and can have an impact on the results (Polit & Beck, 2020, 2021). Data collection for Papers III and IV were conducted over a period of 32 months, from February 2018 to September 2020. The time period coincided with the COVID-19 pandemic. During seven months, (March to September) only one parent at a time was allowed to stay with the child at the PICU. This might have had an effect on the parents' satisfaction, and thereby also the results, nonetheless this has not been verified. One reason for the prolonged duration of data collection can be attributed to the relatively limited number of children meeting the inclusion criteria of a LOS of 48 hours or more.

External Validity is summarized by whether the results can be transferred to another population and context, this implies that results are generalizable and can be transferred outside the specific context of where the study was conducted (Kazdin, 2010). Participants were included out of predetermined inclusion criteria. A total of 234 questionnaires were handed out and 100 were returned (43%). An important aspect that must be taken into account for generalizability is nonresponse bias (Polit & Beck, 2020). We do not have any information concerning why 57% of the parents chose not to participate in the study. The parents were anonymous to us and therefore no reminders were sent ("World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects," 2013). Sandelin (2022) demonstrated that respondents are less likely to respond if the survey is to be answered by hand and then returned by regular mail versus if the survey is web-based. The Empathic-30 questionnaire was to be filled in by hand and returned by regular mail or in a box at the PICU in connection with the child's discharge. Those who did not fill in the questionnaire at the unit in connection with the discharge might have been less motivated to send it by regular mail, which is in alignment with other studies (Sandelin, 2022; Wu et al., 2022). In contrast, Ebert et al. (2018) showed in their study that those who received the web-based questionnaire had a lower response rate (36%) compared to those who received it in paper format (46%), which is in alignment with Manzo and Burke (2012). On the other hand, Badger and Werrett (2005) reported that a common response rate is about 40% and 25-30% is not unusual either, which is in alignment with the response rate in Paper II and IV.

In order to obtain external validity, it is important that internal validity is achieved, and that the population in the study is representative of the population outside the study (Polit & Beck, 2020). As for variation of the sample in Papers II and IV, a limitation that must be addressed is that most of the parents were Swedish (90%) with a higher education (60%). However, there was an even distribution between the sex of the parents, as well as an age variation, ranging from 23 to 61 years. The children had different diagnoses and varied in age between 3 days old and 15 years. They also varied in admission time ranging from two days to 84, which gives a satisfactory variety of the selected children and thereby is representative of the population of children treated in the PICUs in Sweden (Hannegård Hamrin & Eksborg, 2022; Kalzén et al., 2018; Svenska Intesivvårdsregistret, 2024) and thereby a strength for the external validity (Polit & Beck, 2020).

Methodological considerations of the questionnaire Empathic-30

Construct validity reflects upon the structure of the measure and the underlying phenomenon (Kazdin, 2010). The Empathic-30 (Paper II) was evaluated with convergent validity, which is a measurement of the correlation between related measures with similar constructs (Kazdin, 2010; Polit & Beck, 2021). The Swedish version of Empathic-30 was evaluated by interscale correlation for subscales and total scale with acceptable properties. Factor analysis was not carried out for the Swedish version as the number of respondents was too low (n=97). However, factor analysis was carried out for the original version (65-item) (Latour et al., 2011) but not for the shortened version (30-item) (Latour et al., 2013), as the same structure was used in both versions, which also applies to the Swedish version. Further, there was a ceiling effect in all five domains ranging from 27.6% to 63.5%. One reason for the ceiling or floor effect could be that the measurement is not sensitive due to e.g. a limitation of response options, or wrong wording in the items (Lincoln & Guba, 1985). During the translation process, both the expert and parental panels were satisfied with the wording of each item as well as the questionnaire in general. Furthermore, the results in Paper IV are confirmed by the findings in the qualitative Paper III, which indicates that the parents were satisfied with the care. External missing was 57% (Paper II - IV). The reason for external missing is unknown as no dropout analysis was performed. Participation in Papers II - IV was completely voluntary and in line with ethical guidelines ("World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects," 2014). Badger and Werrett (2005) stated that a response rate of 40% is common when using a self-reported questionnaire and according to that the external missing could be interpreted as acceptable. The internal missing was low, only two of the 100 returned questionnaires had missing values, which shows that the questionnaire was well-designed and easy for the respondents to answer (Lincoln & Guba, 1985).

Reliability in measuring instruments shows how reliable a test is, i.e. if the test would be repeated would similar results be obtained (Polit & Beck, 2021). A limitation that should be addressed is that test-retest was not performed for the Swedish version of Empathic-30. Parents of severely ill children were regarded as a vulnerable group and due to ethical reasons, a retest was not conducted. For the Swedish version of Empathic-30 internal consistency was performed using Cronbach's alpha. An instrument is homogeneous, in other words *internally consistent* when the items measure the same construct. An acceptable value of Cronbach's alpha is ≥0.70 (Kazdin, 2010). The Cronbach's alpha for the domains in the Swedish version ranged from 0.548 to 0.792, where the domain *organization* had the lowest value, and the highest value was found in the domain *care and cure*. A low value for a domain shows weak internal consistency (Polit & Beck, 2020). This was primarily related to the item "*The unit was easy to reach the unit by telephone*", which shall be taken into consideration when the questionnaire is used. The same item was the only item that increased Cronbach's alpha when the item deleted was applied. It increased from 0.925 to 0.928 for total scale and from 0.548 to 0.628 for the domain *organization*.

General Discussion of the Results

The overall aim of this thesis was to investigate parents' experiences and satisfaction with family-centered care when their child had been cared for at a pediatric intensive care unit. The findings showed that it was an emotionally strained situation, both during the child's acute stage and over time. This strain also affected the family as a whole (Papers I and III). It was evident that parents' memories from their child's admission time at the PICU were vivid and affected them for a long time afterward. They remembered how they e.g. had to cope with the highly technological environment, their own feelings of powerlessness and being separated as a family (Paper I). According to earlier research findings, such experiences can be eased if care is based on a FCC approach (Jerrold M. Eichner & Johnson, 2012; Mortensen et al., 2015).

Parents experienced an overall high level of satisfaction during their child's PICU admission as confirmed by the results according to Empathic-30 in Paper IV. The Swedish translation and initial validation of the questionnaire Empathic-30 demonstrated acceptable psychometric outcomes, both in terms of validity and reliability (Paper III). This result corresponds with the results from the original version of Latour et al. (2013) and with results from psychometric evaluations regarding translations to other languages (Girch et al., 2022; Lessa et al., 2021). A conclusion can be drawn that the questionnaire can be used in clinical practice and give the caregivers an indication of the overall quality of care at their PICU. The results in Papers III and IV indicated a good quality of care, since satisfaction with care is related to quality of care (Abidova et al., 2020; Alibrandi et al., 2023).

The essence of FCC is to establish a partnership between patients (in this thesis children), families and HCPs. Empathic-30 is based on the framework of FCC (Latour et al., 2013; Latour et al., 2009) and the positive outcome in Papers III and IV indicated that a family-centered approach was established at the units. However, although parents experienced a high level of satisfaction (Paper IV) it was revealed through the qualitative data in Papers I and III that there were areas for improvements related to the principles of FCC in order to achieve a full partnership between the concerned parties (IPFCC, 2017). Therefore, it can be favorable to use both quantitative and qualitative methods when investigating e.g. satisfaction as questionnaires can be seen as blunt measures (Plano Clark, 2017; Timans et al., 2019).

The concept of FCC will now be the guidelines in reflections of the results. The concept of "*respect and dignity*" (IPFCC, 2017), means i.e. that the professional team respects and listens to the patient's and family's desires. Parents were satisfied with the encounter with the HCPs (Paper IV), and they felt that the HCPs showed them compassion in their vulnerable situation (Papers I and III). This finding is in line with other studies, which demonstrates that the HCPs' attitude and behavior are important for the parents to feel support and empathy (Bronner et al., 2010; Erçin-Swearinger et al., 2022; Whyte-Nesfield et al., 2023). In order for the HCPs to support parents a relationship needs to be established between them. This relationship is developed through mutual trust and respect (Crits-Christoph et al., 2019). The findings in Papers I and III showed that parents felt trust in the HCP's competence. This trust was important as it made it easier for them to hand over the care of their child (Papers I and III). A study by Baillie and Gallagher (2011) revealed that respecting and encountering parents´ choices was important both during their child's PICU admission and in terms of recovery after the child´s discharge (Baillie & Gallagher, 2011). The parents most often felt that they were supported by the HCPs, especially in terms of participating in the child's care or when they needed to rest and handing over the care of the child to the HCPs (Paper I and III). On the other hand, some parents lacked support when they made decisions that went against what the HCPs believed was correct. Such as when they e.g. could not bear to be close to their child for longer periods of time due to the child's state. Those parents felt remorse long after the child had been discharged for not being present more at the PICU (Paper I).

When working according to the principles of FCC, participating in care and decision-making is a part that needs to be performed in collaboration between family and the HCPs. *Information* is another concept in the model of FCC (IPFCC, 2017), and it is closely connected to the concept of *participation* as participation requires communication between the parents and HCPs (Carnevale et al., 2016). Parents experienced that sometimes decisions were not made in agreement or in a two-way dialogue between them and the HCPs, for example, in connection with the child's discharge (Paper I and III). This was also demonstrated with lower satisfaction in two items in Empathic-30 focusing *being prepared before the child's discharge* (Paper IV). The use of a two-way dialogue is significant when information is shared between HCPs and the family. When the information is mutually exchanged, the family experiences greater participation, and, as a result of that, there is also an opportunity to be there and protect their child (Richards et al., 2017). Sometimes the parents also experienced receiving conflicting information from physicians and this made them feel uncertain about decisions that were made regarding their child's care (Paper I). The findings of Carnevale et al. (2016) stated that when parents were dissatisfied with the information, the confidence in the HCPs decreased (Carnevale et al., 2016). At times parents felt that the HCPs omitted to inform them because they did not think they could handle the information. Although parents experienced it as being difficult to hear grave information about their child's condition, they still wanted to know everything even if it was hard to take in (Paper I). In line with this result, Stickney et al. (2014) showed in their study about family participation during medical rounds, that parents preferred to have all information even if it was distressing. In contrast, Laudato et al. (2020) stated that parents had different information needs; some parents wanted to receive all information about the child's condition, while others did not want as much information (Laudato et al., 2020). This sets HCPs in a complex situation to determine and identify which parents desire all information versus which parents do not want all information. This further demonstrates that clear communication through a two-way dialogue between HCPs and parents (Frader & Derrington, 2016) is the way to get knowledge about which information parents request. Béranger et al. (2017) highlighted factors that might affect parents' comprehension of information. Such factors were the parents' knowledge and stress level, the child's condition, and the physician's way of giving the information (Béranger et al., 2017). In summary, according to the concept of *information sharing* in the model of PFCC (IPFCC, 2017), continuous, honest, and correct information is emphasized to be able to involve patients and families in care and decision-making (IPFCC, 2017).

Parents need help and guidance to be able to participate in their child's care in a highly technological environment such as a PICU (Paper I and III). Parents described being afraid of e.g. accidentally disconnecting medical equipment and as a result worsening their child's status (Paper I). Although the parents often were invited to participate in the child's physical care (Paper I) there were times when this did not happen. This could be when the HCPs were stressed or when they performed task-oriented care per routine (Paper III). It has been proven that the parents' stress is reduced when they participate in their child's care (Grandjean et al., 2021). Therefore, it is important to invite parents, both in the physical care and decision-making process regarding their treatment. However, it is more common to invite parents to the child's physical care than in care planning and decision-making (Chasweka et al., 2023). This is in line with the results of Papers I, III and IV, where parents experienced that they were not involved in the child's care planning. For some parents, it was self-evident not to participate in such advanced medical care planning (Papers I and III). This was also demonstrated in Paper IV with lower satisfaction for the item *"We were involved in the* *decision-making process of our child's care and treatment"* (5.06). Jane et al. (2015) demonstrated that for parents who participated in decision-making about the child's care, it was easier to process decisions that were made regarding the child's care. Even if the decision was to end life-sustaining treatment, the parents who participated in the decision had less remorse and anxiety afterward than those parents who did not participate (Jane et al., 2015). There are several factors that affect whether the parents are involved in decision-making or not. The most important aspect is communication, as well as the unit's working routines, including supporting parents' involvement in decision-making (Wool et al., 2021). The importance of communication for parents' participation in their child's care was also emphasized in the study by Corlett and Twycross (2006). Person-centered communication is preferable and also an important part of FCC (Marino et al., 2023). McSherry et al. (2023) stated in their study that satisfactory communication is associated with high quality of care.

Collaboration refers, among other things, to the cooperation between patients, families, professional healthcare teams, and healthcare leaders in developing policy documents, research activities etc. (IPFCC, 2017). Often such collaboration takes place in isolated groups where parents are invited to work with developmental issues related to the unit and the HCPs (Kokorelias et al., 2019). According to the results of this thesis, several improvement suggestions emerged from the parents. The use of Empathic-30 can be one way to invite parents to participate in developmental processes that later can be realized in practice. The need for facilities for more private space at the unit was expressed by the parents (Paper I) and this need is also described in other studies (Park et al., 2018; Rennick et al., 2019; Smith et al., 2007). Parents have also described that rooms with larger glass windows and/or when the child shares a room with another child encroach on their private space (Alomani et al., 2022).

Finally, in summary, the overall results indicated that a family-centered approach was introduced at the PICUs but, according to the parents' responses, there were areas for improvement, mainly according to the concept of *information sharing* and *participation* in decisions about the child's care. Introducing person-centered communication (Frader & Derrington, 2016) might be one way to respond to that request. One ought to be aware that using person-centered communication might be challenging for HCPs as this mode of communication is based on parents' expressed needs and not solely on the HCPs' expert knowledge (Hashim, 2017). Further, introducing person-centered communication could also be one way to increase parents' participation in decision-making processes as could the implementation of e.g. family-centered multidisciplinary ward rounds (Marino et al., 2023). Although working according to the principles of FCC can reduce parents´ stress levels (Argent et al., 2022; Debelić et al., 2022) and increase their satisfaction (Abuqamar et al., 2016;

Mortensen et al., 2015), one needs to be aware of that it is, for the HCPs, a changed working method. Including parents might be time- consuming and factors such as a heavy workload might affect the way HCPs provide FCC. Nurses have described a heavy workload as a barrier using existing research conducted in clinical practice (Benoit & Semenic, 2014).

Conclusion and Clinical Implications

The parents demonstrated that they were affected by their experiences even though two years had elapsed since their child was cared for in the PICU. Their recollections were vivid and had affected them both during their stay and after discharge, and had a lasting impact on the family. Parents experienced anxiety and stress when recalling their child's hospitalization in the PICU. Parents' satisfaction with pediatric intensive care was high. Nevertheless, the qualitative findings indicated areas for improvement in relation to the principles of family-centered care, particularly regarding information sharing and participation in decision-making regarding the child's care. Likewise, as in person-centered communication especially in regard to the child's care planning and discharge.

The translation and initial validation of the Swedish version of the questionnaire Emphatic-30 showed good psychometric properties although one item "*The unit was easy to reach the by telephone*" was not in alignment with a Swedish context. One might consider if that question should be excluded in the Swedish version of Empathic-30. Measuring satisfaction with care with a validated questionnaire such as Empathic-30 can contribute to knowledge that can be used to further develop FCC at PICUs and thereby improve the care for parents. This in turn will also benefit children in need of high-technological care as it could reduce parents' stress and increase their participation in the child's care. Furthermore, measuring parents' satisfaction could also serve as a quality indicator for the PICUs as satisfaction with care is related to the quality of care (Abidova et al., 2020; Alibrandi et al., 2023)

Further research

Further important lines of research based on this thesis.

- To illuminate nurses′ and physicians’ attitudes to, and experiences of, FCC as a care model at PICUs
- To illuminate staff in leadership positions attitudes to, and experiences of, FCC as a care model at PICUs
- To illuminate healthcare teams’ views of barriers and facilitators to further develop FCC at PICUs

In addition, including parents who were excluded in this thesis (parents whose child passed away and parents who did not master the Swedish language) as this can give us more knowledge for future improvement opportunities.

In the long run this knowledge could form the basis for developing interventions aimed at further developing family-centered care at PICUs. More precisely, further develop communication strategies and working methods that include parents in care and decision-making,

To supplement the knowledge about the practice of FCC in PICUs interview studies with HCPs could be conducted in the future. Knowledge of the HCPs’ views of FCC can increase our knowledge and increase opportunities for improving the FCC in the Swedish PICUs.

Furthermore, this could also be expanded by interviewing staff in leadership positions to increase the quality of FCC within the PICUs in Sweden.

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