EMpowerment of PArents in THe Intensive Care

A journey discovering parents' experiences and satisfaction with care

Jos M. Latour

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Correspondence: Jos M Latour; Erasmus MC – Sophia Children's Hospital; Department of Pediatrics; P.O. Box 2060; 3000 CB Rotterdam; the Netherlands; email j.latour@erasmusmc.nl

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Empowerment of Parents in the Intensive Care

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Empowerment van ouders in de Intensive Care

Een ontdekkingsreis naar de belevingen en tevredenheid van ouders

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Promotor:
Prof.dr. J.B. van Goudoever

Overige leden:
Prof.dr. A.J. van der Heijden
Prof.dr. D. Tibboel
Prof.dr. A.J. van Vught

Copromotor:
Dr. J.A. Hazelzet

Preface

From the early sixties, special care units for premature infants and critically ill children started to develop and expanded throughout the world. Medical care and technical advancements have taken a great flight over the years and improved the health outcomes of infants and children. At the same time, the nursing profession created special training programs to educate the required technical skills. A few decades were needed, however, to understand the importance of the role of parents in critical care units. To date, many neonatal and pediatric intensive care units recognize parental participation as a matter of course. But the path towards synergy is a long and winding one, and we have apparently not yet reached the destination.

History shapes the future and the current generation is creating opportunities for new directions in pediatric critical care. Pediatricians used to be reluctant to involve parents in medical history taking. Somewhat ironically, they were trained to value parental contribution during clinical assessments but at the same time to distrust it.[1] Fortunately, these clinicians' attitude on the presence of parents during a child's hospital admission has changed. Research on parental participation and family-centered care moreover has gradually transformed the nursing and medical professions towards a model of active parental participation in the care of their child rather than leaving parents as passive recipient.[2] Any boundaries in the role and autonomy of parents are not clearly set. In some regions in the world the parents' autonomy goes as far as primary decision makers, in particular in end-of-life decisions. But in most regions the physicians remain the primary decision makers.[3] Regardless the position of parents in intensive care settings, good information and communication remain central components. In this regard, internet access and other technologies have changed the community and with it public assertiveness. With a new epoch ahead, clinicians might want to reconsider the value of parents as external auditors. To illustrate this, here is a comment from parents in a questionnaire on satisfaction with care: "*We searched the internet for information on ECMO treatment, the information we received from the unit was correct.*" This

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1 Gillis J: Taking a medical history in childhood illness: Representation of parents in pediatric texts since 1850. *Bull Hist Med* 2005;79:393-429

2 Davies R: Marking the 50th anniversary of the Platt report: from exclusion, to toleration and parental participation in the care of the hospitalized child. *J Child Health Care* 2010;14:6-23

3 Devictor D, Latour JM, Tissières P: Forgoing life-sustaining or death-prolonged therapy in the pediatric ICU. *Pediatr Clin N Am* 2008;55:791-804

example indicates it may be worthwhile to revisit family-centered care practices in neonatal and pediatric intensive care.

In a qualitative study interviewing parents of 41 children, described in this thesis, a father told about his son's stay in a pediatric intensive care unit in a southern European country. Twice a day both parents were allowed to see their son behind a glass wall and in the evening only one parent was allowed to sit at the bedside for three hours. After transfer back to a hospital in the Netherlands, both parents could stay with their son for 24 hours, which they did for the first two days to help their son cope with emotions. I believe that research on the empowerment of parents and the attitudes of healthcare professionals towards family-centered care remains a necessity as long as parents are treated as visitors and not as full partners in the care of their child.

Jos M. Latour

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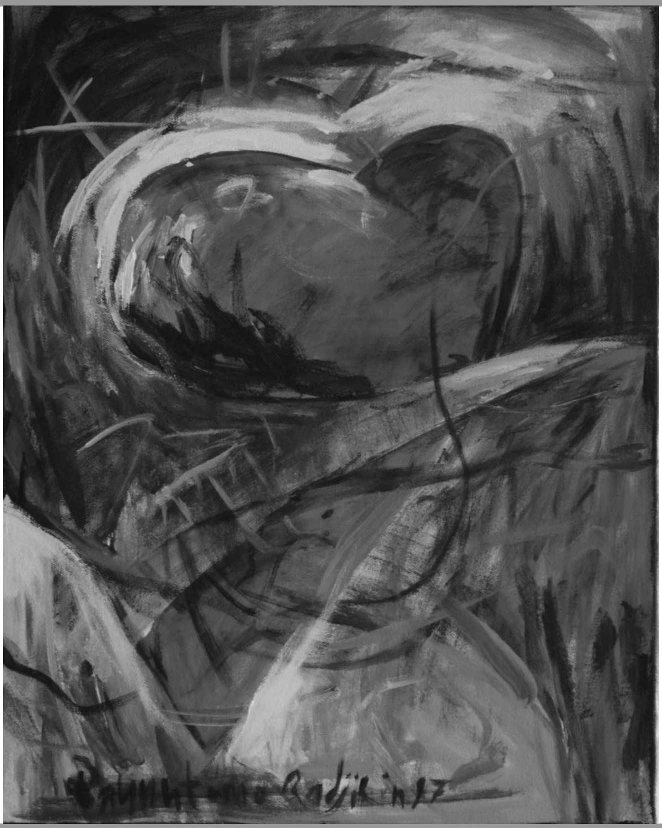

PART I

Introduction

CHAPTER 1

General Introduction

GENERAL INTRODUCTION

Patient satisfaction has increasingly been recognized as an important factor in the assessment of the quality in Dutch healthcare services. This growing interest is the result of the influences of the government, health insurers, patient organizations and healthcare professionals themselves. The government aims at efficient and effective health care, while the health insurers are interested in satisfied customers. In the meantime, patient organizations have become recognized guardians of patients care delivery and hence healthcare institutions must provide satisfactory care to the patients.

Integrating the patients' perspectives in developing quality performance indicators is one of the recent trends in healthcare.[1-2] Patient satisfaction becomes prominent because quality improvement projects aim to improve care to the satisfaction of the patients. Many satisfaction measurements are hospital-wide and do not specifically address the various healthcare specializations.[3-5] In this perspective, Pediatrics holds a special position.[6-11] The sick child in development, from birth until the transition to adult healthcare, requires specific treatment, care, and guidance. Besides, parents have a vital role in the care of their sick child.[12] The present child- and parent-centered care practices encourage the parents to participate in the decision-making process about the treatment and care of their child.[13] Within Pediatrics the complexity of care is diverse. The subspecialties of Pediatric Intensive Care (PICU) and Neonatology Intensive Care (NICU) stand out on account of the often critical nature and complexity of the treatment and the care of critically ill infants and children.[14,15] Measuring satisfaction in children is not always possible due to the complete or partial sedation during the intensive care period.[16] Moreover, most children admitted to an intensive care unit are younger than 4 years of age, a difficult age group – or even impossible – to ask about experiences of their admission. In the Netherlands almost 5,000 children are being admitted to a PICU every year and more than 4,000 infants are being admitted to a NICU. Because admission is often acute, parents have little opportunity to shape expectations about the care for their infant or child. Still, they often face critical decisions and experiences during admission.[17] The way in which parents experience the care for their critically ill child and for themselves is not structurally assessed. Some PICUs or NICUs use self-formulated, non-validated questionnaires to measure the parents' experiences. Unfortunately, there is no uniformity between the units in the Netherlands and it is unclear whether the results really lead to quality improvement.

The aim of parent satisfaction measurements must not exclusively be a benchmark tool for comparison with other institutions nor should it be a tool for self-glorification of the health care professionals. Studies on patient satisfaction seem to be mainly aimed at assessing the care and not so much at the overall experiences with regard to the perceived care.[18,19] The surplus value of satisfaction outcomes is the ability to design interventions leading to quality improvements.[20,21]

A multidisciplinary approach is recommended when it comes to developing a methodologically reliable and valid parent satisfaction questionnaire. Not only the health care professionals, but also the healthcare clients should provide input. With regard to the NICU and PICU, these are usually the parents or guardians of the critically ill infants and children. Their involvement justifies the integration of family-centered care principles. Therefore, the perceptions and experiences of the parents must be incorporated in satisfaction instruments. The implementation of such an instrument eventually provides a tool for a close collaboration between parents and healthcare professionals with a very important outcome: Improvement of care for the critically ill neonates and children, and their parents.

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CHAPTER 2

Is family-centered care in critical care units that difficult?

Jos M. Latour

Nursing in Critical Care 2005;10:51-53

IS FAMILY-CENTERED CARE IN CRITICAL CARE UNITS THAT DIFFICULT?

Although, family-centered care is a well-known concept within all fields of nursing[1], the elements of family-centered care are not always unequivocally understood. This confusion leads to a wide variety of nursing practice in family care, particularly within critical care nursing. For example, the existing visiting restrictions typical of some adult intensive care units (AICUs) make relatives and significant others see themselves as visiting 'guests'. This concept is at odds with the pediatric critical care practice where terms such as visiting hours have been absent from the professional vocabulary for more than two decades. However, there is a trend within adult critical care, for adopting a more focused family-driven healthcare system. An example is a recent paper about open or restricted visitation in AICU.[2] The article considers the positive arguments for open visiting policies such as reduction in patients' stress and effective patient communication when family is present. Although the authors go on to promote development of creative strategies regarding family participation, they continue to mix notions of participation and visitation. Family members are not visitors. They are members of the patient's family with the right to participate in the care of their beloved one. Therefore, the view and attitude of adult critical care nurses should be more directed to the basic principles of family-centered care.

When we talk about family-centered care, who are the family members? In pediatrics, it seems fairly easy to define family members. Mostly, it concerns the parents and siblings of the critically ill child. Although grandparents often play a major role in the care of their grandchildren, they are not always integrated into family-centered practice. Defining a family in adult critical care is in some way easy, in a marital context, the spouse is the first person legally accepted as the closest to the patient. This is particularly an issue when it comes to end-of-life decisions. However, there are situations when the children of a couple are often adults themselves and sometimes they have grandchildren too. They also belong to the patient's family. But in today's pluralistic and multicultural society, it becomes more complex to define the patient's loved once. It requires knowledge and understanding of various rituals, believes, and life styles. For example, what is the decision-making status of the partner in same sex couples? Do we allow the active participation of a tribal medicine man if requested by an African or Asian patient and their family? Do we allow the guide dog of a blind patient to be at the bedside? Such questions illuminate that flexibility and the capacity to respond to the diversity in family-centered care are a challenge for all.

Although these issues are more commonly addressed in pediatric intensive care nursing, they may be less well rehearsed in adult critical care nursing. More emphasis is given to specific topics such as: identifying the needs of patients and families or involvement in treatment plans and decision-making. These issues are intrinsic elements of family-centered care; however, they do not necessarily examine means of improving the interaction process between, and attitude of, nurses and family. Likewise, innovative family care interventions seem not to be recognized as important.[3] Therefore, it is suggested, to develop, implement, and evaluate interventions directed to the participation of family members in critical care useful lessons can be learnt from the pediatric critical care literature where the subject is more widely studied and discussed.

Hutchfield has identified nine major principles from a concept analysis of family-centered care, and recently the American Academy of Pediatrics has described similar ideal standards in a policy statement of family-centered care.[4,5] They are grounded in a collaborative relationship based on respect and open communication. The continuum of family-centered care practice starts with parental involvement where nurses mainly do the care and are advocates for the family.[4] On the other side of the continuum is a more advanced practice where the role of nurses can be defined as consultants and counselors having a dialogue with the parents. Defining the advanced role of nurses is important, but whether this role is taken seriously in practice can be questioned.

Evidence shows that some adult and pediatric critical care nurses find it difficult to build up a relationship with family or parents and to meet their needs.[3,6] In a replication study by Petersen and colleagues, using the Necessary and Current Scale of the Family-Centered Care Questionnaire, pediatric and neonatal intensive care nurses indicated that the principles of family-centered care are important, but, they do not consistently implement these elements into daily practice.[6,7] The reasons for this inconsistency were the range of organizational support, professional development, and autonomy of the nurses within the units included in the studies.

As part of a study tour, Haines traveled to various pediatric intensive care units (PICUs) in order to identify possible opportunities for developing and improving the care of acutely sick children.[8] Haines provides an excellent international overview of critical care outreach teams and early warning assessment tools, in particular the relationship between pediatric critical care units and high dependency units. However, current family practice in the observed units was not investigated. Although a well-established functioning outreach team provides better healthcare outcomes in children, parents are also part of this transitional care aspect. The impact on parental stress during and after a child's PICU admission is well documented.[9] In this respect, Hall's work provides valuable evidence and gives a deeper understanding of the lived-experience of parents in a neonatal intensive care and a pediatric unit.[10] Qualitative studies like this emphasize the importance of nurses' attitudes and communication skills. Yet, having these attributes alone are not enough to meet the basic principles of family-centered care. Implementation strategies or methods to implement specific family interventions are needed. Thomlinson and colleagues argue that several methods of social learning, or a combination of these methods, can accommodate the development of nursing skills in the PICU towards family interventions.[11] A combined learning model of demonstration, role modeling and reflective practice seems to improve family sensitivity. This unit-based practice education needs guidance from experts in critical care nursing in an open and supportive atmosphere. It works two ways; "Clinical practice and caring relationships are privileged ways of meeting the other, and in meeting the other we meet ourselves".[12, p329]

Based on her finding, Hall recommends implementing intervention to enhance family-centered care.[10] The parent educational-behavior intervention on a PICU studied by Melnyk and colleagues is such an example.[13] This three-phase project called Creating Opportunities for Parental Empowerment focus on parental knowledge of the child's behavior during, and after, a hospital admission. It facilitates parents' understanding of their child's psychosocial and physical care. This intervention brought about a significant reduction in parents' and children's stress symptoms in a, respectively, 6 and 12 months period after hospital admission. In addition, this extensive program contributed to family-centered practice by underpinning the holistic child and parents approach. However, efficiency and effectiveness of such interventions needs further evaluation.

Taking care of parents or family members in critical care settings requires specific knowledge and skills. These can not be learned overnight and require vision and teamwork.

Family-centered care is not simply about visiting. It concerns collaboration between family members, patients and healthcare workers with respect to all aspects of care. Basically, we need to create a save passage of patients and family through the critical care period and beyond.

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CHAPTER 3

Families in the ICU: Do we truly consider their needs, experiences and satisfaction?

Jos M. Latour & Caroline Haines

Nursing in Critical Care 2007;12:173-174

FAMILIES IN THE ICU: DO WE TRULY CONSIDER THEIR NEEDS, EXPERIENCES AND SATISFACTION?

In the past few years the journal Nursing in Critical Care has been a platform for an ongoing debate about families visiting the intensive care unit (ICU). The family-centered care concept appears to have been the over-arching issue, and it has been noted that practices across ICUs tend to vary. For most pediatric intensive care units having parents with their child at any time is part of standard clinical practice.[1] In contrast, restricted visiting times for family members within adult intensive care units seems to be an ongoing tradition.

The discussion around families and relatives in the ICU becomes even more complex when we try to define what we mean by ‘family’. How close does somebody need to be to a patient to be defined as a ‘family member’ and therefore to be included in the family-centered care concept? In the pediatric and neonatal ICUs, parents seem to be a clear and logical starting point. Controversies appear to be developing in relation to siblings visiting and the extent to which grandparents may be involved in supporting their children and grandchildren while in the ICU.[2] However, in the adult ICU, it can become more complex with close friends and partners of the patient needing to be considered. Whoever is close to the patient, legally or not, deserves the right to be with their loved ones.[3]

The needs and experiences of relatives and friends of critically ill patients have been studied extensively. Some researchers have concentrated on addressing general issues, whereas others have focused on specific areas such as ‘end-of-life experiences’ or ‘stress and anxiety’.[4-6] Although evidence is available on the effects of interventions and the perceived needs of family members, satisfaction data are increasingly being used in interventional studies to both supplement and justify these. Interestingly, literature surrounding family satisfaction with care provision in respect of critical care settings remains sparse. Surprisingly, only six published satisfaction surveys in neonatal, pediatric and adult ICUs were found.[7,8] Despite progress and a greater focus on the needs of users of healthcare services, information relating to family satisfaction with care provision is minimal. If one were to select between the assessment of family needs, their experiences or satisfaction, the latter would surely be preferred. As stated by Heyland and colleagues, ‘needs assessment are not synonymous with satisfaction because unmet needs do not always translate into dissatisfaction’ and ‘meeting needs does not guarantee satisfaction’.[9,p1413] Additionally, most studies relating to family needs and experiences are limited to the concepts of communication, information, assurance, and proximity. The scope of nursing and medical care in an ICU is more than these elements. Arguably, nurses must find new ways to evaluate the experiences and needs of family members. Whether a satisfaction survey is an option, needs further debate. It is often the term ‘satisfaction’ that leads to discussion; however, the fundamental issue relates to the content the tool measures rather than the label it is given.

Assessing the family's satisfaction is complex. Obviously, the basic need of an ICU patient's family member is that staff do the utmost possible to provide optimal care and save the life of their loved one. In this respect, psychological distress of family members is often inherent in an intensive care experience. To date, limited attention has been given to assessing stress and anxiety measures in the available satisfaction surveys. If these were to be incorporated into such surveys, outcome results of these measures may be significantly high and of key importance for staff to consider. Families may be very pleased with the quality of care provided, however, very distressed by the experience of being on an ICU.

At present, family satisfaction surveys are underused in critical care but are gradually becoming recognized as a quality performance variable.[10] Nevertheless, becoming a performance indicator requires profound development before satisfaction results are recognized and accepted as valid and reliable. Certainly, satisfaction surveys should not be written by hospital staff only because they tend to reflect the views of the authors and not of the consumers of the services. Integration of the family's views in the development of a family satisfaction survey is mandatory if only to enhance the external validity of the instrument.[8] Having family members involved in developing data collection will help to integrate their concerns and priorities, from which measures of satisfaction can be generated. Additional factors need to be considered, such as selecting the appropriate elements to be measured, choosing an appropriate rating scale, considering the lay-out, and deciding on the timing for distribution to collect the broadest amount of information that could inform and develop care provision. A major concern is often the response rate to the survey. In an analysis of 210 satisfaction studies, face to face distribution was associated with an increased response rate, rather than by mail distribution. Interestingly, it also seems that the response rate is not related to the length of the questionnaire.[11] Given this information, we could be forgiven for developing satisfaction surveys with a limited number of elements for investigation. It does, however, give us a degree of freedom to carefully assess and choose the areas to investigate within a satisfaction survey. Family needs, experiences, stress, and holistic family-centered care elements may be considered appropriate to be incorporated. Such instruments might be the ultimate goal to measure the family's satisfaction, and to be accepted as a quality performance measure.

Regardless of this debate, the ultimate question is whether the results of a satisfaction survey actually make a difference, improve or positively change practice, or whether it is just an intellectual exercise for some colleagues? One would hope many ICUs have developed and use a family satisfaction survey or an evaluation tool. The challenge to practitioners must now perhaps be to ensure that the survey or tool used or developed incorporates the above elements as well as meets their local unit needs. Additionally, key to this process is disseminating the satisfaction results, together with identifying core strategies that could improve both care and service provision.[7]

With the continual advancement of new technologies, the intensive care environment is a developing specialty. Maintaining and improving our knowledge and clinical competency to provide optimal and safe care to our patients are imperative. Moreover, the holistic patient care elements must have similar attention paid to them, both in the clinical environment and in our learning curriculum. Consequently, quality performance measures are required to evaluate both the care provided to family members and significant others of our patients, together with identifying areas for improvement. Measuring family satisfaction with care provision should not be viewed as an added extra but must become a vital part of our nursing practice. Eventually, satisfaction data can be used to facilitate and evaluate new quality initiatives.

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CHAPTER 4

Study Aim and Outline of the Thesis

AIM OF THE EMPATHIC STUDY

Emphasizing partnership between parents and healthcare professionals, the eight PICUs in the Netherlands and the NICU of the Erasmus MC – Sophia Children's Hospital have recognized parental satisfaction as a quality performance indicator. This collaborative decision resulted in the multi-center EMPATHIC study (EMpowerment of PArents in THe Intensive Care).

The aim of the EMPATHIC study is to develop and implement validated parent satisfaction questionnaires for the eight PICUs and one NICU in the Netherlands – based on the perceptions of parents as well as healthcare professionals.

The main research questions of the EMPATHIC study are:

1. Which methodology and concepts of parent satisfaction measures related to pediatric critical care are described in the literature?
2. What do nurses and physicians find important in the care for the critically ill infant/child and the parents in a PICU and NICU?
3. What are the perceptions of the parents who had experienced a PICU or NICU admission of their child on satisfaction-with-care issues?
4. Do parents and healthcare professionals have different perspectives on the importance of intensive care practices?
5. Are the constructed parent satisfaction questionnaires reliable and valid to measure satisfaction-with-care?

The EMPATHIC study model is outlined in Figure 1.

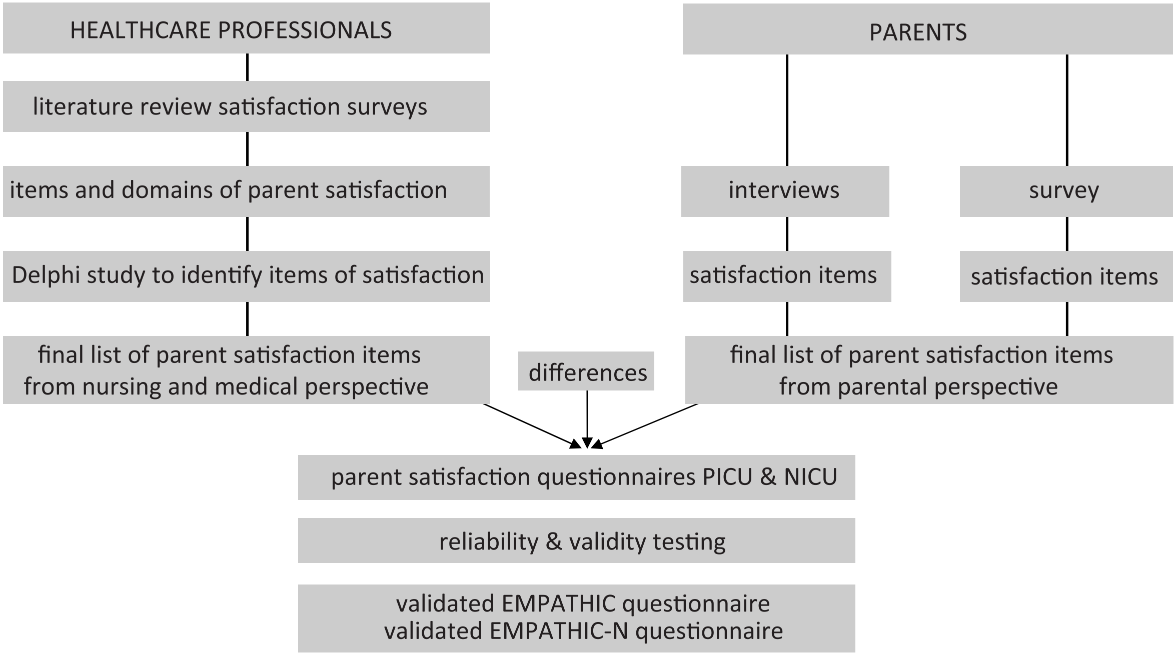


Figure 1 | EMPATHIC Study Model

OUTLINE OF THE THESIS

This thesis presents a consecutive series of studies towards the development and implementation of a validated parent satisfaction questionnaire for the Dutch PICUs and a NICU. The EMPATHIC study reflects a journey discovering the parental experiences and satisfaction-with-care aspects of a child's intensive care admission. Therefore this thesis is built up in sequential parts.

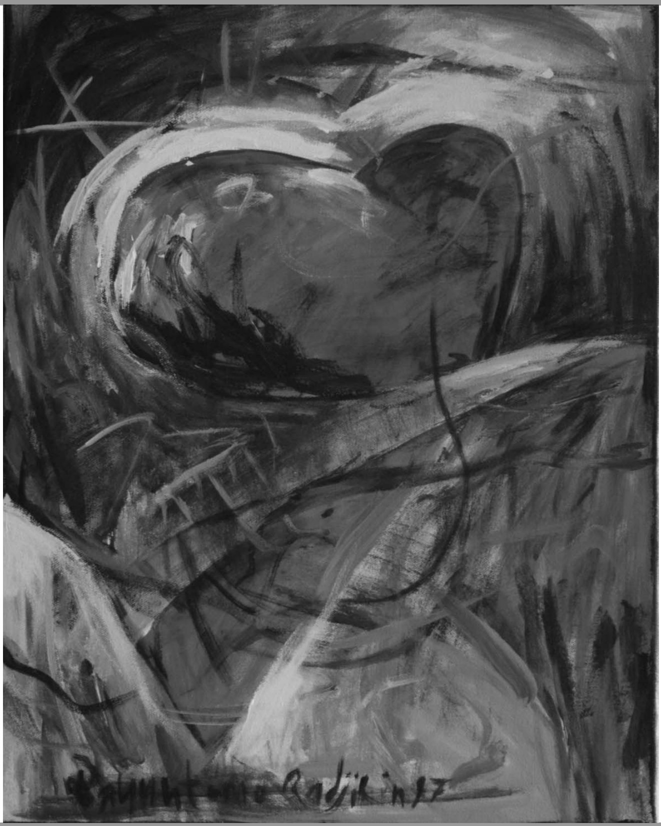
Part II starts with a literature review about the state-of-the-art of satisfaction practices in all intensive care areas as well as general pediatrics. Following this review, related concepts of satisfaction-with-care are discussed, such as family-centered care, parental needs and experiences. Based on these concepts, a framework is proposed providing research action based on partnership between healthcare professionals and parents in pediatric critical care.

Part III contains three chapters exploring the experiences of parents and satisfaction-with-care issues. The first chapter is a qualitative study to discover and unravel today's parental experiences via in-depth interviews. The following two related chapters start with a Delphi study among healthcare professionals aiming at discovering their views on the importance of satisfaction-with-care issues. The results of this study formed the basis for a survey study among parents with the same aim; to gain a quantitative understanding of how important parents rated the proposed care issues.

The two chapters in Part IV discuss the differences and similarities in perceptions of parents and healthcare professionals on clinical practices. One chapter is devoted to the PICU practices; the other chapter concentrates on NICU practices.

Based on the previous exploratory parts of this thesis, Part V presents two chapters on the construction and testing of two satisfaction-with-care questionnaires; the EMPATHIC questionnaire for PICU services and the EMPATHIC-N questionnaire for NICU services.

Finally, Part VI traces back the EMPATHIC study journey. Based on the current scientific evidence a model of parent satisfaction in pediatric critical care is proposed and discussed. Shortcomings of the study as well as future directives complement this part.



PART II

Framework

CHAPTER 5

Parent satisfaction in pediatric intensive care: A critical appraisal of the literature

Jos M. Latour, Jan A. Hazelzet, Albert J. van der Heijden

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ABSTRACT

Objective: To assess the content and characteristics of satisfaction surveys for the development of a parent satisfaction questionnaire to improve clinical practice in pediatric intensive care.

Design: A structured literature review process. The databases PubMed and CINAHL were searched, via identified search terms, for relevant articles published between May 1994 and May 2004. Assessment and analysis of the material was related to development, content, reliability and validity, scales for scoring, and distribution of the satisfaction questionnaires.

Main Results: Twelve original studies were identified using ten different satisfaction surveys in pediatric, neonatal or adult intensive care units or in general pediatric wards. All surveys counted a total of 248 questions or statements. Six satisfaction questionnaires categorized the questions or statements in 21 different formulated domains. Most questionnaires showed sufficient results on reliability and validity. Except for one satisfaction instrument, Likert type scales were used for rating. One study described the distribution of the questionnaire after discharge of the hospital while other questionnaires were distributed during hospital admission.

Conclusion: The use of parent satisfaction surveys in pediatric intensive care is not well documented. Family-centered care becomes widely accepted as an important issue in quality of care, and satisfaction surveys arise as a valuable resource for measuring and improving clinical practice. Parent satisfaction surveys need to be developed based on the needs and experiences of parents and emphasis should be put on methodological issues to have the results accepted as valid and effective for possible changes in clinical practice.

INTRODUCTION

Interest in the area of patient satisfaction in healthcare was generated almost half a century ago. Early reports in the 1970s demonstrated the relationship between patients and professionals followed by a series of studies interested in the patients' view of medical and nursing care.[1-4] In the 1980s, the concept of quality of care became a major issue in monitoring and improving health care. Consequently, and due to the public exerting its influence in healthcare, patients' opinions became an important issue in the assessment of the quality of services.[5,6] Today's healthcare is influenced by politics, healthcare insurance and patient organizations to provide a more patient-driven care. As a response to this demand and the incentive of the healthcare professionals for continuous quality improvement, a quality gap was recognized between theory and practice.[7] Recently, patient-centered care, providing care with regard to a patient's preferences, needs, and values, was one of six aims defined by the American Institute of Medicine to redesign healthcare systems to provide safe and high-quality care.[8] In view of this framework, new strategies to optimize care became the source of control of our work. Therefore, evaluating patient satisfaction and responding to patients' priorities is a key domain in quality-of-care improvement.[9,10]

Most satisfaction surveys are developed to assess patients' feedback on general issues of hospital care. The results are mainly used for benchmarking or belong to hospital-wide overall quality improvement.[11-13] If patient feedback is to have any value, satisfaction surveys need to be clearly linked to action that provides sound changes in patient care. In essence, a patient satisfaction questionnaire should be developed and validated on patients' needs and priorities in different inpatient settings. Studies on parent or family satisfaction in critical care settings are limited in number and scope. The few existing studies mostly concentrate on specific topics in intensive care, such as decision-making processes or end-of-life care.[14-16] In pediatrics in general and in pediatric intensive care in particular, most children are unable to express their needs and to reflect on the perceived care. In this respect, parents are important partners to collaborate in measuring satisfaction and to improve the quality of care based on their experiences.

Traditionally, pediatric intensive care units (PICUs) evaluate the care based on valid and standardized clinical variables such as mortality, length of stay, severity of illness, and other measures. Currently, our PICU uses a self-developed evaluation form to demonstrate parent satisfaction. After 1 year of evaluation, this questionnaire proved to be insufficient to extract comprehensible issues for quality improvement. The close-ended questions in the form are broad formulated, and the instrument has not been tested on its validity and reliability. As family-centered care and parental influence in care are being recognized as outcome measures of care[17], we want to add parent satisfaction to the PICU quality indicators to assess and eventually improve clinical practice.

This review aims to analyze the current concept of parent satisfaction in intensive care settings as described in the literature and to identify domains and items of importance for parents in order to development a reliable and valid parent satisfaction instrument specifically for pediatric intensive care settings in the Netherlands.

METHOD

The literature review was performed by a modified step and strategy procedure for searching the literature.[18] After formulating the aim of the review, the following search terms were identified: satisfaction, parent(s), intensive, critical, care, pediatric(s), and neonatal. The choice of the electronic database was PubMed, National Library of Medicine, because this database contains data of medical and nursing peer-reviewed journals. Several limitations in the electronic database search were formulated. Time limit was set from May 1994 to May 2004 due to the assumption that psychosocial, cultural, and economic values and norms among the population may change. Furthermore the search was limited to identify terms in the title only, and to 'human' studies. No limitations in PubMed were put on the type of publications, ages, languages, subject, and sex. Criteria were defined to assess the abstracts for its relevance to the aim of the review.

The inclusion criteria were: 1) original studies and 2) study subjects related to pediatric intensive care, general pediatrics, neonatal intensive care, or adult intensive care. Studies based only on satisfaction related to a population with specific needs, pathology or interventions were excluded due to the aim of the review. No attempt was made to gain access to unpublished reports, local unpublished satisfaction surveys, and academic theses not cited. After the PubMed search, the database CINAHL, Cumulative Index to Nursing and Allied Health Literature, was consulted using various combinations of the search terms. Reference-list mapping of the identified studies was performed to secure any pitfalls in the electronic literature search.

After collecting the material, the articles were reviewed for a general understanding of the content. Specific analysis of the material was related to the development and content of the instruments (domains and items), reliability and validity, scales for scoring, and distribution of the questionnaires.

RESULTS

The literature search resulted in 11 articles, published between May 1994 and May 2004. All reference lists were assessed, and one article seemed to be relevant according to the criteria but did not emerge in the electronic search. The final result of the search was a list of 12 original articles fulfilling the criteria (Table 1). Six studies were related to critical care settings; one in PICU[19], two in neonatal intensive care units[20,21], and three in adult intensive care units.[22-24] The remaining six studies focused on parents with children admitted to general pediatric departments.[25-30] In total, ten developed satisfaction questionnaires were identified in the 12 studies. The two articles of Heyland et al.[22,23] described and used the same questionnaire, the Family Satisfaction with Care in the Intensive Care Unit. Two other articles were related to the Pediatric Family Satisfaction Questionnaire. This questionnaire was developed by Budreau and Chase[26], and Bragadottir and Reed[25] tested this instrument on reliability and validity.

The majority of the studies briefly stated in the introduction a positive relationship between satisfaction measurements and quality improvement. Only one study described the implication of parent satisfaction to practice and provided several practice changes that have been implemented after reviewing the results of the satisfaction survey.[29] The illustrated changes in practice were: parents' identification bands for discharge, colored-coded arm bands for overnight visitors, parents sleeper chairs, more single and double rooms, parents' feedback shared with staff, and survey results part of new staff orientation.

In eight studies, the items in the satisfaction questionnaire were categorized into domains. The 21 identified domains were generally related to three major issues: clinical care, information and attitude, and organizational issues (Table 2). In total, 248 statements or questions were calculated from the ten identified satisfaction questionnaires (the complete list is available from the authors). All 248 individual items were critically assessed by comparing concepts of measurement. Among 192 items, strong similarity or duplications in terms of the measuring concept was observed, and 56 items were uniquely formulated, measuring its unique concept (Table 3). The 192 duplicated or similar worded items were combined resulting in 39 individual concepts. The final result was a list of 95 topics of parent or family satisfaction in pediatrics or critical care.

Reliability and validity of the satisfaction questionnaires were described in eight articles, as this was generally the aim of the studies (Table 4). The used methods in testing the psychometric properties of the instrument were diverse. Overall, the interclass correlation coefficient (alpha) was used to establish reliability. The authors established content validity mainly by focus groups and by reviewing the literature. In some studies, construct validity was measured by means of factor analysis, nonlinear principal component analysis, or correlation analysis. Only two articles described the limitations of testing the criterion validity due to the lack of similar validated satisfaction instruments.

Table 1 | Studies on parents' and family satisfaction in critical care and pediatrics

Reference No.	Aim	Method – Design	Setting	Population	Instrument
19	To development a parent satisfaction in PICU	1 item selection, 2 item reduction, 3 pre-testing, 4 testing	PICU in teaching hospital	Parents n = 66	Parents satisfaction survey
20	To develop a valid and reliable parent satisfaction measure for medical care in NICU	1 item selection, 2 item reduction, 3 pre-testing, 4 testing, 5 reliability test, 6 validity test	Two tertiary level NICUs	Parents n = 125 (item selection) Clinicians n = 63 (item selection) Parents n =47 (reliability test) Parents n = 832 (validity test)	Neonatal Inventory Parental Survey (NIPS)
21	To develop a Parent Feedback Questionnaire.	Literature review needs of parents in NICU	NICU	Mothers n = 26 (for validity test)	Parent Feedback Questionnaire (PFQ)
22	To develop and test feasibility of a questionnaire to measure family satisfaction in ICU	Item generation via conceptual frameworks of satisfaction, decision-making and end-of-life care	ICU general hospital	Family members n = 21 (pretest) Professionals n = 16 (pretest) Family members n =37 (reliability test) Family members n = 47(final study)	Family satisfaction questionnaire in ICU
23	To determine level of satisfaction of family members in ICU	Multi-center prospective cohort study	6 university affiliated ICU	Family members n = 624	Family Satisfaction questionnaire in ICU
24	To develop and validate the Critical Care Family Satisfaction Survey	Instrument validation study	Acute Critical Care Units (adults)	Professionals n = 8 Family members n = 237	Critical Care Family Satisfaction Survey (CCFS)
25	Psychometric evaluation of the Pediatric Family Satisfaction Questionnaire	Retrospective data analysis	Pediatric units (incl. PICU)	Parents n = 848 (incl. 8% from PICU)	Pediatric Family Satisfaction Questionnaire (PFSQ)

Reference No.	Aim	Method – Design	Setting	Population	Instrument
26	To develop the Pediatric Family Satisfaction Questionnaire	Item generation via focus group with parents	Pediatric Division of a University Hospital	Parents n = 7 (focus group) Parents n = 65 (ranking items)	Pediatric Family Satisfaction Questionnaire (PFSQ)
27	To determine aspects of nursing practice predictive for parent satisfaction	Telephone survey	Tertiary pediatric hospital	Parents n = 3299	Parent satisfaction questionnaire
28	To development and use of parent satisfaction	Item selection by professionals and pilot test	Children’s Hospital	Parents n = 80 (pilot) Parents n = 240	Parent satisfaction questionnaire
29	To revise the Parental Satisfaction Survey	Retrospective review of parent surveys Content analysis narrative responses Literature review	Children’s Hospital	Response self-reported parent surveys n = 1405	Revised Parent Satisfaction Survey
30	To apply and validate an adapted adult patient questionnaire in a study of parental satisfaction with pediatric care	cross-sectional, anonymous questionnaire method	University Children’s Hospital	Parents n = 624	Parent Questionnaire

Table 2 | Domains used in satisfaction questionnaires

General Issues	Domains (References No.)
Clinical care issues	Nursing Care (25,26,30)
	Medical Care (25,26,30)
	Care of Family (22,23)
	Care of Patient (22,23)
	Professional Care (22,23)
	Child Life Therapy (25,26)
	Participation / Parenting (21,30)
	Caring (29)
	Safety (29)
Informational and attitude issues	Communication (29)
	Deliberation (22)
	Staff Attitudes (30)
	Assurance (24)
	Information: illness/routines/needs (21,22,23,24,30)
	Support / Emotional / Spiritual (21,24)
Organizational issues	Hospital Service and Accommodation (21,25,26)
	ICU Environment (22,23)
	Physical Setting (29)
	Proximity / Accessibility (24,30)
	Comfort (24)
	Staff Work Environment (30)

In six identified satisfaction instruments, a 5-point Likert-type scale was used. The wording in the scales was adjusted according to the questions or statements used in the questionnaires. The method of distributing the questionnaires was mostly related to the aim of the study. One study described having distributed the questionnaire after discharge from the unit, whereas the other studies had chosen to give the questionnaire during admission or at the time of discharge.

Table 3 | Similarities and uniqueness of items in satisfaction surveys

Name of Instrument (Reference No.)	No. of Items	Items with Concepts of Similarity	Items with Unique Concepts
Parents satisfaction survey (19)	24	21	3
Neonatal Inventory Parental Survey (20)	27	18	9
Parent Feedback Questionnaire (21)	15	12	3
Family Satisfaction questionnaire in ICU (22,23)	27	17	10
Critical Care Family Satisfaction Survey (24)	20	18	2
Pediatric Family Satisfaction Questionnaire (25,26)	35	27	8
Parent satisfaction questionnaire (27)	16	14	2
Parent satisfaction questionnaire (28)	22	18	4
Revised parent satisfaction survey (29)	19	18	1
Parent Questionnaire (30)	43	29	14
Total	248	192	56

Table 4 | Characteristics of the satisfaction questionnaires

Name of Instrument (Reference No.)	No. of Domains[a]	No. of Items	Reliability Tested	Validity Tested	Scales	Distribution
Parents satisfaction survey (19)	None	24 statements	Test-retest, Internal consistency	Content validity	5-point Likert type scale	During admission
Neonatal Inventory Parental Survey (20)	None	27 questions	Test-retest, Intra-class correlation coefficient	Construct validity	7-point Likert type scale	During admission at ≥48 hrs
Parent Feedback Questionnaire (21)	5	15 statements	Not applicable	Content validity	5-point Likert type scale	At time of discharge
Family satisfaction questionnaire in ICU (22,23)	6	27 statements	Test-retest, Internal consistency	Content validity, Construct validity	5- point scale	At time of discharge; if patient died, family approached via mail after 3-4 weeks
Critical Care Family Satisfaction Survey (24)	5	20 statements	Internal consistency	Discriminant validity, Construct validity	5-point Likert type scale	Not clearly stated
Pediatric Family Satisfaction Questionnaire (25,26)	4	35 statements	Internal consistency	Construct validity	5-point Likert type scale	At time of discharge on pediatric unit; after discharge from PICU or bone marrow transplant unit
Parent satisfaction questionnaire (27)	None	16 questions	Not mentioned	Not mentioned	5-point Likert type scale	2-3 wks after discharge
Parent satisfaction questionnaire (28)	None	22 questions	Internal consistency	Construct validity	5-point Likert type scale	During admission at ≥48 hrs
Revised parent satisfaction survey (29)	4	19 statements	Not mentioned	Content validity	Not mentioned	During admission or before discharge
Parent Questionnaire (30)	8	43 questions	Internal consistency, Confirmatory factor analysis	Content validity, Construct validity, Discriminant validity	4-point Likert type scale	At arrival to the unit

[a] *For domain names, see table 2*

DISCUSSION

The purpose of this review was to identify domains and items used in satisfaction surveys and the methodological issues of parent satisfaction related to pediatric intensive care. The value of measuring satisfaction becomes increasingly important because the public sector requires hospitals to document the quality of care as perceived by the patients.[31] With regard to this pressure, attitudes of health care workers have changed towards the understanding of the importance of the patient's view. Nowadays, it is acceptable and even obligatory that patients judge healthcare services, and that their voice is necessary for the improvement of the quality of care.[8,17,32] Besides the patient's feedback to improve the quality of care, satisfaction surveys used over time are important to monitor and evaluate the implemented changes.

Parent's Involvement. It has been documented that measuring patient satisfaction is basically related to the perceived expectations of the patients.[31] Patient perceptions play a vital role in the reflection of the perceived care and can be influenced by various characteristics. Socioeconomic environments, age, severity of illness, or previous hospital admission are factors influencing the patient's view of care. It is therefore important to develop satisfaction surveys based on the experiences of the patient.[33] The use of qualitative research designs to measure satisfaction, with or without a combination of quantitative survey measures, may contribute to an in-depth understanding of the perceived care by patients and parents. In this respect, the evaluation of care might have a positive effect on improvements in care that are based on the parents' expressions of their values and experiences.[34,35] Another strategy that is gaining popularity is the use of narratives of parents.[36,37] Although parents' narratives might be limited in scope, they can provide clinicians with knowledge of parental feelings, and at the same time, they might be beneficial for the parents. In this review, all the studies are of a quantitative nature; however, in the development of the satisfaction questionnaire, four studies demonstrated qualitative methods to obtain parental or family input.[19,20,26,27]

Content of Satisfaction Surveys. In eight studies, the satisfaction surveys categorized the questions or statements in domains. Reviewing the items used in the questionnaires in relation to the used domains, there seemed to be three major issues: clinical care, information and attitude, and organizational issues. The items related to hospital organizational aspects tended to measure issues that nurses and physicians in clinical practice can hardly influence. However, despite the limited influence of healthcare workers on organizational issues, these aspects might count in the overall satisfaction.[38] However, satisfaction questionnaires should be developed by a clear vision to fulfill the scope of the primary aim to improve clinical practice. Not surprisingly, in satisfaction surveys, emphasis is given to issues of information and attitudes because these topics are often identified as important needs for parents and family members in critical care.[39-41] Unfortunately, the statements and questions were not always clearly formulated to pinpoint the actual topic. Some examples are statements such as "Understanding information" and "Nurses respond slowly to my child's needs" or questions like "the doctors in the ICU answer my questions thoroughly?" and "Were you informed about the emergency setting?" The answers given on these items remain vague, and in addition, no attempt was made in any surveys to formulate successive in-depth questions. The same issue, missing the relevant questions, occurs in the domains related to clinical care. In that domain, an area that does not receive much attention in satisfaction measurements is the care during discharge or transfer from the intensive care unit. The transition from a PICU to a pediatric ward can be stressful for parents.[42] Measuring parents' experiences in this period of the PICU admission seems justified as long as the satisfaction instrument is effectively formulated with respect to possible identifying interventions to improve the quality of care.

Although some authors claim to establish a relationship between the developed satisfaction surveys and the improvement of the quality of care, the diversity of the content and the number of items used in the surveys show limited guidance for quality improvement. Attention must be drawn to formulating the content of the questionnaire in a manner in which the aim is to improve clinical practice according to the results of a satisfaction questionnaire. As suggested by Heyland and Tanner[22], areas that show less satisfaction need to be explored by a deeper assessment method using other tools to explore the precise problems.

Reliability and Validity. The subject of rating a satisfaction survey is often based on feelings, expectations and experiences. Therefore, reliability and validity testing of an instrument is important for profound results and valid conclusions.[43] Unlike the dramatic results of a review by Sitzia[44], where it is stated that of 181 quantitative satisfaction studies, only 11 studies reported a well-established validity and reliability, the studies in this review reported having a sufficient degree of reliability and validity. For reliability, most studies calculated the internal consistency using the Cronbach's alpha to estimate the average correlation among the items in the instrument. Validity refers to whether an instrument accurately measures what it supposes to measure or truly reflects the concepts of measurements. Most reviewed satisfaction instruments have demonstrated the content validity via members of expert or focus groups who have reached consensus in the questions or statements identified. As previously stated, some studies also justify the content validity by incorporating the parents or family members in the development of the instrument. None of the studies has tested the instrument on criterion validity and on the correlation of the new instrument toward a validated existing instrument due to the lack of other validated instruments. However, most studies have demonstrated construct validity, the extent to which the items measure the attributes or domains, via various methods. Conducting a pilot study in the instrument-developing process seems to have become more common practice and helps to receive sufficient credibility for the satisfaction questionnaire.[44]

Scales and Distributing. The statements and questions used in the satisfaction surveys identified were close-ended and were presented in various formats for rating. The Likert-type scales were frequently used because these scales generally enable researchers to analyze the data quickly. Most satisfaction instruments used an uneven Likert-type scale, giving the possibility for neutral rating, but this might cause problems because the neutral choice is generally the most frequent response and consequently difficult for interpretation. Evidence shows generally high ratings in satisfaction studies.[45] Basically, close-ended questionnaires with rating scales have a great chance to produce misleading information because respondents are not likely to explain their answers. For more comprehensive results, it is suggested to add free space in a questionnaire in order to gain qualitative data.[46] Some satisfaction questionnaires discussed used this strategy and integrated an open question at the end of the questionnaire.

Distributing questionnaires requires methodical considerations like the needs and preferences of participants, the skills and resources of the research teams, and the nature of study.[47] In addition, receiving a sufficient response rate is of importance in the approach of distributing questionnaires. The satisfaction questionnaires reviewed were administered during admission and in general given via hand-outs, an approach proven to result in significantly higher response rates.[48] Depending on the nature of the study, examination of the nonrespondents is sometimes necessary to understand the underlying characters of the subjects, although no statistical difference has been documented between responders and non-responders of a parents' satisfaction questionnaire.[49] Finally, an examination of 210 patient satisfaction studies reported no relationship between the length of a questionnaire and the response rate.[48] This evidence might be an argument not to develop a satisfaction survey with limited questions as the primary aim of a satisfaction survey should be legible to identify issues within the total care process and eventually guide professionals to improve care accordingly.

Measuring parent satisfaction is increasingly recognized in many PICUs, but publications in this area remain rare. A limitation of this review concerns the scope of the search using only published studies on satisfaction. It is expected that a wide variety of locally developed satisfaction surveys exists and is in use. These best practices might be valuable for developing a valid and reliable satisfaction tool. Another limitation of the review was the choice of original articles. The recognizable work performed by established institutions was not taken into account.[33,50] Although these organizations might have developed valid and reliable satisfaction tools important for clinical practice, to date, no instrument has been identified specifically for pediatric intensive care. The third limitation was the search in the electronic database. The search was performed by identifying the key terms in the titles only because, in the first three attempts and for several combinations of the key terms, over one thousand references per search appeared. However, we limited the chance of missing any important article by assessing the reference lists of the identified articles. Despite the limitations, the discussed material in this review has led to recommendations for future development of parent satisfaction instruments.

RECOMMENDATIONS

The identified questionnaires are fairly wide in scope when the aim is to develop a satisfaction instrument that documents the parents' view on the complete services we deliver and to isolate specific topics for quality improvement. Nevertheless, the known items and domains in the literature should be recognized as a framework for further in-depth questionnaires. Furthermore, parental participation in the development process is of vital importance. Based on experience, it is expected that parents of children with a planned admission might have different expectations and needs than those with children with an acute admission in a PICU. Cultural diversity might also influence the PICU services and, eventually, the satisfaction of various ethnic groups of parents. Therefore, studies on parents' expectations, experiences, and needs are justified to have a comprehensive understanding of the phenomenon.[51]

Besides the literature and the parents' view, the opinion of the healthcare professionals should also be integrated in the development process. In this respect a wide-ranging parent satisfaction questionnaire based on the input of literature, parents, and professionals can improve healthcare services in PICU. The professionals need to take the responsibility to develop such an in-depth questionnaire. Longitudinal use and the results of this kind of parent satisfaction questionnaire can possibly lead to quality improvement via cyclic quality projects.

CONCLUSION

Measuring patient satisfaction in healthcare is not new, as it has been documented frequently in previous decades. The use of parent satisfaction surveys in pediatric intensive care is less documented. As family-centered care becomes an important issue within the framework of quality care, satisfaction measures become a valuable resource for improving the quality of clinical practice. The development of a parent satisfaction survey with in-depth questions to assess parents' experiences of the perceived care in PICUs is justified because the current surveys show a limited range of topics that evaluate the care from admission to discharge. Ultimately, the aim of such an instrument is to make it easier for parents to express their voice in healthcare and to enable healthcare to change its clinical practice. Attention is needed towards formulating relevant items in a satisfaction questionnaire. Determinants related to the needs of parents and psychosocial variables should be taken into account. Several methodological issues were discussed in this review. Of course, testing the instrument on its reliability and validity is mandatory. Emphasis should be given to methodologic issues relevant to response rate. The layout, choice of rating, and the manner and moment of distributing the satisfaction surveys are important to be able to accept the results as valid and effective for possible changes in clinical practice. For years, parents have been involved and have participated in the care of their children in PICUs. Hence, the concept of family-centered care is not new in this specialty. Whether the child's and parents' focused care is consequently accepted and agreed on by the needs of parents can only be answered by parental satisfaction measures.

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CHAPTER 6

Parent Satisfaction in the Pediatric Intensive Care Unit

Jos M. Latour, Johannes B. van Goudoever, Jan A. Hazelzet

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SYNOPSIS

Parents are important partners to collaborate with the multidisciplinary team to improve quality of care. The aim of the paper is to discuss a framework for action towards quality improvement in pediatric intensive care by parental empowerment through parent satisfaction with care. Incorporating the concepts of family-centered care, parental needs and experiences into a parent satisfaction instrument may provide quality improvement projects based on the empowerment of parents and eventually may facilitate the implementation and evaluation of quality initiatives.

INTRODUCTION

Various strategies and models have been developed to improve quality of healthcare. Initiatives such as evidence-based medicine and evidence-based nursing[1,2], quality improvement circles[3], or clinical performance indicators[4] have been found valuable. Less attention has been given to the empowerment of patients and families as a means of increasing health care standards based on their needs.

Despite the efforts to improve quality in health care, the American Institute of Medicine (IOM) identified six areas in today's health care system that still are below standard: safety, effectiveness, timeliness, patient-centeredness, efficiency and equity.[5] A major challenge for health care workers is putting patients in the center of care, giving them autonomy and accepting them as partners in care. Professionals therefore need to find methods to empower patients. In pediatric intensive care most children may be unable to express their needs and experiences. Here the experiences of parents are recognized as being fundamental for the definition of quality.[6] In this perspective the principles of family-centered care mandate incorporation of parents in daily care. Subsequently, measures of parent satisfaction become a valuable tool in establishing a family-centered and parent-driven care model that would benefit quality of care.

Satisfaction surveys are suggested to be relevant for patient-driven care models.[7] Although patient satisfaction is studied widely in various medical services, most surveys take a medical or nursing perspective rather than focusing on the patients' needs and experiences. Thus, parental input in developing a comprehensive pediatric ICU (PICU) satisfaction survey is indispensable.[8] Action for rigorous assessment of parent's needs and experiences of the perceived care and consequently the integration of their views in satisfaction surveys is warranted. So far, only a few studies have demonstrated this method.[9,10] This article analyzes and discuss a parental satisfaction framework for action towards quality improvement in pediatric intensive care by parental empowerment through the use of parent satisfaction measures.

METHOD

The authors performed a PubMed literature search focusing on three themes: parent satisfaction; parental needs and experiences; and family-centered care. For parent satisfaction and family-centered care a time limit was set between January 1990 and June 2007. No time limit was used for parental needs, because the authors were aware of some relevant references published before 1990. Search terms for parent satisfaction and parental needs were "parent(s)," "satisfaction," "pediatric," "intensive care," "needs," and "experience(s)". Search terms for family-centered care were "respect," "information," "education," "coordination of care," "physical," "emotional," "involvement," "parents" and "family-centered care." Besides these terms, all searches included the term "quality." References of the identified articles were screened to account for omissions in the electronic search. The literature on family-centered care provided extensive references. For the purpose of this paper, only key references supporting the rationale of the framework are used.

FAMILY-CENTERED CARE

The principles of family-centered care in the PICU should be grounded in collaborative relationships between health care professionals and parents. Six domains have been identified in the literature:[5,11,12]

- Respect
- Information and Education
- Coordination of Care
- Physical Support
- Emotional Support
- Involvement of Parents

These domains relate to the roles of the professionals and the parents. Although the principles of family-centered care are well-known by the health care professionals, current practice seems not to be consistent to these concepts.[13,14] Evidence demonstrates that health care professionals find it difficult to built up a relationship with the family or parents and to meet their needs.[15] PICU physicians and nurses need to develop interventions to improve family-centered care.[16]

Respect

The global attention to equity in health care for all children and parents has increased awareness of the need to safeguard the outcome of critically ill children and the well-being of the parents unrelated to their background. Inconsistencies in the unequivocal approach to children and parents are related to discrimination in health care access and treatment based on personal characteristics.[4,17] A recent study in the USA provides data that children from ethnic minorities experience significant difficulties in accessing health care compared with white children.[18] National insurance policies often are to blame for this discrepancy. In Europe, the health care systems provide access to medical treatments for all children. Health care professionals, however, need to be aware of the needs and preferences of each individual child and its parents, regardless of their ethnic background and beliefs.[19,20] Respect and understanding must come from knowledge of different cultural and religious perspectives.

Information and Education

Providing information and education to parents is a major challenge for professionals. It is within the realm of information where professionals and parents come together and collaborate in the care of the critically ill child. Effective and understandable communication between parents and professionals does not only benefit the child, it also decreases parental stress and anxiety levels, and is basis for trust.[21,22] Increasing attention is paid to interventions aimed at improving communication. Most intervention studies, however, originate from neonatology, general pediatrics, and anesthesiology; contributions from pediatric intensive care are still scarce.

Coordination of Care

PICUs by nature are mostly transitional units. The critically ill child usually is admitted from an emergency department or a pediatric ward. Discharge often is planned to a pediatric ward. Transfers must be carefully coordinated between services. Transitional care, however, also encompasses other aspects, such as consultations, procedures, tests or basic daily care. For parents, these processes become clear when communication by professionals is timely and accurate. Documented effective interventions to improve admission or discharge planning in PICU settings are limited.[23]

Physical Support

By nature, parents are concerned about their child's pain and comfort. The child's pain and discomfort may influence parental stress. In a multi-center study, parents reported that their infants had experienced more pain than they had expected; they also worried about the long-term effects of pain.[24] These worries were predictors of increased parental stress levels. Although validated pain and comfort assessment instruments are available in PICU, professionals may not always be willing to use these instruments in daily practice.[25,26] Improving the attitude of the health care professionals might benefit the recovery of the critically ill child and enhance parental well-being.

Emotional Support

Symptoms of traumatic stress are common among parents of PICU patients and may persist long after discharge.[27] The pioneering work of Carter and Miles[28], who developed and tested the Parental Stressor Scale:PICU, has contributed much to the identification of parental stress and coping strategies. The instrument was designed to measure the overall parental stress response during the admission of their child in the PICU. The 37 items were grouped in seven dimensions (Box 1). Despite many studies examining parental stress, effective interventions to reduce stress are limited in scope. In a randomized controlled trial, the Creating Opportunities for Parent Empowerment (COPE) program, an educational-behavioral intervention, was tested on its positive effects on coping up to 12 months after hospital discharge.[29] The 87 mothers in the COPE group reported significantly less stress after their child was transferred from the PICU to the pediatric ward than the 76 mothers in the control group. Symptoms of depression also were significantly fewer in the COPE group 1 and 6 months after discharge. After 12 months the mothers in the COPE group reported significantly fewer posttraumatic stress disorders. These findings suggest that parenting programs may be valuable in long-term improvement of children's and parents' mental health after PICU admission. A systematic review of 26 parenting programs in pediatrics provide data covering mainly short-term effects.[30] Most programs are effective and seems to contribute significantly to the psychosocial health of the mothers.

Box 1 | Dimensions of the Parental Stressor Scale:PICU

Child's appearance	Descriptions of the child's appearance (three items)
Sights and sounds	Alarms of equipment and surroundings near the child (three items)
Procedures	Tests and procedures that may have been done (six items)
Staff behavior	Behavior of physicians and nurses as experienced by parents (four items)
Parental role alteration	Perception of parents not being able to care for the child (six items)
Staff communication	How physicians and nurses communicate with the parents (five items)
Child's behavior and emotions	Behavioral and emotional responses of the child (ten items)

Involvement of Parents

PICUs provide open visiting hours, participation in care, parental presence during invasive procedures, involvement in (critical) decision-making, and some units even allow parental presence during medical rounds. The focus is on reaching partnership between PICU professionals and parents. The current multicultural changes in societies require health care professionals to be aware of the cultural diversity of the family functioning.[16]

Despite the general agreement on the dimensions of family-centered care, evidence suggests that nurses may find it difficult to build up a relationship with parents and to meet their needs.[31] Physicians also need to invest in providing support to parents. As suggested by Azoulay and Sprung[32], assessments of intervention outcomes in family members would elucidate the extent to which family-centered care matches family expectations.

Family-centered care in the PICU setting is not a new concept, but there still is room for improvement. Knowledge of parental needs and perceived care is essential to achieve improvement. Parent satisfaction surveys that include a core set of items related to the dimensions of family-centered care eventually might provide interventions to improve family-centered care.

PARENTAL NEEDS AND EXPERIENCES

Pediatric intensive care staff should take a leading role by changing their attitudes, gaining in-depth understanding of parents' experiences and acting upon the parental needs. Parental needs in the PICU setting have been studied by various methods. The quantitative studies on this subject[33-36] used modified versions of the 45-item Critical Care Family Needs Inventory (CCFNI), originating from the adult intensive care setting.[37] The ranking of top 20 needs do not differ extensively among these studies (Table 1). Although the intensive care settings are predominately focus predominately on the critically ill child's health status, the interpersonal interactions should be taken into account to meet the needs and preferences of both the child and parents. These studies have a few possible limitations. First, they generally leave out multi-cultural issues and differences among the parents. These omissions could affect the identification of issues important for individual parent-centered care. Second, these studies date from the 1990s. Parental needs and preferences might have changed since then. Items related to information provision have ranked high over the years, however (Table 1). Finally, Noyes[38] raised methodologic issues regarding the validity of the instruments, sample sizes, and the defined variables. It was suggested that the questionnaires used were inadequate to explore the parents' experiences. Indeed, although needs and experiences are two related concepts, different strategies should be used to explore each of them.

Several studies focused on parents' experiences during admission. A recent study interviewed 20 parents whose children had been hospitalized, either in the PICU (n = 11) or in the pediatric ward (n = 9).[39] Experiences explored regarded illness onset, actual admission, stay, and the discharge process. In the PICU group, parents were less reassured at admission because of the child's severity of illness and the start of medical interventions. Interaction with the medical team during the PICU stay was a barrier for some parents and could turn into a source of stress and anxiety. Minor failings in the PICU discharge process generated a greater anxiety in the parents, although parents generally were satisfied with the aftercare by the pediatric outpatient departments. Similar findings were found in a study among fathers who had a child in the PICU (n = 15) and in a general pediatric ward (n = 10) using two stressor scales to identify specific sources of stress and stress symptoms.[40] Fathers whose children were in the PICU reported the technical procedures on the child and the parental role as most stressful to them. Surprisingly, professional staff communication was experienced as less stressful. These findings differ from the previous study[39], showing that parents who had children in the PICU were less content with the provision of information during admission and at discharge. These contrasting findings might result from differences in PICU environment and staff. Therefore, every PICU should assess carefully its own professional approaches towards parental guidance.

Table 1 | Ranking top 20 needs of parents in pediatric intensive care

Need	Ranking[a]			
	Kirschbaum[35] 41 parents	Farrell and Frost[33] 27 parents	Fisher[34] 15 mothers 15 fathers	Scott[36] 21 mothers
Knowing how child is treated medically	1	3	4	1
Feeling there is hope	1	6	2	n.m.
Assured the best possible care is given	1	5	6	1
Knowing specific facts concerning progress	2	n.m.	4	n.m.
Having questions answered honestly	2	1	4	1
Knowing exactly what is being done	2	n.m.	5	n.m.
Being called at home about changes	3	1	5	1
Feeling the personnel care about my infant	3	n.m.	5	1
Knowing the prognosis/outcome	4	2	1	1
Receive information once a day	4	n.m.	5	2
Knowing what is wrong with the child	n.m.	1	n.m.	n.m.
Understandable explanations	7	3	n.m.	n.m.
Talking with the doctor	9	4	6	n.m.
Talking with the nurse	20	5	n.m.	n.m.
Have a nurse with me at the bedside	n.m.	5	n.m.	n.m.
Knowing why things were done for my child	5	n.m.	2	n.m.
Knowing my child is being treated for pain and/or is comfortable	n.m.	n.m.	2	n.m.
Knowing my child may still be able to hear me if she/he is not awake	n.m.	n.m.	3	n.m.
Seeing my child frequently	6	n.m.	4	1
To visit at any time	8	n.m.	n.m.	1

Abbreviation: n.m, not mentioned; [a] Ranking numbers can appear more than once because they have the same values in the results (mean or percentages).

Combining the findings from the parental needs studies with those of the parental experiences studies may instill a fundamental understanding of means to ensure the empowerment of parents in critical care settings. Parent satisfaction measures based upon both the needs and experiences of parents could provide comprehensive results that eventually might steer the professionals towards family-centered care improvement.

FRAMEWORK FOR ACTION

The PICU is a complex setting, particular for the child and parents. Professionals involved in PICU probably do their utmost to provide the child and parents a safe passage through this critical period. Whether these efforts are well received by the parents is usually not documented. It is not known whether many PICUs measure parental satisfaction. So far, only two satisfaction studies have documented how parents perceive PICU care.[9,10] Both studies developed a parent satisfaction questionnaire based on literature reviews, parent consultation, and multidisciplinary input. Despite this rigorous instrument development, a gap remains between a framework and assumptions on the research topic. Furthermore, Haines and Childs[10] found the tool developed by McPherson and colleagues[9] insufficient in covering all areas of their PICU service. They therefore developed their own instrument for local use. Based on the results of the satisfaction survey of 110 families, Haines and Childs were able to identify strategies to optimize the service (Box 2).

Box 2 | Identified strategies to improve practice by Haines and Childs

- Review timing and opportunities of preadmission visits
- Standardize planned PICU admissions
- Provide assistance for novice PICU nursing staff in bedside support of parents
- Improve communication with parents about unit routines and closure practices
- Improve availability of written communication
- Optimize the role of senior nurses in providing verbal information for parents
- Clarify communication channels when multiple medical team are involved
- Optimize continuity in nursing allocations
- Improve the preparation of parents for the transition from PICU to wards
- Improve teamwork and communication during discharge process

Data from Haines C, Childs H. Parental satisfaction with paediatric intensive care. Pediatr Nurs 2005;17(7):37-41.

Patient-centeredness in particular focuses on the patient's experience and perceived care. The uniqueness of PICU, with parents serving as proxies for their critically ill child, necessitates a clear distinction between the concepts patient centeredness and family-centered care. The domains of family-centered care, as described previously, have the IOM goals of time, equity, effectiveness, efficiency, and safety. The synergy of these aims within family-centered care provides this concept with a comprehensive basis for health care improvement.

Family-centered care, parental needs, and parental experiences seem to be the core concepts that reflect the nature of multidisciplinary care for parents in the PICU. Extensive work on various care aspects of family-centered care has been done. A recent review identified 43 evidence-based guidelines to support family members in critical care.[41] Because satisfaction usually was not an outcome variable, the question remains whether these guidelines will be well received by the parents.

The framework shown in the Figure 1 puts parent satisfaction in this center line, because this concept can include measurable items. Parental needs and experiences are placed in the middle ring, impacting both the outer ring's six domains of family-centered care and the inner circle's parent satisfaction outcomes. During and after a PICU admission, parents build up a certain degree of understanding of the complexity of intensive care. This framework reflects the underlying philosophy of taking the parent's preferences into account. The satisfaction framework provides action towards research that crosses borders between professionals and parents and works towards partnership in pediatric intensive care. Eventually, the results of satisfaction studies need to trigger professionals to develop and test new interventions to meet the needs and preferences of the parents in the PICU.

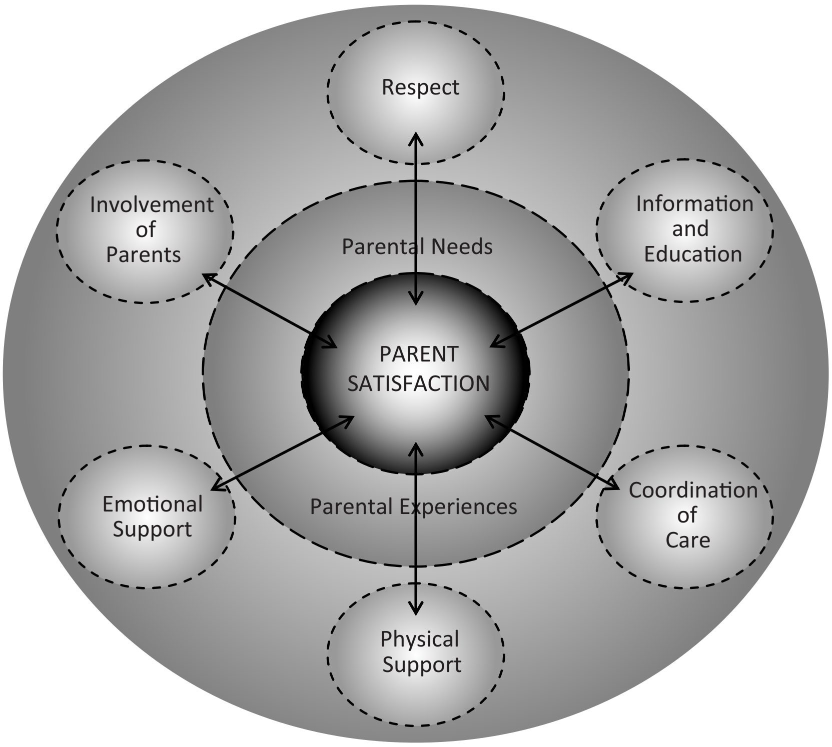

Figure 1 | Framework parent satisfaction in pediatric intensive care.

SUMMARY

he IOM's six aims to improve health care in the twenty-first century provide a useful framework for pediatric intensive care professionals. It is particularly the aim of patient centeredness that encompasses quality of compassion, empathy, and responsiveness to the needs, values, and expressed preferences of the individual patient. For the pediatric intensive care setting this concept can be translated into family-centered care because the parents and the critically ill child constitute one family unit with the right to the best possible care in relation to the best possible outcome for the child and parents.

Incorporating the concept of family-centered care, parental needs, experiences, and parent satisfaction into the development of a parent satisfaction instrument may achieve a fundamental improvement in quality of care based on the empowerment of parents. Parent satisfaction survey can become quality performance indicators and may facilitate the evaluation of quality initiatives.

- The principles of family-centered care are well-known but are not consistently implemented into practice.
- Parent satisfaction outcomes are not widely accepted as quality performance indicators.
- Empowerment of parents in the development of parent satisfaction instruments can provide accepted quality performance indicators.
- Measuring parent satisfaction requires involvement and participation of parents as well as partnership between parents and health care professionals.

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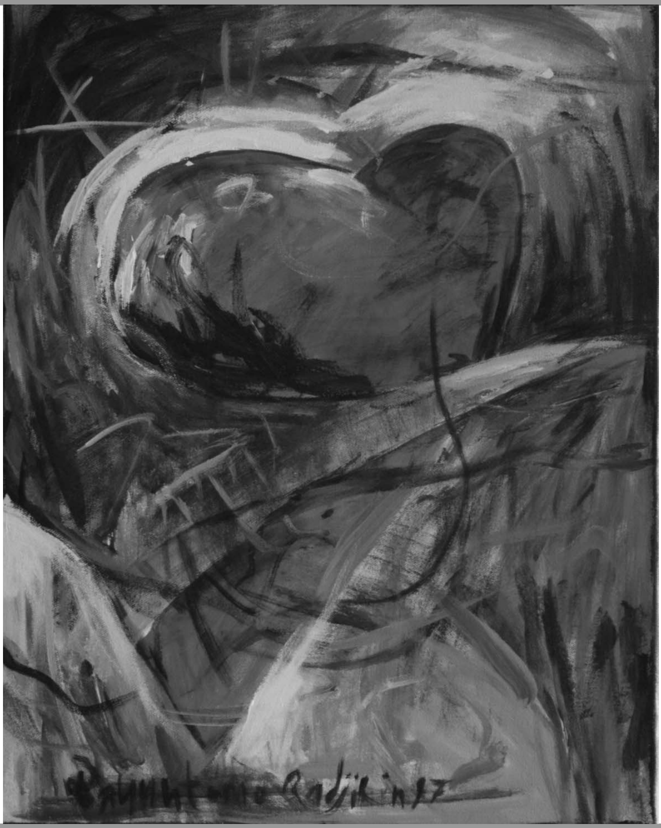

PART III

Explorations

CHAPTER 7

A qualitative study exploring the experiences of parents of children admitted to seven Dutch pediatric intensive care units

Jos M. Latour, Johannes B. van Goudoever, Beatrix Elink Schuurman, Marcel J.I.J. Albers,
Nicolette A.M. van Dam, Eugenie Dullaart, Marc van Heerde, Carin W.M. Verlaat,
Elise M. van Vught, Jan A. Hazelzet

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ABSTRACT

Purpose: To explore parents’ experiences during the admission of their children to a pediatric intensive care unit (PICU).

Method: Qualitative method using in-depth interviews. Thematic analysis was applied to capture parents’ experiences. Thirty-nine mothers and 25 fathers of 41 children admitted to seven of the eight PICUs in university medical centers in the Netherlands were interveiwed.

Results: Parents were interviewed within 1 month after their child’s discharge from a PICU. Thematic analysis identified 1,514 quotations that were coded into 63 subthemes. The subthemes were categorized into six major themes: attitude of the professionals; coordination of care; emotional intensity; information management; environmental factors; parent participation. Most themes had an overarching relationship representing the array of experiences encountered by parents when their child was staying in a PICU. The theme of emotional intensity was in particular associated with all the other themes.

Conclusions: The findings provided a range of themes and subthemes describing the complexity of the parental experiences of a PICU admission. The subthemes present a systematic and thematic basis for the development of a quantitative instrument to measure parental experiences and satisfaction with care. The findings of this study have important clinical implications related to the deeper understanding of parental experiences and improving family-centered care.

INTRODUCTION

“I know a PICU is usually quite sterile but human feelings are not sterile and they really do count” [mother].

Admission in a pediatric intensive care unit (PICU) is often a transitional phase in the child’s recovery from a critical illness. Most parents experience a PICU admission with a certain emotional impact.[1,2] In addressing parental stress, many studies have documented the psychological impact of a PICU admission.[3] Other researchers concentrated on parental needs and documented that hope, honesty, accessibility, and information are parents’ top priorities.[4-6] Lastly, the overarching themes identified by qualitative studies on parental experiences seem to be related to the role of parents, the parents-professional relationship, and emotional burden.[1,7] The common outcome of all studies documents a firm impact on the parents.

Only a few validated instruments are available to quantify parental stress or needs in PICU, such as the Parental Stressor Scale: PICU[8] and the Critical Care Family Needs Inventory (CCFNI).[9] These instruments are limited in that they measure the concepts of stress and needs only. The Parental Stressor Scale: PICU includes items related to care aspects such as environmental factors, communication with staff, and the appearance of the child. Nevertheless, the response categories only relate to the level of stress. A similar limitation applies to the CCFNI, a set of family needs items measuring how important parents rate the needs. In contrast, parental experiences have mainly been assessed via qualitative methods. These studies usually identify four to six themes describing the parents’ experiences and often provide valuable information to develop quantitative questionnaires measuring parental experiences or satisfaction with care. Although experience and satisfaction are distinct concepts, to a certain extent they are related to each other.[10] Parents’ experiences of a PICU admission are often related to their roles, stress factors, and needs.[7,11] Satisfaction, on the other hand, has been conceptualized to measure the degree of congruence between parents’ expectations and their actual experiences of the perceived care. The key concepts, in this respect, are affective support, health information, decisional control, and professional/technical competencies.[12] Certainly, clinicians must be aware of the parents’ expectations, experiences, and satisfaction.[13,14] Not until then can they optimize family-directed care, meet the needs, and increase satisfaction with care.

A qualitative study was planned to better understand today’s parental experiences of a PICU admission.[15] The aim of this study was to explore and to identify accounts of the parents’ experiences of a PICU admission of their child.

METHODS

In-depth interviews were conducted to facilitate the description of retrospective parental experiences, thereby expanding the general understanding of the parents' experiences of their child's PICU admission.[15,16] The interviews were conducted between October 2006 and April 2007. The study was approved by the medical ethical review board of the Erasmus Medical Center in Rotterdam and subsequently by the participating centers.

Settings

Of the eight PICUs in the Netherlands, seven participated in the study. In 2007, bed numbers ranged from 8 to 24. Total admissions were 4,840. Patients had a median age of 2.4 years ($P_{25\text{-}75}$0.4-8.8), stayed a median of 3 days ($P_{25\text{-}75}$2-6) and needed ventilation for a median of 2 days ($P_{25\text{-}75}$1-6).[17]

Participants

Parents of six children per participating PICU were recruited, providing a purposive sample per center and nationally.[18,19] Eligible parents were those whose child had been admitted to the PICU for at least 24 h and who were able to communicate in Dutch. Excluded were parents whose child died during or after the PICU admission to avoid an unnecessary emotional burden and possible differences in parental experiences.

Parents were recruited by the local research coordinators. To avoid selection bias, the recruitment took place on the first day of a predetermined week within the data collection period. Parents were given a written invitation including information about the study, privacy regulations, and contact details of two independent study experts. After parents had provided informed consent, the researcher (JML) arranged for the interview to take place. Parents themselves could chose the time and place of the interview, either at home or in a quiet room in the hospital.

The final planned interview was cancelled because the parents withdrew consent. No new participants were recruited as the last two interviews had revealed data saturation, i.e., similar experiences were addressed with only minor nuances. Thus, 41 interviews were conducted.

Data collection and analysis

The data collection and analysis are described in detail in Appendix 1 (Electronic Supplement Material). In brief, the interviews were held within 1 month after PICU discharge. A protocol was developed to conduct the interviews. Thematic analysis was performed by using a qualitative data analysis software, ATLAS.ti, version 5.5, Berlin.[20,21] Descriptive statistics served to calculate frequencies, median, mean, and quartile scores of the characteristics of children and parents using SPSS (version 15, Chicago, IL).

RESULTS

Of the 41 interviews, 23 were held with both mother and father, 16 with the mother only, and 2 with the father only. The children's characteristics are listed in Table 1; the parents' demographics are summarized in Table 2. The mean interview duration was 54 min (range 24-108 min).

Table 1 | Characteristics of the children (n = 41)

Gender, male	24 (58.5%)
Age in months; median ($P_{25\text{-}75}$)	16 (4-75)
Unplanned PICU admission	25 (61%)
Planned PICU admission	16 (39%)
Length of stay PICU; median ($P_{25\text{-}75}$)	8 (4-13)
Children on mechanical ventilation (n)	39
Ventilation days; median ($P_{25\text{-}75}$)	6 (2-9)
PICU diagnosis	
Cardiovascular	2
Infection	1
Neurology	3
Respiratory	17
Shock – Sepsis	1
Trauma	3
Post Procedure diagnosis	
Cardio thoracic surgery	9
Other	5

PICU: Pediatric Intensive Care Unit

Table 2 | Parents' demographics

Gender	
Mothers	39
Fathers	25
Age	
Mothers; years, mean (min-max)	35 (19-49)
Fathers; years, mean (min-max)	37 (28-49)
Family composition of children[1]	
One child	8 (20%)
Two children	20 (49%)
Three children	10 (24%)
Four children	1 (2%)
Six children	2 (5%)
Education level mothers	
Lower education	1 (2%)
Middle education	21 (54%)
Higher education	14 (36%)
University	3 (8%)
Education level fathers	
Lower education	4 (16%)
Middle education	11 (44%)
Higher education	8 (32%)
University	2 (8%)
Previous experience of pediatric wards admission	33 (81%)
Previous experience of PICU admission	17 (42%)

PICU: Pediatric Intensive Care Unit; [1] Two mothers were single parents

Thematic analysis identified 1,514 relevant quotations coded into 63 subthemes. These were clustered into six themes: attitude of the professionals; coordination of care; emotional intensity; information management; environmental factors; parent participation (Table 3). The presented quotations are annotated with study number and an 'M' for mother or 'F' for father. Confidentiality was protected by changing names to an alias. An online supplement of the qualitative findings related to the validity of the subthemes and themes is provided (Table 4, Electronic Supplement Material).

Table 3 | Themes and selected subthemes

Attitude of professionals	
	Awareness of parental needs
	Trust in safety
	Listening to advice of parents
Coordination of care	
	Transition PICU to pediatric ward
	Teamwork
	Having a first responsible nurse
Emotional Intensity	
	First hours of admission
	Appearance of child
	Critical situations
Information management	
	Timing of receiving information
	Test and procedures
	Honesty
Environmental factors	
	Privacy of a single room
	Catering
	Sound and light
Parent participation	
	Involvement in treatment decision-making
	Participation in child’s care
	Presence during test and procedures

PICU: Pediatric Intensive Care Unit

Attitude of Professionals

Most parents described their PICU experience from their interaction with the nurses and physicians. From the interviews a vivid picture emerged of how these health care professionals attended to the needs of the child, parents, and siblings. Parents whose child was in a PICU for the first time were surprised by the possibilities to make the child's stay as comfortable as possible. The professionals' attitude was also related to behaviors such as empathy, commitment, and respect. Situations on these subthemes as expressed by many parents were often related to non-verbal communication, such as: *"The attention…yes I can see it from their faces, they do not have to give it, you can read it from the face"* [23:F].

Coordination of Care

Parents raised issues documenting inconsistency in the care of their child and themselves. The subtheme consistent work by professionals was related to differences in the nurses' approach and the disparity of care delivery. A PICU is generally a transitional unit. Many parents often experienced differences in the care between a PICU and a pediatric ward, such as: *"That was a weakness of the PICU, they did not…, well, the pediatric ward has no knowledge of trachea canula care. We can do it, but we are not 24 h on the ward, so then there were daily phone calls between the PICU and the ward, and two ward nurses came to the PICU to learn about canula care"* [35:M].

Emotional Intensity

In almost all interviews (n = 39) parents expressed experiences that reflected a certain level of emotional intensity. Parents' first impressions of the admission tended to be similar as *"you live in a mist"* [11:M]. The stories then often continued with examples representing bewilderment. The uncertainty emerging from these examples was coded as the subtheme 'being in the dark.' The events often raised parental stress levels through a sense of unreality and feeling powerless, for example: *"That we were scared of how we would find him… there is this fear that stayed with you all the time"* [20:M]. In the course of the PICU admission, several other subthemes emerged, reflecting a level of emotional intensity, such as the child's critical illness, its appearance, and seeing other children.

Information Management

Most parents provided ideas about improving information provision, particularly the 'moment' of providing information; *"plan more moments to tell how the situation is or what will happen, yes give a little more information between times…"* [17:M]. Many parents also addressed honesty in information provision. Fathers were more outspoken about the need to receive honest information from the clinicians, while mothers often related honesty to a feeling of certainty. A father said: *"The communication of how things are going with your child I found a bit less, you have to pull things out of them… you need to be open to people, being honest"* [15:F]. Parents do appreciate honesty even if the picture of the child's condition is not complete. Telling parents about any uncertainty might have a positive effect on their trust and security, like one mother stated: *"Briefly they (physicians, nurses) told us how they looked at the current situation, and that showed a lot of uncertainty because they did not know about the diagnosis, and they said in all honesty that they did not know, and expressing uncertainty provides a form of confidence"* [34:M]. Furthermore, discharge planning was addressed by many parents. Many said that timely information on discharge and in the post-PICU period would have helped them to cope with the transition.

Environmental Factors

Differences were observed between parents whose child had a single room and those whose child was in a shared room. Generally, a single room was preferred for the privacy and quiet environment. Parents felt then more at ease to express their emotions: *"Yes, you just have more peace in that room, it has more privacy"* [28:M]. Parents also recalled several issues related to the subtheme organization of the PICU, such as the availability of a locker or a notice board indicating who was taking care of their child.

Parent Participation

All parents talked about involvement and participation in the care of their child. Regarding treatment decisions, most parents expressed their belief that the physician was the one who should make such decisions. However, the participating centers seem to vary in the level of involving parents in decision-making processes. In one PICU a mother said, *"But I often felt like, who is the professional here? I was so involved while thinking, just do it"* [1:M], whereas in another PICU parents had different experiences, *"They just said this and this needs to be done. We were not asked for our opinion"* [7:M, F]. Many parents appreciated that nurses took the initiative to involve them in the care of their child. Parents did not experience difficulties in the 24 h accessibility. Some parents said that they could stay at night or sleep next to their child. In other cases, most parents did not mind leaving the PICU late evening.

Association between Themes

Although the six themes characterize separate areas of care, most of the themes seem to have an overarching relationship representing the continuum of a PICU admission (Figure 1). Several text fragments were coded with two or more subthemes belonging to more than one theme. The findings and description of the association between themes are detailed in Appendix 2 (Electronic Supplement Material).

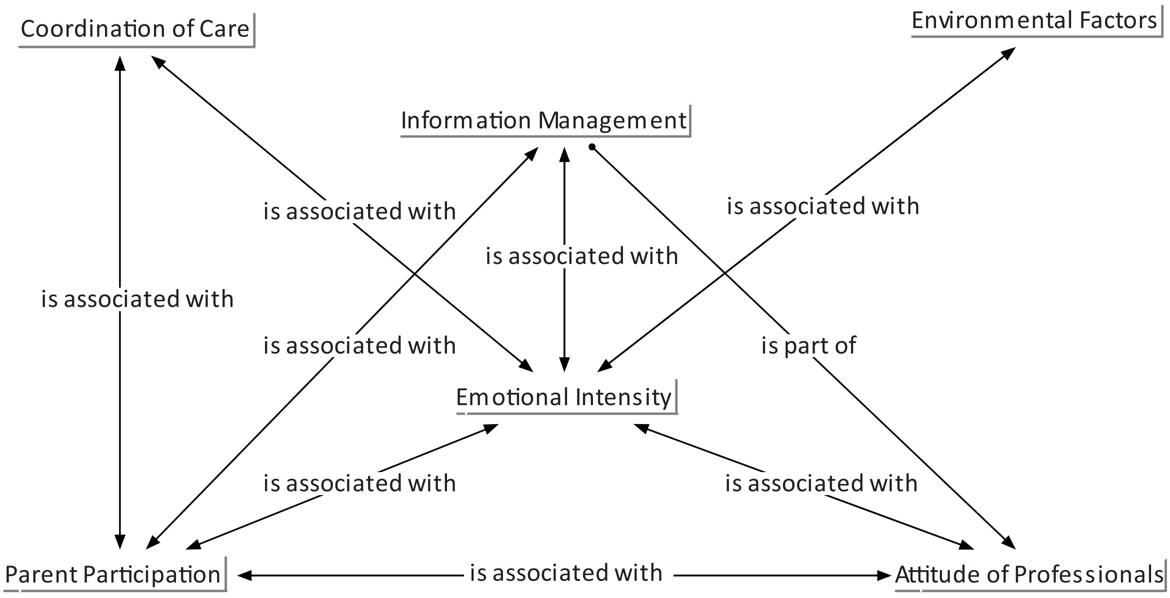

Figure 1 | Associations between themes

DISCUSSION

The major findings of this study are the 63 subthemes categorized into six major themes reflecting the PICU experiences of the parents. Some themes have been addressed in previous work, particularly 'emotional intensity'.[22] Staff communication has also been described as an influencing factor for distress among parents.[23,24] The findings of the present study provide a more thorough explanation of these concepts, for example by the association among the themes emotional intensity, information management, and professionals' attitudes. These associations replicate the complexity of PICU care where poor information provision might raise parents' stress, particularly when parents do not acknowledge empathic staff behavior. A similar association was identified from interviews with parents of children with severe antecedent disabilities in which communication and sympathy within the parent-professional relationship were frequently addressed.[25] Thus, the interaction between parents and professionals seems to be an important factor not only for parents of children with specific health care needs, but for all parents whose child needs intensive care treatment. Besides, from the interviews of the present study, it appears that themes like staff attitude, emotional intensity, and information management play a role from the onset of the admission till discharge. This finding was confirmed in a study exploring psychological outcome among 20 parents of children admitted to a PICU or to a pediatric ward. Interaction with the medical team was one of the three factors influencing poorer outcomes among PICU parents for the total duration of stay.[26]

The use of thematic analysis made it possible to generate an overall description of the PICU services and to analyze the parental stories in a wider concept. Parents often described their experiences of an event and were able to combine facts and emotions into a larger concept. The text fragments brought out evident relationships among several themes. Obviously, a PICU experience cannot be broken down in separate themes. A qualitative study interviewing six parents about their child's transition from the PICU to the pediatric ward revealed several theme clusters that were sorted into two categories: emotional response and organizational issues.[27] The narrative process of the themes showed that the transition created paradoxical feelings. On the one hand the parents were happy with the child's health improvement; on the other hand the change in environment led to negative feelings of anxiety or insecurity. The negative feelings were often related to stress due to poor communication and preparation. Using a transfer protocol might help to reduce the negative experiences and increase satisfaction with communication and information.[28] The association of the themes derived from the interviews in our study confirms that any intervention or action is related to many subjects that collectively fit into the overall care delivery and partnership with parents. Therefore, when implementing and evaluating new strategies we must take care to measure not only the content of the process, but also related influential aspects.

Partnership is based on mutual respect and responsibility.[29] Insights into the parents' experiences allow clinicians to tailor the care to the individual needs. In addition, various subthemes show similarities with the satisfaction-with-care items emerging from a large sample of parents (n = 559) who experienced a PICU admission and from other satisfaction instruments.[30-32] Therefore, the clinical relevance of the present findings can direct health care professionals toward the development of a satisfaction instrument.

A common critique of studies on parental experiences is the lack of views of fathers; they are either underrepresented or not represented at all.[7] While the aim of the present study was to gain a general understanding of the parents, no attempt was made to have an equal number of fathers and mothers. Whether this would influence the findings is debatable since no conflicting text fragments were observed in the interviews with parent couples. In contrast, two studies on stressors among fathers and mothers indeed revealed differences.[33-34] Fathers (n = 15) reported the 'tube in my child' as the highest specific source of stress[33], while mothers' (n = 31) most important stressors were 'injections' and 'watching heart rate on monitor'.[34] PICU admission remains stressful and may cause post-traumatic stress in both fathers and mothers.[35,36]

Most children in the study were mechanically ventilated for a median of 6 days; length of stay for the whole group was a median of 8 days. These durations are 4 to 5 days longer than those documented in PICU registries.[17,37,38] An explanation could be the period of data collection, which was during the winter months when generally more children are admitted with respiratory syncytial viruses requiring mechanical ventilation. This is also reflected in the relatively high number (n = 17, 42%) of respiratory diagnoses. Nevertheless, mechanical ventilation and severity of illness were not of overarching concern within the interviews.

The available evidence on parental experiences originates mainly from the USA and UK.[1,10] The findings of our study contribute to the body of knowledge of clinicians working in Dutch PICUs. Particularly the identification of several new subthemes might reflect the dynamic changes in socio-cultural contexts. For example, subthemes about safety, medications, and the influence of the media seem to be new areas that might influence parents to have other expectations. Whether these findings are only relevant for the Dutch PICUs is debatable. Future research is needed to examine the generalizability and transferability of these findings into clinical practice in other socio-cultural settings.

By design, a limitation of this study was the exclusion of non-Dutch speaking parents. Differences in cultural background might result in different parental expectations and experiences. However, experiences of Chinese parents in Hong Kong were comparable to those in the present study.[39] Specifically the role of nurses to support parental participation in care was recognized as valuable in both. Still, it is advisable to further study this issue. Another study limitation is the exclusion of parents whose child died in the PICU. Future research should examine bereaved parents as well because these parents might have different experiences and specific needs, and therefore their support should be directed to individual support and follow-up services.[40,41]

In conclusion, the findings of this interview study are a range of themes and subthemes providing insight into the complexity of the parental experiences of a PICU admission. The subthemes may provide groundwork for the development of items for an instrument measuring parental experiences and satisfaction with care. The clinical implications of the findings might be transferable to other PICUs to gain insight into understanding and collaboration between parents and health care professionals. Then, the momentous transitional PICU period might be less stressful both for the child and the parents.

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Appendix 1 (Electronic Supplement Material)

Method – Data Collection

The interviews were held within one month after PICU discharge. All interviews were conducted by one researcher (JML), a nurse with extensive PICU experience. The researcher had followed a university course on interview techniques and had previous qualitative research experiences. The interviewer had not developed a relationship with the parents while their child was admitted to the PICU and therefore the interviewer was anonymous to the parents. If parents would become distressed during the interview, upon agreement with the parents, the interviewer was to contact the responsible physician of the participating PICU to arrange follow-up service for the parents. An interview protocol was developed starting with an introduction section explaining the interview process to the parents. Parents were made aware that the interviewer had extensive PICU clinical experience. The next section started off with one open-ended question, 'Your child has been admitted to the PICU, how did you experience this?'. During the interviews in-depth questions were raised to expand the parent's stories such as 'What was it like for you?' or 'Can you tell some more about this situation?'. Field notes were taken to document (non-verbal) communications and observations. The interview protocol contained an evaluation section to obtain parents' demographic details and appreciation for their participation. Parents were asked if they would like to receive the text of the interview and provide comments afterwards. The interviews were audio-taped and transcribed ad verbum partly by the researcher (JML) and partly by a professional typist. The transcriptions were sent to 26 parents who wanted to receive the text. One parent provided textual changes and additional information.

Method – Data Analysis

Thematic analysis was deployed to identify subthemes and themes. This method is a step-by-step process focusing on the search of repeated patterns of meaning across the data sets. The transcribed interviews were uploaded in ATLAS.ti (version 5.5, Berlin), a workbench for qualitative data analysis. As a first step, two researchers (JML, BEL) read the interviews to familiarize themselves with the data. In the next step they independently formulated initial codes (subthemes) across the data. Then, the researchers together examined their defined codes till consensus was reached. Several codes were renamed or merged providing a deeper understanding of the phenomenon. The third step was collating and reviewing the codes to identify potential themes. The final step was the search for vivid extract examples relating back to the study aim. The rigor and credibility of the analysis was ensured by an auditor (JAH). The auditor provided constructive feedback till consensus was achieved on the text fragments, subthemes, and themes.

Table 4 | (Electronic Supplement Material) Quotations related to subthemes and themes

Themes/subthemes	**Quotations**
Attitude of Professionals	
Awareness of parental needs	*That a nurse really asked me how I felt.[11:M]*
Professionalism	*You just know that on that unit your child is well taken care of. They try everything possible to do their best. [9:M]*
Trust in safety	*If she (child) needs the PICU again, I would go with her again to this PICU. [21:M]*
Listening to advice of parents	The nurses ask also the parents how the child was at home, how the child reacts at home, how the child was before. So they asked our experiences of our child.[25:M]
Empathy	*Giving us a feeling of trust and not been treated like a number.[2:F]*
Interest in the child's needs	*Even when she was sedated those first days, what they did, they were always concerned… they were always asking, would you like a television set…[36:M]*
Attention to siblings	*And what I liked was that Maria (sister) was also welcome. [29:M]*
Attention to pain and comfort of the child	*She liked it to lay with the head and foot of the bed elevated and she could tell if she was comfortable and they (nurses) listened to her. [17:M]*
Being recognizable	*They were all very kind and they all introduced themselves by their name and who they were.[12:M]*
Psycho-social support	*They (nurses) asked me four times if everything was okay at my work or if there were any problems…indeed, they also thought about us. [41:M,F]*
Respect	*With all the emotions I still have, if I look back, about the human aspect towards us, yes, I found that we were treated with a lot of understanding. [29:F]*
Support in critical situations	*They should not have leave me alone there (waiting room), of course I understand that they had to go back but they could have send another nurse. [16:M]*
Feeling welcome	*We never had the feeling that our presence was too much. [34:M]*
Atmosphere in the PICU	*The nurses were very nice. We had a lot of fun at the PICU… we had a click with the nurses. [18:M]*
Commitment	*The doctors and nurses were dedicated. Of course it is not like we hug each other, I know this too. [6:M]*
Differences in approach	*It was different per nurse. One nurse started to explain directly while the other nurse you had to ask constantly.[41:M]*
Coordination of Care	
Transition PICU to pediatric ward	Because I had the idea that on this ward they had not any idea what exactly the problem was with Liza. [13:M]
Teamwork	*He (physician) tried to arrange three things within one day, a canula change, to the OR for a port-a-cath, and later on the chemotherapy. [6:M]*
Unequivocal work by professionals	*We did too many procedures of which she (nurse) did not expect we could… well one nurse gives you more room than the other. [8:F]*
Having a first responsible nurse	*Of course they tried to have the same face at the bedside and that was succeeded pretty well. [21:M]*

Themes/subthemes	**Quotations**
Difference between PICU and pediatric ward	*That was a weakness of the PICU, they did not…, well, the pediatric ward has no knowledge of trachea canula care. We can do it, but we are not at the ward 24 hours a day, so then there were daily phone calls between the PICU and the ward, and two ward nurses came to the PICU to learn about canula care. [35:M]*
Medical care	*A lot of doctors. At a certain moment you think yes there he comes and then you need to tell the story again. [37:F]*
Emotional Intensity	
First hours of admission	*At that time you are being lived. [26:F]*
PICU stay	*I do not dare to say…we can not bare anything anymore because there is always something happening. [15:F]*
Being in the dark	*That we were scared of how we would find him… there is this fear that stayed with you all the time. [20:M]*
Appearance of child	*If you come in the morning and see your child in bed, everything clean, than you think how wonderful. But we had mornings when she looked different, with secretion in her face, blankets all over the bed. [7:F]*
Seeing other children	*You see and know a lot of the other children in the unit. And then… yes things like that… if that's a child next to yours, it becomes reality.[7:M]*
Critical situations	*We were so scared that he needed to go back again on the dialysis machine or that he would get chronic renal failure. [15:F]*
Information giving	*And than we had a talk (with physician and nurse), and back in the hallway we said to each other, what did they say again. [29:M]*
Lack of clarity	*I had lots of worries like after New Year, another year ahead, without perspectives. [6:M]*
Sounds and lights appearance	*All these lights and alarm, they give so much impressions, even with your eyes closed. [11:M]*
Transition to the pediatric ward	*Yes those several transfers, these were stressful moments. Get used to new people an that sort of things.[11:F]*
Child's critical illness	*And that you almost know everything; her heart beat needs to be like that. So you think; this is not healthy at all. [29:M]*
Feeling powerless	*That we were scared of how we would find him… there is this fear that stayed with you all the time. [20:M]*
Child on mechanical ventilator	*I saw the ventilator on maximum support and he got an incident with his blood gas. Yes, your stress levels went sky high. [22:F,M]*
Hold on to family life	*You also loose your family, because we have another child at home. And everything continues like birthdays and so…Normally I am strong but this time I found it terrible [37:M]*
Leave child behind at the PICU	*I enjoyed it to go to my daughter, but I always cried when leaving. It just did not feel right to leave her alone at the unit. [31:M]*
Stories other parents	*There were parents in the Ronald McDonald House with also a child in the PICU. They told us all. I said, I do not want to go there anymore. [15:M]*
Information Management	
Timing of receiving information	*Plan more moments to tell how the situation is or what will happen, yes give a little more information in between. [17:M]*

Themes/subthemes	**Quotations**
Test and procedures	*Even in the evening they called us at home to tell the results of the tests. [1:F]*
Honesty	*The communication about how things are going I found a bit thin… you need to be open to people, at least this is my feeling. [15:F]*
Discharge planning	*There should be, in a leaflet or the like, some information on what to expect, like less intensive attention. [22:M]*
Written information and diary	They did not explain everything directly. I could read it in the information booklet. [24:M]
Completeness	*But factual information about the disease I have absolutely missed on the PICU… something like, he has this disease and what went with it. [38:M]*
Univocal	*Of course if they would all say the same. [17:M]*
Understandable	*Talk till we understand, they tried to speak German, yes. [3:M]*
Structural information provision	*Plan more moments to tell how the situation is or what will happen. [17:M]*
Preparation for PICU admission	*They invited to come to the PICU after surgery (first time) and I was well prepared what I would see, so it did not scare me. [16:M]*
Influence of media	*I watch TV (ICU soap series), but when it concerns your own child…that is different... you are nervous. [12:M]*
Medication	*There was an error with medication. You do not want to think about what could have happened. [29:F]*
Environment Factors	
Privacy of a single room	*The privacy is a piece of curtain in between two beds. You keep your voice down on such a unit, everybody did that, except the nurses. [37:F]*
Organization of PICU	*I found that strange at the beginning that I had to ring the bell to get in to the PICU. [29:M]*
Catering	*Coffee and tea and around 4.30 PM they ask if we want some soup. [8:M]*
Sound and light	*The only thing I found unpleasant, as far as I remember, was that the ladies and gentlemen talked rather loudly. [1:M]*
Waiting room	*You can go to the family room and relax within a home-look-alike atmosphere. [29:M]*
Parent Participation	
Involvement in treatment decision-making	*But I often felt like, who is the professional here? I was so involved while thinking, just do it because who am I to know about that medication? [1:M]*
Participation in child's care	*Little things, braiding her hair, lotioning her skin, brushing her teeth… these are the little things you can do and I found it very pleasant [36:M]*
Presence during test and procedures	*I just want to see how they cut the sutures and how they take the tube out [12:F]*
24 hours accessibility	*At night he (child) could not sleep. We could stay, but one can ask if this was a good thing to do or not. [2:F]*
Learning care procedures	*Suctioning the trachea canula… and the nurse said that I had to do it. She would stand next to me and see if I could to do it. [35:M]*

Themes/subthemes	**Quotations**
Transfer to and from PICU	*Well, they clearly discussed what we wanted, either transfer our child to a pediatric ward in the university hospital or to a hospital close to our home. We decided to go to the hospital close to our home. [34:M]*
Involvement during admission period	*We always said that whatever you have to do, do it. Surely you do not do things just for fun, it is necessary, so do it and we will hear it later what you have done. [19:M]*
Presence during rounds	*The doctors had the bedside round to discuss your child and in fact we wanted to be present to hear what they say, but this was not possible. [31:M]*

Appendix 2 (Electronic Supplement Material)

Results – Association between Themes

Although the six themes characterize separate areas of care, most of the themes seem to have an overarching relationship representing the continuum of a PICU admission (Figure 1). Several text fragments were coded with two or more subthemes belonging to more than one theme. The theme 'emotional intensity' in particular was associated with all other themes. An example is a fragment bringing together the themes 'emotional intensity', 'attitude of professionals', and 'environmental factors': *"and then he returned to the ICU. He was warmly welcomed, but we were terrified that he had to go back on the dialysis machine…He had yellow eyes, yellow skin and you would not see that on the ICU, artificial light you know… I said immediately he has yellow eyes. The next one came and I said John has yellow eyes. Yes, we learned that; never rely on one person, always three different persons. Everybody who comes to the bedside will be told, always three different persons, because there is always one who picks it up and does something with it."* [15: F, M]. In this case the parents were anxious about their child's health and were less confident about the professional's attitude to act adequately. At the same time they thought that artificial lighting could mislead staff in observations.

'Information management' was related to all themes except 'environmental factors'. While the complexity of the PICU care needs to be discussed with parents, the professionals' approach influences their sentiment. Timely information provision seems a basis for trust, satisfaction and reduces stress levels of the parents, as documented by: *"You hear this later. Like why he is not intubated yet, why the medication has not yet started… And why do we need to be informed like we need to agree or not? At that time I had some difficulty with it… We waited over one hour in the parent room, then you miss some personal attention… they first ask if we want coffee and then 45 minutes nothing."* [9:F, M].

The roles of physicians and nurses were constantly interwoven within several themes, whereas information management seemed to be part of, and not associated with, the attitude of the professionals. Most subthemes within the 'attitude of professionals' theme were related to non-verbal communication and behavior skills whereas the subthemes within 'information management' basically were related to what, how, and when the information was provided. A father documented this assumption as: *"what I experience is that the nursing staff is very clear, but physicians they come, you do not understand what they are saying, they do not introduce themselves…"* [10:18F].

From all interviews emerged only one association between the themes 'environmental factors' and 'emotional intensity. This was related to the association of the privacy of a single room and the freedom to express emotions.

CHAPTER 8

Construction of a parent satisfaction instrument: Perceptions of pediatric intensive care nurses and physicians

Jos M. Latour, Jan A. Hazelzet, Hugo J. Duivenvoorden, Johannes B. van Goudoever

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ABSTRACT

Purpose: The aims of the study were (1) to identify parental satisfaction items through the opinions of pediatric intensive care (PICU) nurses and physicians, (2) to reach consensus on the identified items, and (3) to apply factor analysis to evaluate the items and domains toward a PICU parental satisfaction instrument.

Materials and Methods: Pediatric intensive care unit nurses and physicians working in 8 university hospitals in the Netherlands participated. A 2-round Delphi method was completed. Confirmatory factor analysis was performed on the satisfaction items and domains.

Results: Three hundred two nurses and 62 physicians participated in the Delphi study, and 269 (76%) completed 2 questionnaire rounds. In Delphi round 2, 14 of the 78 items had a mean of less than 8.0 (range, 1 [low importance] to 10 [high importance]). The interquartile range of all domains decreased almost half, and only 10 satisfaction items had a heterogeneity of less than 70%. Structure determination revealed that 4 satisfaction items needed to be excluded. Out of 74 satisfaction items, 72 showed factor loadings greater than 0.50. The reliability estimates, Cronbach's α, for the six domains varied from 0.74 to 0.92.

Conclusions: Priorities in parental satisfaction measures are identified. The findings are fundamental in the development of a PICU parental satisfaction instrument.

INTRODUCTION

Hospitals are increasingly pressured by patient organizations and health care authorities to document the delivered care. Demanding accountability for increasing health care costs, the public in general looks closely into efficiency and effectiveness of hospital care. In the past decades, quality of care received much attention in healthcare. However, the American Institute of Medicine (IOM) identified 6 areas in today's health care system that are still below standard: safety, effectiveness, timeliness, patient-centeredness, efficiency, and equity.[1] The challenge is to place patients in the center of care and to empower them towards more autonomy. Most children in the pediatric intensive care unit (PICU) are unable to express their needs and experiences. In this perspective, the experiences of parents are recognized to be fundamental for quality of care.[2,3] Principles of family-centered care mandate incorporation of parents in daily care.[4] Subsequently, measures of parent satisfaction may be a valuable tool in establishing a family-centered driven care model that would benefit quality of care.

Although the interest in patient satisfaction with care started a few decades ago, the current debate concerns methodological issues and the value of satisfaction data for quality improvement.[5] In addition, patient satisfaction data should enable us to identify core strategies improving care delivery.[6,7]

In pediatric critical care the long-established and accepted evaluation measures refer to clinical parameters such as mortality, length of stay, and severity of illness. A measure like parental satisfaction is not yet widely recognized in medicine, but is gradually being accepted as a quality performance indicator.[8,9] Yet, a satisfaction performance indicator requires profound development before the data are recognized and accepted as valid and reliable.[10] Despite the existence of many patient satisfaction surveys, only 1 validated parent satisfaction questionnaire is known specifically for PICU.[10] The current general satisfaction questionnaires may not be relevant to PICU since parents might experience difficulties in separating the specific PICU care within the general satisfaction items.

All 8 PICUs in the Netherlands identified parental satisfaction as an important quality performance indicator. A multi phase project was designed to establish a reliable and validated parent satisfaction instrument. The initial phase was directed toward the current available evidence and the perceptions of the healthcare professionals working in the PICUs. The findings of this phase will be used for further exploration of the parental perceptions on the satisfaction items in the next phase of this multi-center project. Both projects should eventually result in a validated parent satisfaction instrument for the Dutch PICUs.

The main objective of the multicenter study is to develop a parent satisfaction instrument for the PICUs in the Netherlands. Specifically, the objectives of this phase are (1) to assess parental satisfaction measures based on the perceptions of PICU health care professionals, (2) to reach consensus on the satisfaction items for further exploration among a large group of parents, and (3) to perform factor analysis to evaluate the satisfaction items and domains.

MATERIAL AND METHODS

We used a multiphase design. The first phase concerned the identification and selection of satisfaction performance indicators to be included in a preliminary questionnaire. The second phase encompassed a 2-round Delphi method (Figure 1). This method is a technique of systematically consulting a panel of experts, and of collecting, evaluating and tabulating their opinions without bringing them physically together.[11,12] Its specific characteristics are anonymity, iteration, controlled feedback, and statistical group response.[13] Anonymity of the panel members is achieved through the use of questionnaires. Panel members are thus free to express their own opinion without being pressed by other dominant individuals. Iteration is provided by presenting questionnaires over a certain number of rounds. Controlled feedback and statistical group response take place between the rounds, when results from the previous round are analyzed and communicated back to the participants.

Approval for the study was granted by the Medical Ethical Committee of the Erasmus Medical Center. A signed consent form of the participants was not required by the Medical Ethical Committee.

Participants

There are 8 multidisciplinary level III PICUs in the Netherlands; all units are tertiary referral centers with invasive ventilation, multi-system failure, and other complex procedures and interventions. Yearly total admission rate is around 4500 children between 0 and 18 years of age. The total number of beds per PICU ranges from 9 to 24 beds. The medical and nursing directors agreed to the participation of their PICU staff and provided lists of nurses and physicians. In total, 520 professionals (physicians, n=87; nurses, n=433) were eligible to participate as experts in the Delphi panel. Inclusion for participation was defined as follows: for physicians, being a pediatric-intensivist or a fellow; for nurses, as being a PICU certified nurse or student nurse in training for PICU certification.

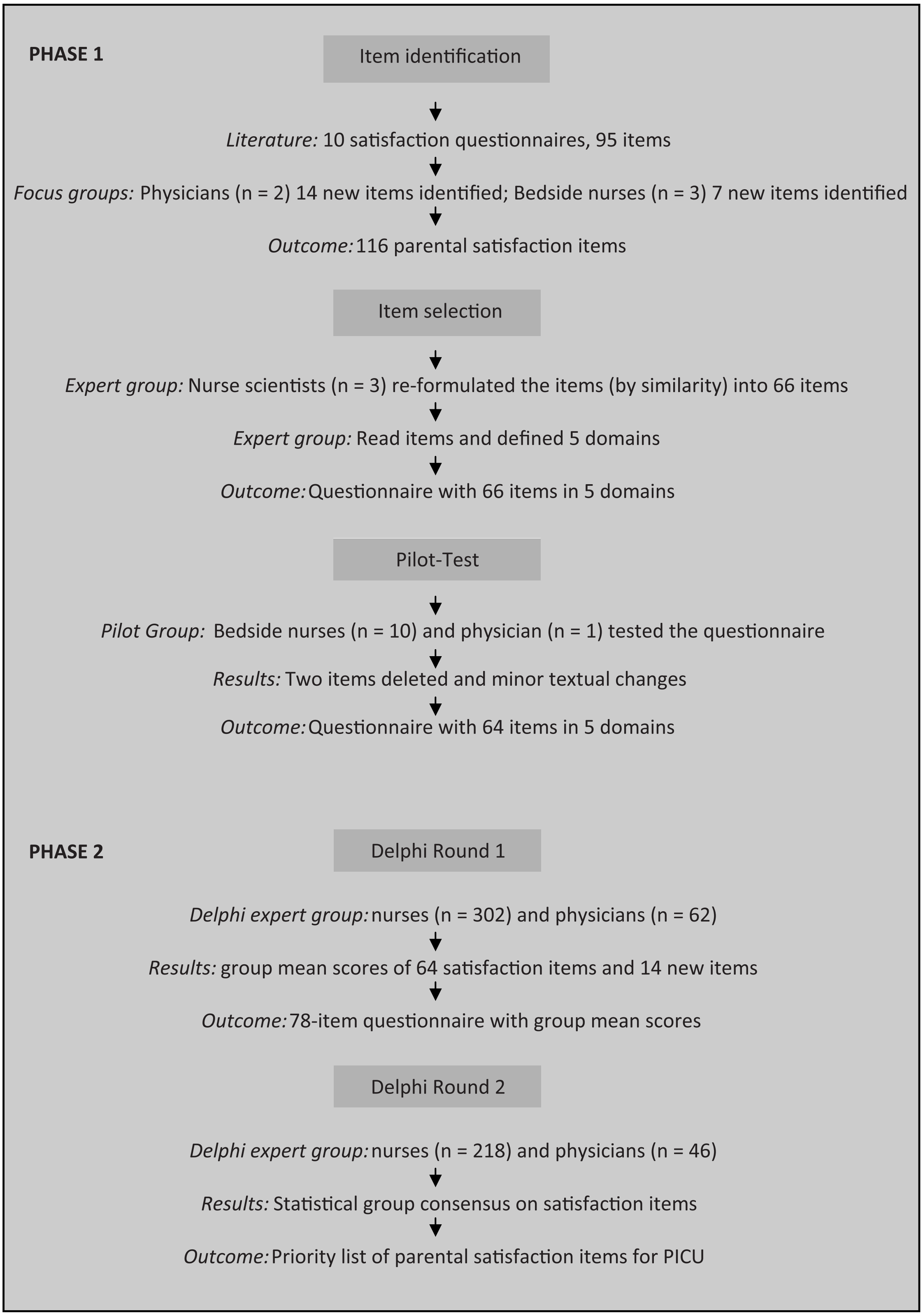

Figure 1 | Process development questionnaire for the Delphi rounds

Questionnaire development

The questionnaire for the Delphi rounds was developed in a 3-step process as summarized in Figure 1. Step 1 was item identification: A literature search revealed 10 satisfaction surveys related to pediatric, neonatal, and adult intensive care and to general pediatrics. A total of 95 unique satisfaction items were identified from these surveys.[7] Further item identification was done by unstructured focus group sessions, one with physicians (n=2) and one with nurses (n=3). Each session started with the open-ended question: What do you think parents find important in the care? At the end of the session, participants were asked to identify domains to categorize the care aspects they had put forward. Audiotapes were used for transcription. The transcripts were coded into text fragments reflecting distinctive care aspects and compared with the 95 unique satisfaction items from the literature review by 2 researchers (JL, JH). This process resulted in 21 new items. Step 2 was item selection. In an expert group session, 3 nurse scientists reviewed the items on content and similarities. Several items were merged or reformulated and consensus on conclusion was achieved via group discussion of the nurse scientists. Item selection thus resulted in 66 remaining items. The expert group defined and reached consensus on 5 domains and the groupings of the items into the domains based on similarities of the construct of the 66 formulated satisfaction items. In the third step, the questionnaire was pilot tested with a sample of 10 bedside nurses and 1 physician to assess content validity. Based on their feedback, 2 items were deleted, resulting in 64 satisfaction items; and some minor textual changes were made.

Delphi Round 1

In April 2006, an invitation, explaining the design and the 2 questionnaire rounds, was sent to the participants. The 64-item questionnaire was enclosed, including demographic information such as sex, age, location of PICU, profession, period of PICU working experience, and period of working experience as professional in general. The respondents were asked to rate each item on a visual analogue scale, ranging from “completely unimportant” to “extremely important”, discretized into 10 equal intervals. An open-ended question offered the opportunity to provide additional issues. Participants were presumed to give informed consent by returning the questionnaire.

Although participants were asked to provide their names and PICU locations, so as to ensure they could be sent the second questionnaire, the returned questionnaires were coded to warrant anonymity of the data.

Delphi Round 2

After completion of round 1, the group mean for each of the items was calculated and added to these items in the questionnaire for round 2. In the first round, 53 suggestions were made in response to the open-ended question. Two authors (JL, JH) reviewed these data and thereupon emended 1 existing item and formulated 14 new items, resulting in the round 2 questionnaire with 78 items. This time, the rating scale was a 10-point scale ranging from 1, completely unimportant, to 10, extremely important. In July 2006 the participants received the second invitation letter, explaining the purpose of the second Delphi round, and the questionnaire. The participants were asked to review the items with the additional group mean information. Factor analysis was performed with the empirical data of the study to evaluate the items and the domains of the instrument.

Statistical Analysis

Descriptive statistics were used to analyze the demographic variables. Mean scores were calculated for Delphi round 1 to provide a group mean for the second round. Mean and standard deviation were used for ranking the importance of the statements. Importance was defined as the highest mean and the smallest standard deviation. The responses of the panel members carried equal weight. Therefore, the median and interquartile range scores of the five domains were calculated to compare the distribution of the variables between the 2 rounds to provide a level of agreement. For the 2 Delphi rounds, the differences between nurses and physicians were tested by a 2-way analysis of variance for repeated measurements on each outcome variable separately.

The empirical data of round 2 were subjected to factor analysis to identify and estimate the dimensional structure and the importance of individual items within that structure. It was not the explorative factor analysis that was applied but, more interestingly, the confirmatory factor analysis (CFA). The reason is that explorative factor analysis does not enable statistical testing, whereas CFA, in addition to possibilities of statistical testing, is flexible in the sense that factors are allowed to be intercorrelated. Furthermore, CFA enables to fix variables on certain factors. These variables are usually considered to be of high salience of the pertinent factors. The loadings can be tested in term of statistical significance level. The adequacy of model fit can be tested on statistical plausibility. The relevant performance measures applied in this study were the χ^2 test of model fit and the χ^2 test of model fit for the baseline model. The value of χ^2, its *P* value, and the number of degrees of freedom (*df*) were examined. A nonsignificant *P* value corresponding to the χ^2 test of model fit is indicated ($P > .05$). The ratio of χ^2/df less than 1.5 would represent a good model fit. Four other tests of model fit were used: comparative fit index (ideally > 0.95), Tucker-Lewis index (ideally > 0.95), root mean square error of approximation (ideally ≈0.05), and the weighted root mean square residual (ideally < 1.00).[14] Finally, CFA enables to analyze nonmetric, in casu ordinal variables and skewed variables. In this study, the ordinal approach was applied.

All data were analyzed using the Statistical Package for the Social Sciences (version 12; SPSS, Chicago, IL) and the software program M*plus*, statistical modeling program (version 5, 2007; Muthén and Muthén, Los Angeles, CA).

RESULTS

Of all 520 nurses and physicians invited to participate in the Delphi study, 364 (70%) returned the questionnaire, that is 302 of 433 (70%) nurses and 62 of 87 (71%) physicians. As 9 questionnaires had been returned anonymously, the second Delphi round involved 355 eligible participants. The overall response was now 269 of 355 (76%), that is, 218 of 293 (74%) nurses and 46 of 62 (74%) physicians. Five were returned anonymously. The demographic characteristics of the health care workers for both Delphi rounds are presented in Table 1. Their ages ranged from 23.0 to 60.0 years. Most respondents were female. In both Delphi rounds, the PICU experience ranged from 0.5 to 31.0 years; general experience was from 0.5 to 38.0 years.

Table 1 | Characteristics of the PICU health care professionals

	R1	**R2**	
	response (n = 364)	**response (n = 269[a])**	**non-response (n = 100 [b])**
Sex (F/M)	281/83	202/62	79/21
Age (y; $\hat{\mu}$, $\hat{\sigma}$)	38.7 (7.34)	38.6 (7.28)	38.8 (7.55)
Profession (nurse/physician)	302/62	218/46	84/16
Experience PICU (y; $\hat{\mu}$, $\hat{\sigma}$)	8.4 (6.50)	8.4 (6.30)	8.5 (7.03)
Experience overall profession (y; $\hat{\mu}$, $\hat{\sigma}$)	17.5 (8.41)	17.6 (8.45)	17.0 (8.32)

R1 indicates round 1; R2 indicates round 2; F, female; M, male; $\hat{\mu}$ =mean; $\hat{\sigma}$ =standard deviation; [a]Missing: 5; [b]Including 5 missing.

Delphi rounds

The satisfaction items were categorized in 5 domains, that is, (1) Information, (2) Care and Cure, (3) Organization, (4) Parental Participation, and (5) Professional Attitudes. The scores for these domains in both Delphi rounds are visualized in the Box-whisker plots (Figure 2). The horizontal bars in the boxes represent the median scores of the domains; it appears they all exceed 8, in both rounds. In round 2, however, the medians of all domains are lower than in round 1. The plot shows smaller interquartile range for every domain in round 2. This reflects reduced data heterogeneity, which can be easily seen as smaller box sizes. The differences between the ends of the whiskers reflect the observed range of the data; and it is worthwhile to note that the range of all domains in round 2 decreases, particularly in the domains Organization and Parental Participation. The domains Care and Cure and Professional Attitude have the highest median values. The conclusion seems justified that the panel members satisfactorily agree on the items.

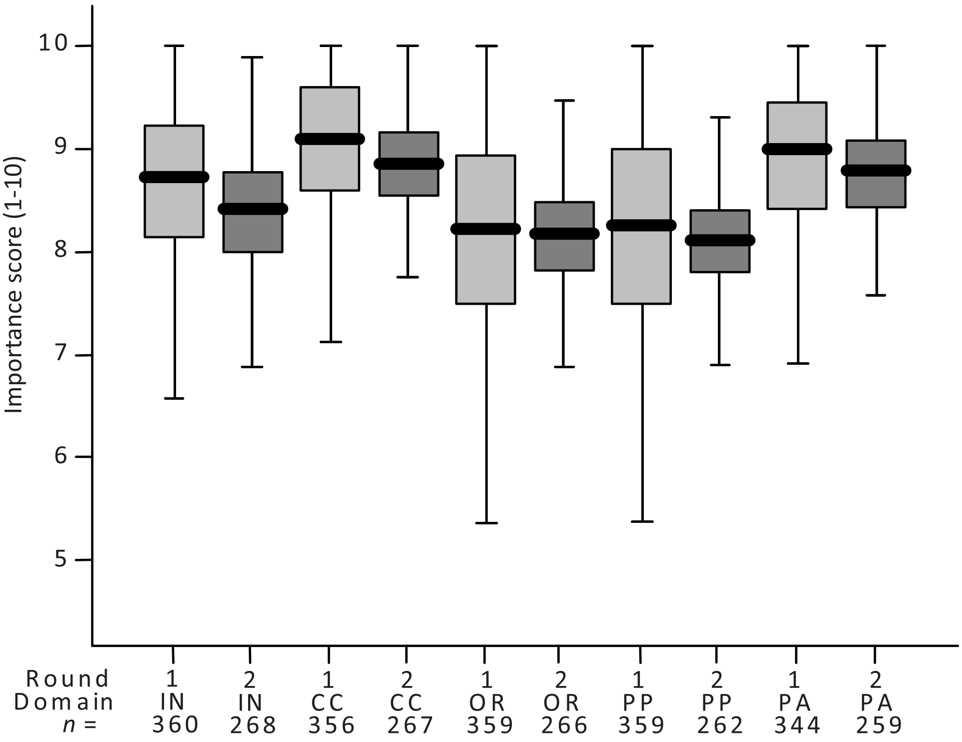

Figure 2 | Importance of the domains Rounds 1 and 2

IN indicates Information; CC, Care and Cure; OR, Organization; PP, Parental Participation; PA, Professional Attitude.

The average scores of the satisfaction items were fairly high. This was not unexpected. Table 2 ranks the items per domain based on the smallest standard deviation of the second round. The standard deviations reflect the heterogeneity of the respondents' perceptions. Mean scores for 14 of 78 (18%) items were below 8, the cut-off point, in both rounds. Note that the standard deviations of these items between the rounds decreased but remain greater than 1.0 at rather low heterogeneity, implying diverging opinions among the experts. Only the domain Cure and Care had high mean scores of greater than 8.0 with standard deviations remaining less than 0.96. The item about the child's pain prevention and treatment had the highest mean score (9.55) and the smallest standard deviation (0.70) in the first round, remaining almost identical in the second round. The high scores for the items in this domain can be ascribed to the primary goal of health care professionals and a high priority given to care aspects in their daily work. This is in contrast with the domain Parental Participation, with 3 of the original 8 items in round 1 retaining mean scores less than 8.0. Surprisingly, the item about providing a diary to parents was given the lowest score in both rounds. In all PICUs in the Netherlands, providing diaries to parents is meanwhile common practice; and maybe, consequently, this item was not rated as very important. Physicians and nurses seem to report their professional attitude as important for the care and satisfaction of parents. Half of the items in this particular domain scored a mean of at least 9.0. Only their attitude toward attention to siblings seems to be less important.

Compared with round 1, in round 2, the heterogeneity in terms of the standard deviation of the 64 items used in both rounds remained at least 70%. In general, between 1 to 5 items per domain showed a heterogeneity less than 70%. Only for 1 domain, Cure and Care, were all items above the standard level. These results can reasonably be accepted as expressing high agreement among the health care professionals on most of the satisfaction items.

Table 2 | Ranking items in domains based on smallest standard deviation of round 2

Rank	Domain and Item	mean		SD		Hetero-geneity[a]
		R1	R2	R1	R2	(%)
Information						
1	Parents are informed about the child’s illness	9.38	9.35	0.87	0.69	79
2	Parents are informed about tests and procedures	9.19	9.22	0.97	0.71	73
3	Caregivers give no conflicting information to the parents	9.37	9.36	1.04	0.75	72
4	Parents have easy access to information	8.89	8.74	1.07	0.75	70
5	Caregivers answer parents’ questions adequately	9.36	9.30	0.90	0.77	86
6	Caregivers inform the parents about the treatment consequences	9.10	9.15	1.01	0.78	77
7	Parents are informed about changes in the child’s condition as soon as possible	9.26	9.26	1.01	0.80	79
8	Caregivers’ communication with non Dutch speaking parents is through an interpreter or the interpreter-telephone	NA	8.97	NA	0.99	NA
9	Parents are informed about the child’s future perspectives	8.92	8.74	1.17	1.00	85
10	Parents are informed about PICU rules	8.43	8.36	1.32	1.04	79
11	The way to the PICU is clearly signposted	8.25	8.07	1.46	1.09	75
12	Parents are informed about the (adverse) effects of the medication	7.92	7.81	1.51	1.10	73
13	Caregivers daily inform parents about the child’s care and treatment	8.71	8.42	1.44	1.18	82
14	Parents are informed about sanitary units	6.96	6.83	1.92	1.41	73
15	Caregivers inform the parents on the best moment for the parents	NA	6.95	NA	1.54	NA
16	Caregivers provide not only oral but also written information	NA	6.72	NA	1.55	NA
17	Parents are informed of visiting hours for other family members	7.03	7.21	2.47	1.68	68
Care and Cure						
1	Caregivers are alert to the child’s comfort	9.38	9.37	0.76	0.62	82
2	Caregivers react promptly to changes in the child’s condition	9.43	9.47	0.88	0.63	72
3	Caregivers know their profession	9.55	9.55	0.73	0.64	88

Rank	Domain and Item	mean		SD		Hetero-geneity[a]
		R1	R2	R1	R2	(%)
4	Pain is prevented and/or treated	9.59	9.54	0.70	0.64	91
5	Caregivers work with a team spirit	9.09	9.03	0.97	0.69	71
6	At discharge, caregivers provide clear information to colleagues	9.22	9.15	0.91	0.70	77
7	Caregivers jointly pursue one goal: adequate care and treatment of child and parents	9.28	9.33	0.83	0.70	84
8	Caregivers are aware of the child's medical history	8.98	8.89	0.95	0.72	76
9	Caregivers provide emotional support	8.96	8.79	0.99	0.77	78
10	Caregivers display a caring attitude towards child and parents	8.97	8.81	0.94	0.79	84
11	The correct medication is given at the right time	9.01	8.92	1.00	0.79	79
12	An assigned physician and nurse serve as contacts for parents during prolonged ICU-stay	NA	9.02	NA	0.86	NA
13	Parents know which physician and nurse are responsible for the care of their child	8.77	8.67	1.09	0.87	80
14	Parents are adequately prepared for the child's discharge	8.71	8.52	1.20	0.90	75
15	Caregivers are alert to the child's developmental growth	8.53	8.41	1.10	0.91	83
16	Caregivers adequately meet the needs of the parents	8.56	8.32	1.03	0.93	90
17	Caregivers prepare child and parents to a PICU admission	8.51	8.45	1.27	0.94	74
18	Caregivers are considerate to the child's wishes	8.48	8.34	1.16	0.95	82
19	A caregiver always advices parents during acute admission or an acute situation	NA	8.32	NA	1.07	NA
20	Parents realize they cannot always have a caregiver's immediate attention	NA	8.35	NA	1.15	NA
Organization						
1	The caregiver are efficiently organized	8.84	8.74	1.05	0.69	66
2	The PICU is well accessible by phone	9.09	9.08	0.99	0.74	75
3	The PICU is clean	8.93	8.83	1.10	0.82	75
4	The child's bed space is amply enough	8.84	8.74	1.11	0.87	78
5	Noise in the PICU is muffled as far as possible	8.50	8.44	1.25	0.89	71
6	The PICU is imbued with a sense of safety	8.49	8.34	1.17	0.94	80
7	The PICU's design is child-friendly	8.23	8.19	1.41	0.96	68
8	The child's bed is clean	8.20	8.33	1.43	0.98	69
9	Written information on unit rules, diseases and procedures are available on the PICU	NA	8.60	NA	0.99	NA
10	Moment of discharge is not influenced by bed capacity	8.13	8.11	1.55	1.00	65
11	The waiting room is fitted out comfortably	7.57	7.49	1.57	1.11	71
12	The PICU has comfortable furniture	7.59	7.56	1.55	1.13	73
13	Aggression by parents or caregivers is not tolerated on the PICU	NA	9.16	NA	1.16	NA
14	Visiting hours are flexible	8.01	8.05	1.69	1.17	69
15	Rooming-in near the PICU is possible	NA	8.22	NA	1.25	NA

Rank	Domain and Item	mean		SD		Hetero-geneity[a]
		R1	R2	R1	R2	(%)
16	Catering for parents is well taken care of	6.73	6.69	1.96	1.43	73
17	A locker on the PICU is available for all parents	6.82	6.63	2.14	1.50	70
Parental Participation						
1	Parents trust the caregivers	9.35	9.28	0.84	0.71	85
2	Caregivers facilitate parents in expressing their feelings	8.35	8.16	1.41	0.90	64
3	Caring aspects are discussed before discharged	8.54	8.48	1.30	0.91	70
4	Parents show respect to the caregivers	NA	8.59	NA	1.00	NA
5	Caregivers regularly inform after parental experiences during the course of admission	8.31	8.10	1.30	1.01	78
6	At admission, caregivers ask parents their expectations	7.59	7.41	1.77	1.03	58
7	Caregivers stimulate the parents to be close to their child	8.46	8.24	1.30	1.05	81
8	Parents share in the decision-making on the care and treatment of their child	7.96	7.63	1.74	1.24	71
9	Parents receive and are suggested to keep a diary	7.21	7.17	1.83	1.32	72
10	Caregivers stimulate parents to stay close to their child during procedures and tests	NA	7.79	NA	1.38	NA
Professional Attitude						
1	Caregivers adopt principles of hygiene	9.37	9.35	0.87	0.63	72
2	Caregivers provide equal care; irrespective of race, religion, sex, and education	9.40	9.49	0.91	0.63	69
3	Caregivers safeguard privacy of child and parents	9.02	9.00	1.02	0.72	71
4	Caregivers respect the child and parents	9.31	9.24	0.91	0.74	81
5	Caregivers always work agreeably together	9.14	9.05	0.94	0.79	84
6	Caregivers refrain from unnecessary discussions at the child's bedside	9.03	9.06	1.20	0.84	70
7	Caregivers give the highest priority to the child's health	NA	9.25	NA	0.87	NA
8	Child and parents feel welcome at admission	8.97	8.79	1.21	0.92	76
9	Caregivers show empathy to child and parents	8.40	8.30	1.28	0.92	72
10	Parents are offered religious / spiritual support	8.13	8.18	1.37	0.93	68
11	Caregivers introduce themselves with name and position	8.66	8.57	1.23	0.99	80
12	Regardless the work pressure, the caregiver's attention towards child and parents is not allowed to slacken	NA	8.35	NA	1.04	NA
13	Caregivers are alert to the cultural background of the child and parents	NA	8.11	NA	1.07	NA
14	Caregivers pay attention to siblings	7.98	7.94	1.58	1.14	72

Scores were rated on a 10-point scale from "completely unimportant" to "extremely important".
NA indicates not applicable; SD, standard deviation; [a] $SD_{R2} / SD_{R1} \times 100$.

The differences of the scores of the domains between the nurses and the physicians are presented in Tables 3 and 4. The results showed that overall the opinions of the nurses differed significantly from the physicians on all domains. The changes between round 2 compared to round 1 was significant for 3 domains; Information, Care and Cure, and Organization. The mean scores of the domains in round 2 appeared to be consistently lower than in round 1, except for the domain Organization. The trend is that nurses scored higher than physicians in all domains in both rounds. The magnitude of the differences between the nurses and the physicians was the greatest for the domain Information followed by the domain Parental Participation. The smallest effect size in terms of Cohen's d is observed in the domain Professional Attitude.

Table 3 | Level and dispersion of the domains in round 1 and round 2 categorized to type of professional

Domain	R1				R2				ES
	Nurs (n=302)		Phys (n=62)		Nurs (n=218)		Phys (n=46)		
	mean	SD	mean	SD	mean	SD	mean	SD	
Information	8.70	0.79	8.43	0.76	8.46	0.57	8.08	0.58	0.67
Care and Cure	9.08	0.67	8.76	0.74	8.92	0.48	8.72	0.57	0.41
Organization	8.19	0.95	7.85	0.96	8.26	0.59	8.01	0.64	0.42
Parental Participation	8.30	1.03	7.80	1.22	8.17	0.67	7.76	0.80	0.59
Professional Attitude	8.91	0.81	8.70	0.87	8.81	0.55	8.61	0.56	0.37

Nurs, indicates nurses; Phys, physicians; ES, Cohen d; SD, standard deviation

Table 4 | Statistical testing

Domains	Change R1 – R2			Type Profession					
	A			B			A x B		
	F	*df* [a]	P	F	*df*	P	F	*df*	P
Information	29.41	1;260	.000	11.11	1;260	.001	1.07	1;260	.31
Care and Cure	4.80	1;256	.03	9.06	1;256	.01	1.66	1;256	.20
Organization	3.35	1;258	.07	6.64	1;258	.02	0.50	1;258	.48
Parental Participation	1.20	1;259	.28	13.23	1;259	.000	0.44	1;259	.51
Professional Attitude	2.51	1;243	.12	4.17	1;243	.05	0.01	1;243	.93

Two-way analysis of variance for repeated measurements.

[a] Degree of freedom (denominator) less than 260 implies missing.

Determination of dimensional structure for the satisfaction items

The structure determination of the individual domains revealed that 4 satisfaction items needed to be deleted: (1) parents are informed of visiting hours for other family members, (2) parents realize they cannot always have a caregiver's immediate attention, (3) aggression by parents or caregivers is not tolerated on the PICU, and (4) parents show respect to the caregivers. The domain Information turns out to be 2-dimensional (Table 5). The first dimension "Care Issues" is characterized by items such as parents are informed about the child's illness and caregivers informing the parents about the treatment consequences. Examples of items belonging to the second dimension "Accessibility" are parents having easy access to information and caregivers providing not only oral but also written information. Briefly, despite the fact that the model fits of most domains are weak (Table 6), it has to be stressed that the standardized factor loadings are discernible (Table 5).

Table 5 | Standardized factor loadings and reliability estimates for individual items

Items and Domains	**Factor loadings**	**Corrected item-total correlation**	**Cronbach α if item deleted**
Information – Care			
Caregivers answer parents' questions adequately.	0.81	0.66	0.86
Caregivers give no conflicting information to the parents	0.70	0.54	0.87
Parents are informed about changes in the child's condition as soon as possible	0.77	0.59	0.86
Parents are informed about the child's illness	0.84	0.69	0.86
Caregivers inform the parents about the treatment consequences	0.96	0.76	0.85
Parents are informed about tests and procedures	0.90	0.75	0.85
Parents are informed about the (adverse) effects of the medication	0.70	0.57	0.87
Parents are informed about the child's future perspectives	0.70	0.63	0.86
Information – Accessibility			
Caregivers daily inform parents about the child's care and treatment	0.59	0.38	0.72
The way to the PICU is clearly signposted	0.61	0.47	0.71
Parents have easy access to information	0.83	0.54	0.71
Parents are informed about sanitary units	0.62	0.58	0.68
Parents are informed about PICU rules	0.55	0.44	0.71

Items and Domains	**Factor loadings**	**Corrected item-total correlation**	**Cronbach α if item deleted**
Caregivers inform the parents on the best moment for the parents	0.41	0.36	0.73
Caregivers provide not only oral but also written information	0.48	0.43	0.72
Caregivers' communication with non Dutch speaking parents is through an interpreter or the interpreter-telephone service	0.64	0.40	0.72
Care and Cure			
Caregivers work in team with a strong group cohesion	0.67	0.55	0.92
Parents are adequately prepared for the child's discharge	0.76	0.68	0.91
At discharge, caregivers provide clear information to colleagues.	0.67	0.52	0.92
Pain is prevented and/or treated	0.76	0.54	0.92
Caregivers know their profession	0.66	0.47	0.92
The correct medication is given at the right times	0.55	0.47	0.92
Caregivers are aware of the child's medical history	0.63	0.51	0.92
Caregivers are alert to the child's developmental growth	0.72	0.63	0.91
Caregivers react promptly to changes in the child's condition	0.75	0.57	0.92
Caregivers are considerate to the child's wishes	0.73	0.66	0.91
Caregivers prepare child and parents for a PICU admission	0.73	0.65	0.91
Caregivers jointly pursue one goal: adequate care and treatment of child and parents	0.76	0.62	0.92
Caregivers are alert to the child's comfort	0.79	0.64	0.92
Parents know which physician and nurse are responsible for the care of their child	0.73	0.64	0.91
Caregivers provide emotional support to child and parents	0.87	0.70	0.91
Caregivers adequately meet the needs of the parents	0.85	0.71	0.91
Caregivers display a caring attitude toward child and parents	0.80	0.68	0.91
A caregiver always advises parents during acute admission or an acute situation	0.58	0.51	0.92
An assigned physician and nurse serve as contacts for the parents during prolonged ICU-stay	0.61	0.50	0.92
Organization			
The PICU has comfortable furniture	0.75	0.64	0.87
The PICU is imbued with a sense of safety	0.77	0.67	0.87

Items and Domains	**Factor loadings**	**Corrected item-total correlation**	**Cronbach α if item deleted**
Moment of discharge is not influenced by bed capacity	0.52	0.42	0.87
The waiting room is fitted out comfortably	0.78	0.69	0.86
The child's bed is clean	0.59	0.45	0.87
The PICU's design is child-friendly	0.72	0.63	0.87
The caregivers are efficiently organized	0.64	0.48	0.87
The PICU is well accessible by phone	0.68	0.54	0.87
Visiting hours are flexible	0.53	0.40	0.88
The child's bed space is amply enough	0.69	0.56	0.87
Catering for parents is well taken care of	0.60	0.57	0.87
A locker on the PICU is available for all parents	0.59	0.54	0.87
The PICU is clean	0.63	0.48	0.87
Noise in the PICU is muffled as far as possible	0.71	0.59	0.87
Written information on unit rules, diseases and procedures is available on the PICU	0.62	0.49	0.87
Rooming-in near the PICU is possible	0.50	0.42	0.88
Parental participation			
Caregivers facilitate parents in expressing their feelings	0.78	0.69	0.86
At admission, caregivers ask parents their expectations	0.73	0.68	0.86
Parents receive and are suggested to keep a diary	0.73	0.67	0.86
Caregivers regularly inform after parental experiences during the course of admission	0.86	0.75	0.86
Parents share in decision-making on the care and treatment of their child	0.70	0.63	0.87
Caregivers stimulate parents to be close to their child	0.79	0.72	0.86
Parents trust the caregivers	0.65	0.51	0.88
Home care aspects are discussed before discharge	0.66	0.56	0.87
Caregivers stimulate parents to stay close to their child during procedures and tests	0.58	0.52	0.88
Professional Attitude			
Caregivers introduce themselves with name and position	0.67	0.61	0.87
Caregivers show empathy to child and parents	0.70	0.59	0.87
Caregivers adopt principles of hygiene	0.70	0.52	0.88

Items and Domains	Factor loadings	Corrected item-total correlation	Cronbach α if item deleted
Caregivers safeguard privacy of child and parents	0.77	0.61	0.87
Caregivers provide equal care; irrespective of race, religion, sex, and education	0.70	0.53	0.88
Parents are offered religious / spiritual support	0.66	0.58	0.87
Caregivers pay attention to siblings	0.70	0.58	0.87
Caregivers respect the child and parents	0.72	0.61	0.87
Caregivers refrain from unnecessary discussions at the child's bedside	0.71	0.59	0.87
Staff always work agreeably together	0.66	0.55	0.88
Child and parents feel welcome at admission	0.76	0.64	0.87
Regardless the work pressure, the caregivers' attention towards child and parents is not allowed to slacken	0.57	0.49	0.88
Caregivers are alert to the cultural background of the child and parents	0.61	0.55	0.88
Caregivers give the highest priority to the child's health	0.53	0.45	0.88

Table 6 | Performance of the models

Domains	Items No.	n	χ^2 test of model fit			CFI	TLI	RMSEA	WRMR
			Value	*df*	P value				
Information Care and Accessibility	16	264	209.70	37	0.01	0.92	0.96	0.13	1.26
Care & Cure	19	263	322.54	45	0.01	0.88	0.96	0.15	1.54
Organization	16	263	475.65	43	0.01	0.70	0.91	0.11	1.65
Parental Participation	9	263	102.78	19	0.01	0.93	0.98	0.13	0.82
Professional Attitude	14	262	290.96	36	0.01	0.84	0.93	0.16	1.45

CFI indicates comparative fit index; TLI, Tucker-Lewis index; RMSEA, root mean square error of approximation; WRMR, weighted root mean square residual

Reliability estimates

The reliability was estimated on both the satisfaction items and the domains (Tables 5 and 7). On domain level, the Cronbach α for 5 domains are greater than 0.80. Only the domain "Information accessibility" appears to be 0.74; this might be qualified as acceptable.

Based on corrected item-total correlations for the domains, values vary from 0.30 to 0.76. As a measure of internal consistency, the values of Cronbach α were greater than 0.80, with the exception of “Information accessibility” (Table 5).

The overall values of Cronbach α for the domains are presented in Table 7, which again indicates a good level. Furthermore, for each domain, the number of items, the mean score, and the standard deviation are presented.

Table 7 | Descriptives and reliability estimates for domains

Domains	Items No.	n	mean	SD	α
Information-Care	8	253	72.27	4.88	0.88
Information-Accessibility	8	260	63.21	5.76	0.74
Care and Cure	19	247	168.96	9.57	0.92
Organization	16	248	130.24	9.80	0.88
Parental Participation	9	256	72.23	6.97	0.88
Professional Attitude	14	249	122.87	7.66	0.88

SD, standard deviation; α, Cronbach’s Alpha

DISCUSSION

The objective of this study was to assess the perceptions of Dutch PICU nurses and physicians on satisfaction for the development of a national parent satisfaction instrument. The scores of the satisfaction items in both Delphi rounds were relatively high. To our knowledge, no similar study has been reported, making it difficult to compare the findings. However, from a methodological perspective, our developmental process of the parent satisfaction instrument has some similarities with the development and validation of the Critical Care Family Needs Inventory (CCFNI). The 45 statements of family needs were developed from a literature review and a survey of 23 graduated nursing students.[15] In a follow-up study, the statements were tested psychometrically, resulting in high Cronbach α coefficient ranging from 0.88 to 0.98.[16,17] Meanwhile the CCFNI has been used extensively to identify and to evaluate the needs of family members in the adult intensive care unit. Recently, an adapted 30-item CCFNI was used to compare the perceptions of family members and nurses and also to the extent the needs were met.[18] Although the samples were small, 30 nurses and 20 family members, the results revealed that 9 items of the CCNFI did significantly differ between the nurses and family. In a similar study using the 45-item CCFNI with participants divided in 3 groups – family members (n = 200), physicians (n = 38), and nurses (n = 143) – showed differences on 24 individual needs.[19] These studies stress the logical need for parental opinion in the development of the parent satisfaction instrument.

The Delphi technique has been widely used in medical and nursing research. This method is often used to establish priorities on certain topics like research priorities[20] or to identify and to reach consensus on care indicators.[21,22] To identify the needs of critically ill children, a related study using the Delphi method was conducted by Endacott et al.[23] By using 2 case scenarios, 19 PICU nurses were able to identify 21 areas of needs to be considered as standard practice. Not surprisingly, that some areas cover the care of the parents, such as accommodation for parents, refreshment facilities, and aspects of family-centered care. Similar topics were found and incorporated in the satisfaction instrument of our study. The Delphi method is an easy applicable method and is legitimate for use in the development of reliable and valid questionnaires.

A PICU can be defined as a micro-system in a hospital organization interacting with related departments for transitional care of the child and parents.[2] The aim of a parental satisfaction survey is to assess care aspects from a patient's or parent's perspective and to improve these accordingly based on these results.[10] Therefore, it can be argued whether hospital-wide satisfaction items such as parking facilities or catering need to be included in a unit based satisfaction form. A unit might have little influence on these aspects. It is observed that the satisfaction items in our study concentrate mainly on issues related to the services and care of a PICU. Compared to other ICU satisfaction instruments[24-26], our study generated substantially more items. The difference appears in specifying the items. For example, items measuring information issues can be questioned on general information level such as "completeness of the information", but a more in-depth question about what information has been given and received satisfactorily might give a deeper understanding of the services provided by health care professionals. The consequence is indeed that a satisfaction instrument might add up to numerous questions. It could be questioned that the sheer size of the questionnaire in our study, 74 items, negatively influences the response rate when using among parents. Jenkinson et al studied this effect using a short and long form of questionnaires: 15 items vs 108 items.[27] The 949 (65.7%) returned questionnaires revealed no differences in response rates and data quality. Thus a shorter questionnaire might not have yielded a higher response rate.

Involving parents or family members in measuring satisfaction of care provides a collaborative environment in the ICU. However, several factors need consideration to gain a sufficient response, such as selecting the appropriate elements to be measured, rating scale, lay-out, and timing of distribution. In an analysis of 210 satisfaction studies, face-to-face distribution was associated with an increased response rate instead of distribution by mail.[28] Consequently, a more important issue is the possible differences between the results of face-to-face, for example, in-hospital distribution versus distribution by mail after hospital discharge. To our knowledge, this issue has not been documented yet.

High ratings of satisfaction surveys can become a problem in selecting areas for improvement. Out of the box thinking becomes an art to identify core strategies tailored to improve both care and service provision. This is what resulted from a satisfaction survey performed by Haines et al among 220 parents in a PICU.[29] With a response rate of 50%, those parents rated the care as excellent on most of the items. The health care team reviewed these high scores and was able to identify 10 areas for improvement. Considering the high scores in our study, all items are defined as important on the grounds of the chosen cut-off point 8. It can be argued whether they are all valid satisfaction quality performance measures. In this perspective, the advice could be not to limit the items in the development of a satisfaction survey.[30,31]

Whether the perceptions of satisfaction in health care professionals meet those of the parents can be questioned. It is not inconceivable that parents highly appreciate the satisfaction items ranked lowest by the professionals. Discrepancies in family needs perceptions have been noticed between physicians, nurses, and family members in neonatal and adult intensive care units.[19,32] However, evaluation of family needs does not allow a direct translation into a certain degree of satisfaction with care. Unmet family needs do not always imply low satisfaction rates, while meeting the family needs does not necessarily promise satisfied parents.[33] Hence, in view of these discrepancies, parents' perceptions on the satisfaction items used in our Delphi questionnaire will be explored in a next phase of our project.

The study has some limitations to consider. The attrition between the 2 rounds was somewhat high. Nonetheless, most Dutch PICU physicians and nurses completed both rounds, warranting a representative opinion of the parental satisfaction items. Regarding the Delphi method, a qualitative round for item identification among all PICU professionals was not carried out because of the assumption that a 3-round Delphi method would increase the workload too much and might, consequently, decrease commitment. Other satisfaction items might have been proposed if the Delphi study had started with an inventory round among all PICU professionals. Therefore, an open-ended question to the questionnaire in round 1 was added, resulting in 14 additional satisfaction items. Moreover, it can be argued that, in the item identification phase, only published satisfaction surveys related to PICU were taken into account. A wide variety of additional care elements such as parental needs, experiences, stress factors, and family-centered care issues could give valuable input in selecting the satisfaction items.[34] Recently, family-centered care has been promoted to reduce health disparities and to enhance the quality performance of the health care system.[1,4] The construction of a satisfaction or evaluation questionnaire including family-centered care variables is an opportunity that such an instrument will be accepted as a quality performance measure.

The implication of our study results might affect the awareness of pediatric critical care colleagues to assess parental satisfaction. Although it is expected that a number of PICUs already use a satisfaction survey for parents, yet the fact is that to date only two general surveys are published specifically for PICU.[25,29] McPherson et al reported the development of a reliable 24-item parent satisfaction survey.[25] To evaluate the quality of care delivered in a PICU setting our work provides 74 satisfaction items.

In conclusion, most of PICU nurses and physicians from the 8 Dutch PICUs provided their perceptions on satisfaction items. Besides rating the importance of the items, they suggested several additional items in the first round. Agreement among the healthcare professionals was sufficient, and the ranking of the importance of the satisfaction items provided a priority list per domain of the delivered parental care process. The confirmatory factor analysis of the instrument shows that the underlying empirical structure was satisfying, and reliabilities of the domains are considered adequate. This study provides a scientific basis for further development of a reliable and valid parental satisfaction questionnaire.

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CHAPTER 9

Perceptions of parents on satisfaction with care in the pediatric intensive care unit: The EMPATHIC study

Jos M. Latour, Johannes B. van Goudoever, Hugo J. Duivenvoorden,
Nicolette A.M. van Dam, Eugenie Dullaart, Marcel J.I.J. Albers, Carin W.M. Verlaat,
Elise M. van Vught, Marc van Heerde, Jan A. Hazelzet

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ABSTRACT

Purpose: To identify parental perceptions on pediatric intensive care related satisfaction items within the framework of developing a Dutch pediatric intensive care unit (PICU) satisfaction instrument.

Methods: Prospective cohort study in tertiary PICUs at 7 university medical centers in the Netherlands.

Participants: Parents of 1042 children discharged from a PICU.

Results: A 78-item questionnaire was sent to 1042 parents and completed by 559 (54%). Seventeen satisfaction items were rated with mean scores < 8.0 (1 completely unimportant to 10 very important) with standard deviations ≥ 1.65, and thus considered of limited value. The empirical structure of the items was in agreement with the theoretically formulated domains: Information, Care & Cure, Organization, Parental Participation, and Professional Attitude. The Cronbach's α of the domains ranged between 0.87 and 0.94.

Conclusions: Parental perceptions on satisfaction with care measures were identified and prioritized. Reliabilities of the items and domains were of high level.

INTRODUCTION

Various approaches have been initiated to improve quality of care.[1] As generally accepted quality performance measurements were lacking, an international project defined a set of quality of healthcare indicators[2], including patient-centered care with empowerment of the patient and family. Consequently, patient satisfaction was then gradually recognized as an important tool to evaluate healthcare systems.[3,4]

Over the past few decades, integration of patient and family perspectives in clinical practice evolved slowly. There were some early initiatives concentrating on the needs of patient and family members, but the evaluation tools used did not always take into account their experiences.[5-8] Researchers started to develop instruments to explore user experiences with intensive care a few years ago, but only a few reliable family satisfaction surveys claim to be driven by patient and family experiences.[9-13] It would seem that the continuous assessment of patient satisfaction as a quality performance indicator has not yet been widely accepted.[14]

Similar to adult intensive care units, PICUs tend to concentrate on clinical outcome parameters such as mortality, morbidity, length of stay, or survival outcomes to justify quality of care. Emphasizing partnership between parents and healthcare professionals, the PICUs in the Netherlands have recognized parental satisfaction as a quality performance indicator. This collaborative decision resulted in the multicenter EMpowerment of PArents in THe Intensive Care (EMPATHIC) study, a multiphase project designed to develop and implement a PICU parent satisfaction instrument. The study started with identifying satisfaction items described in the literature.[15] The next phase was a descriptive study on perceptions of nurses and physicians working in the PICUs.[16] In the present study we explored how parents perceived the identified satisfaction with care issues. The objectives were twofold: (1) to assess perceptions of parents who had experienced a PICU admission of their child on parental satisfaction issues, and (2) to perform factor analysis to evaluate the satisfaction items within domains.

METHODS

The study was designed as a multicenter prospective cohort study. Seven of the eight multidisciplinary PICUs in the Netherlands participated in the study. All PICUs are level III tertiary referral centers with the capacity to provide transport facilities, (non)invasive ventilation, support multi-system failure management, post surgical care, and other complex procedures and interventional care. Number of beds per PICU ranges from 8 to 24. The annual total number of admissions is approximately 4500. In 2005 the median age of admitted children was 1.8 years (P_{25-75} 0.3-7.8 years), the median length of stay was 3 days (P_{25-75} 2-6 days), and 55.8% were mechanically ventilated.[17] One 14-bed PICU, with approximately 600 yearly admissions, did not participate because the parents were already involved in another study. The study protocol was approved initially by the medical ethical review board of the Erasmus Medical Center in Rotterdam and subsequently by the review boards of the participating centers.

Participants

The study population consisted of parents or legal caretakers of children discharged from a PICU in the period July through October 2007. No minimum stay was defined, because the overall aim of the project was to develop a satisfaction instrument for all parents. Excluded from the study were parents whose child had died, either during PICU admission or after discharge from the PICU, and parents of children who had been readmitted in the study period (Figure 1). The rationale for excluding parents of children who had died was the assumption that other research methods would be more appropriate for this group.[18-20] In the eventuality of transferal from one to another PICU, the parents' opinion was sought for the first admission only.

Ethnicity was determined by checking the child's first and family name using the combined name method.[21] Ethnicity was categorized into Dutch and non-Dutch.

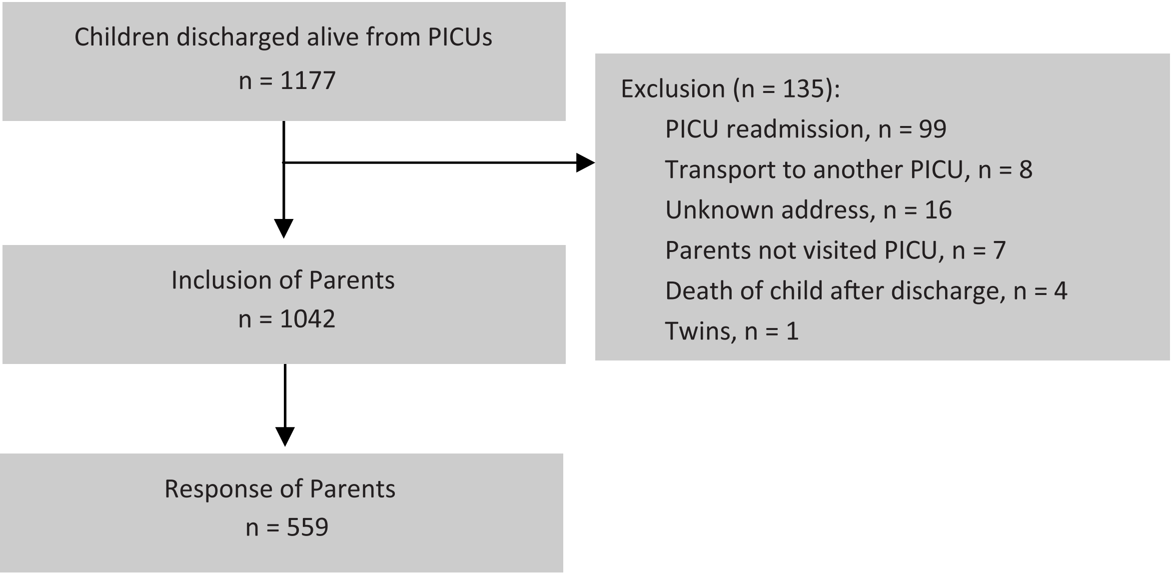

Figure 1 | Flowchart of the inclusion study participants

Questionnaire

In a previous Delphi study, a self-administered questionnaire had been developed from literature data and opinions of nurses and physicians in eight PICUs.[16] The questionnaire included 78 items of satisfaction with care in five domains: Information, Care and Cure, Organization, Parental Participation, and Professional Attitudes. Based on the empirical data of the nurses and physicians, factor analysis showed that 72 items had standardized factor loadings above 0.50. The Cronbach's α of the domains varied from 0.74 to 0.92.

Parents received a letter explaining the aim and content of the study 2-3 weeks after discharge. Attached were the above-mentioned questionnaire, a consent form, and a post-paid reply envelope. Parents were asked to rate the importance of the items. The rating scale was a ten-point scale ranging from 1, completely unimportant, to 10, extremely important. An open-ended question was included asking for any comments. As the Netherlands is a multicultural society, the questionnaire was available, apart from in Dutch, in Arabic, Turkish, and English. Parents could obtain translated versions by returning a reply slip in three languages included in the invitation letter. The Dutch and English versions were also available online at www.empathic.nl through an individual code provided in the invitation letter.

Statistical Analysis

Descriptive statistics were used to calculate mean scores and standard deviations of the satisfaction items for ranking the importance of the satisfaction items. Importance was defined as the highest mean and the smallest standard deviation.

Each centre provided data of the participating children via the Pediatric Intensive Care Evaluation database. Anonymity was protected by coding. Distribution-free tests, i.e. the Mann-Whitney test for two independent samples and the χ^2 test, served to compare characteristics of respondents and nonrespondents.

The empirical data of the parents were subjected to factor analysis aimed at identifying and estimating the dimensional structure and importance of individual items within that structure. Confirmatory factor analysis (CFA) was chosen instead of explorative factor analysis because the latter has limitations in statistical testing. In addition, the adequacy of model fit could be tested on statistical plausibility. The performance measures applied were the χ^2 test of model fit and the χ^2 test of model of fit for the baseline model. Values of χ^2, *P* values, and degrees of freedom (*df*) were scrutinized. For an adequate model fit the χ^2 test of model fit had to be non-significant, which meant that the identified model adequately represented the interrelationship of data, the so-called observed correlation matrix. The reproduced correlation matrix, calculated from the identified model, must closely correspond to the observed correlation matrix. The ratio of $\frac{\chi^2}{df} < 1.5$ would represent a good model fit. Other tests used for the model fit were: comparative fit index (preferably CFI > 0.95), Tucker-Lewis index (preferably TLI > 0.95), root-mean-square error of approximation (preferably RMSEA ≈ 0.05), and the weighted root mean square residual (preferably WRMR < 1.00).[22]

As a measure of relative importance of the individual items, the standardized factor loadings, theoretically varying from -1 to +1, are presented. Reliabilities of the domains were estimated by the Cronbach's α, with theoretically a maximum value of 1.0.

The data were analyzed using SPSS (version 15, Chicago, USA) and the statistical modeling program M*plus* (version 5, 2007, Los Angeles, USA).

RESULTS

In the 4-month data collection period 1,177 children were discharged alive from the participating PICUs. Parents of 1,042 children were eligible to participate in the study. A total of 559 parents (54%) completed the questionnaire (Figure 1). The response rate per center ranged between 49% and 60%. No more than 34 parents (3%) completed the questionnaire online. Only three requests were received for translated versions: one for the Arabic version and two for the Turkish version. Most children were Dutch (n = 805, 77.3%). In the non-Dutch group (n = 237), 47 (4.5%) were Turkish, 70 (6.7%) were Moroccan, 43 (4.1%) were Surinamese, and 77 (7.4%) were categorized as "other". Characteristics of the children in the response and non-response groups are presented in Table 1. Significant differences between these groups were noted for ethnicity, PICU admission (unplanned versus planned), and number of ventilation days.

Table 2 presents the mean scores and standard deviations (SD) for the individual items**;** they are ranked per domain on the highest mean and lowest standard deviation. The item "Caregivers give the highest priority to the child's health" was ranked as most important. Parents felt an organizational issue to be least important: "A locker on the PICU is available for all parents". For 17 satisfaction items the mean score was below eight. This cut-off point was determined from the empirical data due to lack of scientific rationale. The standard deviations of these 17 items exceeded 1.65 (Table 2). Six were related to information giving, in particular the accessibility and manner of information giving. The mean scores of the domains were: Information 8.64 (SD 0.86); Care and Cure 8.92 (SD 0.88); Organization 8.36 (SD 1.07); Parental Participation 8.39 (SD 1.11); Professional Attitude 8.72 (SD 0.91).

Table 1 | Characteristics of the children

	Response n	Response	Nonresponse n	Nonresponse	*P*
Gender					0.20
Male	327	52.2%	300	47.8%	
Female	232	56.2%	181	43.8%	
Age in months; median ($P_{25\text{-}75}$)	558	29 (4-115)	479	28 (5-91)	0.85
Ethnicity					<0.01
Dutch	483	60.0%	322	40.0%	
Non-Dutch	76	32.1%	161	67.9%	
PICU admission					0.01
Unplanned	279	50.3%	276	49.7%	
Planned	279	57.9%	203	42.1%	
Type of admission					0.13
Surgical	321	55.9%	253	44.1%	
Medical	237	42.5%	226	47.2%	
Length of stay PICU; median ($P_{25\text{-}75}$)	558	3 (2-6)	479	3 (2-5)	0.07
Ventilation days; median ($P_{25\text{-}75}$)	550	1 (0-3)	468	0 (0-2)	0.02
Mortality Risk PRISM 2; median ($P_{25\text{-}75}$)	558	0.02 (0.01-0.04)	478	0.02 (0.01-0.05)	0.11
Mortality Risk PIM 2; median ($P_{25\text{-}75}$)	558	0.01 (0.01-0.03)	478	0.01 (0.01-0.03)	0.40

Total numbers of respondents and nonrespondents vary on individual characteristics due to missing data; percentages are presented in row percentages; χ^2 *test for categorical data; Mann-Whitney test for nonparametric data; PICU, pediatric intensive care unit; PRISM, pediatric risk of mortality; PIM, pediatric index of mortality*

Table 2 | Mean, standard deviation, standardized factor loadings, and reliability estimates of the satisfaction items

	mean	SD	Factor loadings	Corrected item-total correlation	Cronbach's α if item deleted
Information – Care					
Parents are informed about the child's illness	9.54	0.88	0.66	0.78	0.89
Parents are informed about changes in the child's condition as soon as possible	9.53	0.91	0.52	0.75	0.89
Parents are informed about tests and procedures	9.52	0.89	0.91	0.83	0.89
Caregivers inform the parents about the treatment consequences	9.51	0.90	0.91	0.83	0.89
Caregivers answer parents' questions adequately	9.40	0.96	0.77	0.67	0.90
Parents are informed about the child's future perspectives	9.21	1.34	0.82	0.68	0.90
Parents are informed about the (adverse) effects of the medication	9.20	1.23	0.95	0.74	0.89
Caregivers give no conflicting information to the parents	9.15	1.42	0.81	0.57	0.91
Information – Accessibility					
Caregivers daily inform parents about the child's care and treatment	9.35	1.11	0.38	0.41	0.78
Parents have easy access to information	8.99	1.25	0.91	0.43	0.78
The way to the PICU is clearly signposted	7.96	1.66	0.76	0.55	0.76
Parents are informed about PICU rules	7.95	1.66	0.59	0.61	0.75
Caregivers' communication with non Dutch speaking parents is through an interpreter or the interpreter-telephone service	7.89	2.26	0.56	0.46	0.78
Caregivers provide not only oral but also written information	7.75	1.84	0.47	0.57	0.76
Caregivers inform the parents on the best moment for the parents	7.73	1.88	0.78	0.46	0.78
Parents are informed about sanitary units	6.99	2.09	0.74	0.58	0.76
Care and Cure					
Caregivers know their profession	9.56	0.99	0.82	0.59	0.94
The correct medication is given at the right times	9.50	0.98	0.85	0.67	0.94
Caregivers react promptly to changes in the child's condition	9.47	1.02	0.75	0.70	0.94
Pain is prevented and/or treated	9.44	0.96	0.74	0.64	0.94

	mean	SD	Factor loadings	Corrected item-total correlation	Cronbach's α if item deleted
Caregivers jointly pursue one goal: adequate care and treatment of child and parents	9.27	1.04	0.78	0.70	0.94
Caregivers are aware of the child's medical history	9.22	1.21	0.88	0.67	0.94
Parents know which physician and nurse are responsible for the care of their child	9.11	1.23	0.78	0.67	0.94
At discharge, caregivers provide clear information to colleagues	9.07	1.38	0.73	0.63	0.94
Caregivers are alert to the child's comfort	9.05	1.12	0.83	0.66	0.94
An assigned physician and nurse serve as contacts for the parents during prolonged ICU-stay	8.97	1.32	0.74	0.60	0.94
Caregivers display a caring attitude toward child and parents	8.88	1.26	0.79	0.78	0.94
Caregivers prepare child and parents for a PICU admission	8.79	1.29	0.76	0.70	0.94
Caregivers are alert to the child's developmental growth	8.68	1.34	0.79	0.69	0.94
Caregivers are considerate to the child's wishes	8.62	1.35	0.88	0.66	0.94
Caregivers provide emotional support to child and parents	8.56	1.41	0.76	0.75	0.94
Parents are adequately prepared for the child's discharge	8.53	1.45	0.60	0.62	0.94
Caregivers work in team with a strong group cohesion	8.53	1.48	0.57	0.51	0.94
Caregivers adequately meet the needs of the parents	8.17	1.49	0.80	0.70	0.94
A caregiver always advises parents during acute admission or an acute situation	8.05	1.65	0.57	0.65	0.94
Organization					
The PICU is clean	9.18	1.21	0.72	0.56	0.91
The child's bed is clean	9.12	1.16	0.75	0.61	0.91
The PICU is well accessible by phone	9.11	1.28	0.74	0.61	0.91
Moment of discharge is not influenced by bed capacity	9.10	1.33	0.77	0.46	0.91
Rooming-in near the PICU is possible	9.01	1.54	0.71	0.47	0.91
The caregivers are efficiently organized	8.86	1.23	0.72	0.62	0.91
Visiting hours are flexible	8.59	1.67	0.76	0.48	0.91
Noise in the PICU is muffled as far as possible	8.42	1.59	0.75	0.68	0.91
The PICU is imbued with a sense of safety	8.40	1.49	0.74	0.69	0.91
The PICUs design is child-friendly	8.38	1.61	0.77	0.64	0.91

	mean	SD	Factor loadings	Corrected item-total correlation	Cronbach's α if item deleted
Written information on unit rules0. diseases and procedures is available on the PICU	8.38	1.66	0.74	0.65	0.91
The child's bed space is amply enough	8.18	1.71	0.58	0.72	0.91
The PICU has comfortable furniture	7.30	1.90	0.60	0.68	0.91
The waiting room is fitted out comfortably	7.27	1.96	0.64	0.71	0.91
Catering for parents is well taken care of	6.78	2.38	0.75	0.63	0.91
A locker on the PICU is available for all parents	6.67	2.45	0.74	0.65	0.91
Parental participation					
Parents trust the caregivers	9.41	0.97	0.74	0.50	0.86
Home care aspects are discussed before discharge	9.06	1.25	0.81	0.64	0.85
Caregivers stimulate parents to stay close to their child during procedures and tests	8.77	1.46	0.77	0.62	0.85
Caregivers stimulate parents to be close to their child	8.58	1.58	0.64	0.63	0.85
Parents share in decision-making on the care and treatment of their child	8.57	1.57	0.79	0.56	0.86
Caregivers facilitate parents in expressing their feelings	7.91	1.65	0.64	0.67	0.85
At admission caregivers ask parents their expectations	7.74	1.80	0.79	0.65	0.85
Caregivers regularly inform after parental experiences during the course of admission	7.58	1.97	0.69	0.67	0.85
Parents receive and are suggested to keep a diary	7.04	2.33	0.77	0.57	0.86
Professional attitude					
Caregivers give the highest priority to the child's health	9.69	0.73	0.64	0.53	0.88
Caregivers adopt principles of hygiene	9.51	0.87	0.75	0.57	0.88
Caregivers provide equal care; irrespective of race, religion, sex, and education	9.36	1.14	0.74	0.59	0.87
Regardless the work pressure the caregivers' attention towards child and parents is not allowed to slacken	9.18	1.09	0.87	0.64	0.87
Caregivers respect the child and parents	9.14	1.15	0.61	0.69	0.87
Child and parents feel welcome at admission	9.06	1.25	0.85	0.67	0.87
Caregivers refrain from unnecessary discussions at the child's bedside	9.03	1.40	0.84	0.63	0.87
Staff always work agreeably together	8.89	1.28	0.79	0.70	0.87
Caregivers safeguard privacy of child and parents	8.83	1.23	0.80	0.64	0.87

	mean	SD	Factor loadings	Corrected item-total correlation	Cronbach's α if item deleted
Caregivers introduce themselves with name and position	8.62	1.38	0.68	0.58	0.87
Caregivers show empathy to child and parents	8.54	1.32	0.66	0.65	0.87
Caregivers are alert to the cultural background of the child and parents	7.77	2.00	0.80	0.53	0.88
Caregivers pay attention to siblings	7.46	2.04	0.51	0.53	0.88
Parents are offered religious / spiritual support	6.98	2.35	0.79	0.40	0.89

SD, standard deviation; PICU, pediatric intensive care unit

Parents of the non-Dutch group rated two cultural-related items with higher means than did the parents of the Dutch group. The first item concerned the use of interpreters or interpreter-telephone services: mean 8.09, SD 2.24 versus mean 7.86, SD 2.26 (*P* = 0.43). The second item was the alertness of the cultural background of child and parents: mean 8.19, SD 1.71 versus mean 7.71, SD 2.04 (*P* = 0.03).

Altogether 203 (36.3%) parents commented in response to the open-ended question. Of these, 37 comments were words of thank to the PICU team. The remaining comments were analyzed by two researchers (J.M.L., B.E.S.) comparing the parental narratives with the topics of the questionnaire. No additional items were identified from the qualitative data. Comments generally complemented the items in the questionnaire. For example, "What surprised us was the limited space around the bed, and a lot of, in our view, moving of the beds. As parents you soon feel yourself in the way. Annoying were the noise and open discussions across the whole unit about patients" [respondent 233-038]. This quote was categorized to four satisfaction items related to bed space, noise levels, unnecessary discussions at the bed side, and privacy protection.

Confirmatory factor analysis showed that four items did not fit the empirical structure of the domains to which the items belonged. These items were removed from the empirical structure for further analysis. Furthermore, four domains appeared to be unidimensional. The Information domain was two dimensional, with items specifically related to the dimensions Care and Accessibility (Table 2).

Although the model fits of the factor structures of the domains were weak (Table 3), the standardized factor loadings of the individual items were adequate with values above 0.50 except for one item, "Caregivers daily inform parents about the child's care and treatment" (0.38). Reliability was estimated for both the items and the domains (Tables 2, 4). On the domain level, the reliabilities (estimated by Cronbach's α) for five of the six domains were above 0.80. The sixth domain Information – Accessibility had a Cronbach's α of 0.79, which might still be qualified as acceptable. The corrected item-total correlations for the domains varied from 0.4 to 0.83. As a measure of internal consistency, the values of Cronbach's α were above 0.85, with the exception of all items in the domain Information-Accessibility (Table 2).

Table 3 | Performance of the models

Domains	**Items no.**	**n**	**Chi-Square test of model fit**						
			Value	***df***	***P*-Value**	**CFI**	**TLI**	**RMSEA**	**WRMR**
Information: Care and Accessibility	16	559	1031.67	35	0.01	0.90	0.94	0.23	2.70
Care and Cure	19	559	646.90	58	0.01	0.90	0.97	0.14	1.59
Organization	16	551	943.67	42	0.01	0.82	0.93	0.20	2.19
Parental Participation	9	557	427.81	15	0.01	0.88	0.93	0.23	1.91
Professional Attitude	14	557	745.57	42	0.01	0.87	0.96	0.17	1.73

df, degrees of freedom; CFI, comparative fit index; TLI, Tucker-Lewis index; RMSEA, root mean square error of approximation; WRMR, weighted root mean square residual

Table 4 | Descriptives and reliability estimates for domains

Domains	**Items no.**	**n**	**mean**	**SD**	**α**
Information – Care	8	545	75.05	6.80	0.91
Information – Accessibility	8	511	64.70	8.85	0.79
Information (Total)	16	503	139.83	13.53	0.87
Care and Cure	19	510	170.93	16.41	0.94
Organization	16	514	132.80	17.48	0.91
Parental Participation	9	526	74.78	10.22	0.87
Professional Attitude	14	528	122.03	12.64	0.88

SD, standard deviation, α, Cronbach's alpha

DISCUSSION

Intensive care professionals are increasingly concerned about patient and family-centered care and involving family members in the care of the patient. In addition, the past decade showed an increase in explorative studies on perceptions of patient and family member. Both have led to the issuing of clinical practice guidelines on family-centered care in intensive care units.[23] It is debatable whether the healthcare providers have truly gone along with these recommendations.[6,24] Assessment of parental experiences would elucidate the extent to which family-centered care corresponds to the parental expectations. Standardized parental satisfaction outcomes may then ultimately provide interventions to improve clinical practice. The parents in our study classified the importance of satisfaction measures, providing insight into their perceptions and experiences.

Several studies have provided state-of-the-art knowledge of parental needs in the PICU, as established by the modified 45-item Critical Care Family Needs Inventory.[25-28] The top 20 needs in these studies tend to focus on information provision, such as information on illness, progress, prognosis, and “knowing what is being done”.[29] Similar findings were reported in a systematic review of 115 articles on families with critically ill children.[30] Nevertheless, the authors concluded that most reports were anecdotal, often had small sample size, and that some showed methodological flaws.

Our data set of 78 satisfaction items covered a wider range of care aspects than only the parental needs. The large sample in our study rated several items in all domains very high, indicating that issues other than just receiving adequate information at the right moment are important. Not surprisingly, the child’s care is of importance to them, as well as behavior and attitude of the healthcare professionals. Some of these issues emerged also from a recent qualitative study among 20 parents of hospitalized children: 11 in a PICU and 9 in a general ward.[31] Parents of children in the PICU had more stress, and this affected their psychological outcomes. Importantly, stress factors were related to the severity of the child’s illness, varying from admission to post discharge. This implication strengthens our aim to develop a core set of satisfaction items that covers the entire PICU stay, including the discharge process.

The widely used Parental Stressor Scale: PICU, developed by Carter and Miles[32], is a valuable tool to study parental stressors. Two small studies using this instrument demonstrated that the child having to undergo procedures or tests, the child having a endotracheal tube, and overall experiences in the PICU are the most important stressors for mothers (n = 31) and fathers (n = 15).[33,34] Furthermore, particularly mothers stated that receiving information from too many professionals is highly stressful. In this respect, the Creating Opportunities for Parent Empowerment (COPE) program offers a structured information intervention and directs parental participations.[35] In the study by Melnyk et al., mothers in the COPE program group reported significant less stress.[35] Regrettably, satisfaction was not considered as an outcome measure. For deeper understanding of parental experiences of a PICU admission, it might be advisable to combine a satisfaction survey with a stressor scale. Findings from such an approach might guide professionals towards combined interventions aimed at decreasing stress levels among parents, possibly resulting in higher satisfaction outcomes.

Availability of a valid and reliable satisfaction instrument is likely to contribute to general acceptance of parental satisfaction as a quality performance outcome. Measuring parental satisfaction and evaluating outcomes among several PICUs, in all probability, provide opportunities for quality programs based on best practices. In other words, PICUs with low satisfaction ratings on certain care aspects may learn from a PICU with high satisfaction ratings on these aspects. Via these best practices the PICUs are able to work on continuous collaborative quality improvement.

The limitations of the study should be addressed. First, parents' characteristics were not taken into account, albeit on purpose. The overall aim was to develop a parental satisfaction instrument for the general population in the PICU. Additional questions about family composition and characteristics would have raised the already high number of items in the survey and could have reduced the response rate. This argument is counteracted, however, by a study from Jenkinson and colleagues that reported no significant differences in response rate between a satisfaction survey with 15 items and one with 108 items.[36]

Second, the satisfaction items had been generated from the existing literature and the opinions of PICU professionals. It could be argued that, in the initial stage of the developmental process, an explorative study among parents might have been appropriate to identify the satisfaction items. Such a qualitative study might have resulted in other satisfaction items. We believe, however, that the approach we opted for created a firm enough basis for further development.

Third, the overall response rate of 54% is fairly low. Comparable studies using data collection via mail obtained response rates between 60 and 70%.[37-39] Still, we made some efforts to achieve a high response rate, i.e., translating the questionnaire, providing an online submission option, and sending a reminder. The face-to-face approach might be a better method in future studies, since it is associated with a significant higher response compared to mailing the survey.[38]

In conclusion, a large group of parents of children admitted to a PICU in the Netherlands provided their perceptions on satisfaction with care topics based on their experiences. These valuable perceptions will make it possible to further develop a satisfaction instrument specifically for the PICU and based on the empowerment of parents. The empirical structure of the satisfaction items and domains can be considered adequate and the reliabilities of the domains are of high level. The results provide a scientific basis for further modification of the instrument. Redundant items that measure the same concept might be eliminated, leaving a still reliable and valid satisfaction instrument for the PICU services.

Future research should also include open-ended questions asking parents for suggestions on how care could be improved. These important qualitative date can clarify and complement the quantitative results and the synergy of these data makes it possible to identify areas to improve clinical practice.[9,40] Furthermore, it might be recommended to design satisfaction instruments that allow to discriminate groups of parents such as parents of different cultural backgrounds. Also, parents of children hospitalized for postoperative care are assumed to have different experiences than parents of a child admitted with a life-threatening condition. Finally, parents of different cultural backgrounds hardly made use of one of the translated versions of questionnaires. Different approaches such as giving face-to-face the questionnaire in their own language might be recommended to increase their participation.

Ultimately, the instrument should be able to provide parents a tool to collaborate with the healthcare professionals in quality improvement of the PICU services.

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PART IV

Perceptions

CHAPTER 10

Differences in the perceptions of parents and healthcare professionals on pediatric intensive care practices

Jos M. Latour, Johannes B. van Goudoever, Hugo J. Duivenvoorden, Marcel J.I.J. Albers, Nicolette A.M. van Dam, Eugenie Dullaart, Marc van Heerde, Majorie de Neef, Carin W.M. Verlaat, Elise M. van Vught, Jan A. Hazelzet

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ABSTRACT

Objective: To explore similarities and differences in perceptions on pediatric intensive care practices between parents and staff by using data of two studies.

Design: A two-round Delphi method among nurses and physicians followed by an empiric survey among parents.

Settings: Pediatric intensive care units at eight university medical centers.

Subjects: Parents whose child has been admitted to a pediatric intensive care unit, nurses, and physicians.

Interventions: None.

Measurements and Main Results: Outcome measures were 74 satisfaction-with-care items divided into five domains: 1) information; 2) care and cure; 3) organization; 4) parental participation; and 5) professional attitude. The Delphi study was completed by 218 nurses and 46 physicians and the survey by 559 of 1042 (54%) parents. Parents rated 31 items more important than the professionals based on the standardized mean difference (Cohen's d, 0.21-1.18, $p < .003$). Ten of these were related to information provision. Information on the effects of medication had the largest effect-size (Cohen's d 1.18, $p = .001$). Correct medication administration by professionals was also rated significantly more important by parents (Cohen's d 0.64, $p = .001$). The professionals rated 12 items more important than the parents (Cohen's d -0.23 to -0.73, $p < .005$), including three about multicultural care. Significant differences remained on two of the three multicultural care items when the Dutch (n = 483) and non-Dutch parents (n = 76) were separately compared with professionals. On domain level, parents rated the domains information and parental participation more important than the professionals (Cohen's d 0.36 and 0.26, $p = .001$).

Conclusions: Compared with the parents' perceptions, nurses and physicians undervalued a substantial number of pediatric intensive care items. This finding may reflect a gap in the understanding of parental experiences as well as incongruity in recognizing the needs of parents.

INTRODUCTION

Parents have a central role in the care of their child in the pediatric intensive care unit (PICU). Serving as the surrogate for their child, they have specific needs that should to be recognized and acted on by clinicians. This is not always the case. For example, a study in adult intensive care concluded that clinicians underestimated the needs of family members.[1] Furthermore, parents of children with a short-stay pediatric ward admission sometimes expected a different level of participation in care than did pediatric nurses.[2] It is therefore interesting to gain more in-depth understanding of the parents' perceptions to provide a safe passage of the child and parents through the PICU period and beyond.[3] After all, improving our knowledge and clinical competency of family-driven care is imperative to optimize safety of care.

Perceptions and needs of parents have been increasingly recognized as a standard of care assessment in critical care settings. Studies identifying parents' needs in the PICU originate mainly in the early 1990s.[4-6] The past few years there seems to be a shift from assessing parental needs to assessing satisfaction with care. Indeed, measuring satisfaction often provides more information, because having met the needs does not always reflect positive satisfaction.[7]

In the Netherlands, two studies provided valuable insight in the perceptions of parents, nurses, and physicians about pediatric intensive care practices.[8,9] The objective of the present study was to use data from the two previous studies to identify differences and similarities between parental and professional perceptions on pediatric intensive care practices.

MATERIALS AND METHODS

Two studies were conducted, first a two-round Delphi study for nurses and physicians followed by an empirical survey among parents. Healthcare professionals of all eight PICUs in the Netherlands participated in the Delphi study; parents of children admitted to seven PICUs participated in the survey. The medical ethical review board of the Erasmus University Medical Center, Rotterdam, approved both studies.

Delphi study

Details of the two-round Delphi study have been published in 2009. It aimed at identifying and prioritizing satisfaction-with-care items among PICU nurses and physicians.[8] Briefly, this study was a multiphase design starting with an identification phase resulting in a list of 64 satisfaction-with-care items. This list was used in the next phase consisting of two Delphi questionnaire rounds. The first Delphi questionnaire yielded an additional 14 items. The resultant 78-item questionnaire was subsequently presented in the second round to prioritize the items.

Empiric survey

The empiric survey, published in 2009, was designed and conducted to identify parents' perceptions on the satisfaction-with-care items.[9] Briefly, 2-3 wks after PICU discharge, the parents received an invitation to participate. The questionnaire was available not only in Dutch, but also in Arabic, Turkish and English. Ethnicity was classified into Dutch and non-Dutch by checking the child's name and family name.[10]

Questionnaire

The 78-item questionnaire used a 10-point rating scale from 1, completely unimportant, to 10, extremely important.[11] Confirmatory factor analysis showed that 4 items did not fit into the domains. The resulting 74 items comprised the domains information (16 items), care and cure (19 items), organization (16 items), parental participation (9 items), and professional attitude (14 items). The reliabilities of the domains in both studies were sufficient, as demonstrated by Cronbach's αs between 0.74 and 0.94.

Statistical analysis

Means and SDs were used for ranking the importance of the care items. The Cohen's d, the standardized mean difference, was used to estimate the effect-size between the data of parents and professionals. The interpretations of the Cohen's d values are: 0.20 is small, 0.50 is medium, and 0.80 is large.[12] The *t* test for independent observations was used for analyzing statistically significant differences between parents and professionals. Statistical testing took place at a .05 level of significance (two-tailed). The data were analyzed using SPSS (version 15; Chicago, USA).

RESULTS

Of the 364 professionals participating in the first Delphi round, 269 (74%) completed the questionnaire presented in round two. Five respondents returned an incomplete questionnaire, resulting in 264 (218 nurses and 46 physicians) questionnaires for analysis. In the empiric survey 559 of 1042 (54%) invited parents responded.

Analysis revealed significant differences between parents and healthcare professionals on 43 care items. Parents rated 31 items more important than did the nurses and physicians (Table 1). In contrast, the professionals rated 12 items more important than did parents (Table 2). The largest effect size, rated more important by parents than by professionals, was the item related to information provision on the (adverse) effects of medication (Cohen's d 1.18, p = .001). An item receiving medication administration was also rated significantly higher by parents.

Table 1 | Care items (n = 31) ranked by parents as more important than healthcare professionals

	Parents (n = 559)		**Professional (n = 264)**			
	Mean	**SD**	**Mean**	**SD**	**Cohen's d**	***p* (Two-Tailed)**
Domain Information						
Parents are informed about the (adverse) effects of the medication	9.20	1.23	7.81	1.11	1.18	.001
Caregivers daily inform parents about the child's care and treatment	9.35	1.11	8.43	1.17	0.80	.001
Caregivers provide not only oral but also written information	7.75	1.84	6.73	1.55	0.60	.001
Caregivers provide information at a convenient moment for the parents	7.73	1.88	6.98	1.53	0.44	.001
Caregivers inform the parents about the treatment consequences	9.51	0.90	9.16	0.79	0.41	.001
Parents are informed about the child's future perspectives	9.21	1.34	8.76	1.00	0.38	.001
Parents are informed about tests and procedures	9.52	0.89	9.23	0.71	0.37	.001
Parents are informed about changes in the child's condition as soon as possible	9.53	0.91	9.27	0.80	0.31	.001
Parents have easy access to information	8.99	1.25	8.75	0.76	0.24	.001
Parents are informed about the child's illness	9.54	0.88	9.36	0.70	0.23	.001
Domain Care & Cure						
The correct medication is given at the right time	9.50	0.98	8.95	0.73	0.64	.001
A caregiver always advises parents during acute admission or an acute situation	9.03	1.30	8.34	1.06	0.58	.001
Caregivers are aware of the child's medical history	9.22	1.21	8.91	0.70	0.33	.001
Caregivers prepare child and parents for a PICU admission	8.79	1.29	8.45	0.94	0.31	.001
Caregivers are alert to the child's developmental growth	8.68	1.34	8.42	0.91	0.23	.002
Caregivers are considerate to the child's wishes	8.62	1.35	8.37	0.94	0.22	.002
Domain Organization						
Moment of discharge is not influenced by bed capacity	9.10	1.33	8.12	1.00	0.85	.001
The child's bed is clean	9.12	1.16	8.37	0.87	0.74	.001
Rooming-in near the PICU is possible	9.01	1.54	8.24	1.25	0.55	.001
Parents know which physician and nurse are responsible for the care of their child	9.11	1.23	8.68	0.87	0.41	.001

	Parents (n = 559)		Professional (n = 264)			
	Mean	SD	Mean	SD	Cohen's d	*p* (Two-Tailed)
Visiting hours are flexible	8.59	1.67	8.07	1.18	0.37	.001
The PICU is clean	9.18	1.21	8.85	0.81	0.33	.001
Domain Parental Participation						
Caregivers stimulate parents to stay close to their child during procedures and tests	8.77	1.46	7.79	1.39	0.69	.001
Parents share in decision-making on the care and treatment of their child	8.57	1.57	7.62	1.25	0.67	.001
Home care aspects are discussed before discharge	9.06	1.25	8.49	0.91	0.53	.001
Caregivers stimulate parents to stay close to their child	8.58	1.58	8.24	1.06	0.25	.001
At admission caregivers ask parents their expectations	7.74	1.80	7.41	1.04	0.23	.001
Domain Professional Attitude						
Regardless the work pressure the caregivers' attention towards child and parents is not allowed to slacken	9.18	1.09	8.36	1.04	0.77	.001
Caregivers give the highest priority to the child's health	9.69	0.73	9.26	0.87	0.53	.001
Child and parents feel welcome at admission	9.06	1.25	8.81	0.92	0.23	.001
Caregivers show empathy to child and parents	8.54	1.32	8.30	0.92	0.21	.003

PICU, pediatric intensive care unit. Scoring scale was a 10-point scale: 1 = completely unimportant to 10 = extremely important; ranking of items is based on Cohen's d (unit weighted).

Of the 12 items rated more important by the professionals, three concerned multicultural care, ie, communication through interpreters, offering religious support, and alertness to the cultural background. On these items, the Dutch parents (n = 483) and non-Dutch parents (n = 76) separately were compared with the PICU professionals (n = 264). Statistical differences between all groups remained the same for two of the three items, whereas the outcomes on the item about alertness to the cultural background differed. The Dutch parents rated this item lower than professionals (Cohen's d -0.26, *p* = .001), whereas the non-Dutch parents did not differ from the professionals (Cohen's d 0.05, *p* = .76).

Most of the differences pertained to the information domain. Parents rated ten of the 16 items in this domain more important, resulting in a difference on domain level (Cohen's d 0.36, *p* = .001). Differences were also calculated in the parental participation domain (Cohen's d 0.26, *p* = .001). Parents rated five of the nine items in this domain more important. The other domains, care and cure, organization, and professional attitude, did not yield significant differences.

Table 2 | Care items (n = 12) ranked by healthcare professionals as more important than parents

	Parents (n = 559)		Professional (n = 264)			
	Mean	**SD**	**Mean**	**SD**	**Cohen's d**	***p* (Two-Tailed)**
Domain Information						
Caregivers' communication with non Dutch speaking parents is through an interpreter or the interpreter-telephone service	7.89	2.26	8.97	1.00	-0.67	.001
Parents are informed about PICU rules	7.95	1.66	8.41	0.96	-0.35	.001
Caregivers give no conflicting information to the parents	9.15	1.42	9.37	0.75	-0.21	.003
Domain Care & Cure						
Caregivers work in team with a strong group cohesion	8.53	1.48	9.04	0.69	-0.47	.001
Caregivers are alert to the child's comfort	9.05	1.12	9.38	0.61	-0.38	.001
Caregivers provide emotional support to child and parents	8.56	1.41	8.81	0.76	-0.23	.001
Domain Organization						
The child's bed space is amply enough	8.18	1.71	8.74	0.87	-0.43	.001
Domain Parental Participation						
Caregivers regularly inform after parental experiences during the course of admission	7.58	1.97	8.11	1.01	-0.36	.001
Caregivers facilitate parents in expressing their feelings	7.91	1.65	8.17	0.90	-0.20	.005
Domain Professional Attitude						
Parents are offered religious / spiritual support	6.98	2.35	8.18	0.93	-0.73	.001
Caregivers pay attention to siblings	7.46	2.04	7.95	1.14	-0.31	.001
Caregivers are alert to the cultural background of the child and parents	7.77	2.00	8.12	1.07	-0.23	.001

PICU, pediatric intensive care unit. Scoring scale was a 10-point scale: 1 = completely unimportant to 10 = extremely important; ranking of items is based on Cohen's d (unit weighted).

DISCUSSION

A 74-item questionnaire was constructed to identify PICU satisfaction-with-care items that parents and professionals consider most important. Dissimilarities between parents' and professionals' perceptions were found for a considerable number of care items. Others have used the 45-item Critical Care Family Needs Inventory to document the perceptions of family members and parents in intensive care settings.[13-15] A comparison is hampered by the fact that the Critical Care Family Needs Inventory specifically measures family needs and that the instrument has only been validated in adult intensive care settings. Similarity in outcome on a few items is apparent, however, notably with regard to informational needs. Family members rated these needs more important than did adult intensive care professionals, in particular information about the prognosis and having questions answered honestly.[1] These needs bear a relation to the outcome on the more detailed items in our study such as information about tests, changes in the child's condition, and consequences of treatment. Although both parents and professionals rated these items as highly important, parents still found them significantly more important. Identifying parent's perceptions is important for future family-centered care directives, quality of care improvement, and improving parental satisfaction.[16,17]

The importance of communication between caregivers and family members has been addressed in intensive care settings.[18] Our results show that parents rated ten of the 16 information items as more important than did professionals. Thus, although the importance has been recognized, the caregivers still might underestimate the informational needs and the impact on parents if these needs are not met sufficiently. Not only does oral information seem to be of relevance, but also access to written information.[19] We recommend consulting parents regularly to evaluate insufficiencies of informational services.

The Institute of Medicine's 2001 report on quality in healthcare portrays six dimensions of limits in current care delivery: safety, effectiveness, efficiency, timeliness, patient centeredness, and equity.[20] Stimulated by this report, healthcare systems have taken these dimensions into consideration.[21] Particularly safety receiving medication administration received a lot of attention. Through the media, the public domain became aware of the magnitude and impact of medication errors. This might have influenced parents' views in our study seeing that they rated the items receiving medication information and administration as significantly more important than did professionals. Equity is another dimension that has received increased attention, particularly in multi-cultural societies. In our study, the professionals and the non-Dutch parents agreed on the importance of alertness to cultural backgrounds. Two additional cultural items, communication through interpreters and religious support, were rated more important by professionals, reflecting certain awareness on multicultural care. However, there is a limitation in that our questionnaire contained no more than three cultural-related items thus not adequately reflecting multicultural care. Aspects of multicultural care are important measures because parental preferences might vary by ethnical background. For example, the involvement of parents in decisionmaking was shown to differ between Canada (Quebec) and France.[22] The Canadian parents often were the decisionmakers, whereas the French parents tended to prefer good communication and have the physicians make treatment decisions.

A possible bias in the interpretation of the study findings could be the reasons and motives behind the perceptions of the parents and professionals. A child's PICU admission is for parents often a single experience. Factors such as the child's severity of illness, parental stress, and family ethnicity might influence the parents' perceptions. Additionally, studies in the United States confirmed that parents of ethnic minorities and white parents experience the communication with physicians differently.[23,24] Concerning the PICU staff's perceptions, their working experience might have an effect on their views on pediatric intensive care practices. The aim of the present study was not to single out various specific groups among parents and professionals. The study aimed to document the general perceptions of the parents and professionals, bringing them together and closing the gap of any care discrepancies. Indeed, future studies need to differentiate the perceptions of various homogeneous groups of parents preferably related to the views of the PICU professionals.

Because the used methods to explore parents' and professionals' perspectives were different, another bias in comparing the results might occur. The Delphi study among the PICU professionals had two questionnaire rounds, whereas the survey among parents comprised just one questionnaire. The questionnaire in the second Delphi round was the one used in the survey among parents. In both studies, the reliability estimates of the six domains were comparable (Cronbach's α between 0.74 and 0.94). Based on this finding it may be concluded that if there is any bias, it could be qualified as minor.

The study findings have several clinical implications. Overall, physicians and nurses should review the issues rated as important by parents and reflect these to their own practice. Particularly, the items related to parent-staff communication are of importance since poor communication might induce conflicts between parents and staff.[25] Furthermore, the results might be valuable for the training of PICU professionals. Using parental experiences in educational programs and in mentoring staff at the bedside might improve the professionals' communication skills since these competencies are not often represented in training sessions.

In conclusion, this study revealed differences between parents' and professionals' views on the importance of a majority of PICU care practices. Knowledge of the perceptions of the parents provides a comprehensive basis for clinicians to reflect on their practices. This may have a beneficial impact on improving family-centered care practices based on the empowerment of parents.

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CHAPTER 11

Perceptions of parents, nurses, and physicians on neonatal intensive care practices

Jos M. Latour, Jan A. Hazelzet, Hugo J. Duivenvoorden, Johannes B. van Goudoever

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ABSTRACT

Objective: To identify satisfaction with neonatal intensive care issues as viewed by parents and healthcare professionals and to explore similarities and differences between parents and healthcare professionals.

Study design: A 3-round Delphi method to identify neonatal care issues (round 1) and to determine the importance of these issues (rounds 2 and 3) was conducted among nurses (n = 84) and physicians (n = 14), followed by an exploratory survey among parents (n = 259). Main outcome measures were 92 neonatal care-related items.

Results: Sixty-eight nurses and 13 physicians completed all 3 rounds. The first round yielded 419 neonatal care related statements, which were clustered into 92 items. The survey was completed by 148 (57%) parents. Parents rated 25 of 92 care items significantly higher than did the professionals (effect size of Cohen's d 0.31 to 1.14, $P \leq 0.02$). Two items related to medication administration had the largest effect size. Professionals rated 7 items significantly higher than did parents (Cohen's d -0.31 to -0.58, $P \leq 0.04$). One of these was assigning a physician and a nurse to the parents. Three were related to multicultural care.

Conclusions: This study revealed disparities between parents and neonatal intensive care unit staff on a number of care issues reflecting incongruity in recognizing parents' desires.

INTRODUCTION

Today's healthcare systems are influenced by politicians, health insurance companies, and patient organizations. These actors exert pressure towards efficiency and effectiveness of customer-driven care with a focus on patient-centered services and outcome measurement**s**. Perceptions of patients have therefore become important outcome variables.[1,2] The complexity of a neonatal intensive care unit (NICU) requires a tailor-made instrument to measure parents' experiences. It should focus on the infant's comfort and on information-related issues, as these have been identified as most important for parents.[3] Another consideration is the family-centered care principle of neonatology.[4-6] Partnerships between parents and healthcare professionals and parental involvement in care processes are 2 examples that have been described as beneficial for parents.[7,8] There are reasons to believe, however, that family-centered care principles are not consistently applied in daily practice.[9,10] Notably, there is evidence that NICU nurses do not consistently work according to these practices.[11] It would be advisable, therefore, to incorporate concepts of family-centered care in satisfaction surveys.

The literature contains only a few satisfaction surveys in neonatology.[12-14] All originate from Northern America and date back to the 1990s. A literature review, parental interviews, and neonatal staff reports lie at the basis of the NICU-Parental Satisfaction Form (NICU-PSF), which, with 62 items, is the most comprehensive tool.[13] There are several arguments against the use of NICU-PSF in today's context. Since the validation of the NICU-PSF, neonatology has seen significant changes. These include, for example, communication strategies oriented toward the empowerment of parents, as promoted by the family-centered care movement. There also is the trend toward multiculturalism. Parents from different cultural backgrounds might require specific attention for different needs. These changes justify new initiatives to develop a parent satisfaction instrument suited to today's needs.[15] It is against this background that we performed 2 related studies.

The objectives of the studies were (1) to identify NICU nurses and physicians' perceptions of parental satisfaction with care issues and to reach a consensus on the identified issues, (2) to explore the parent's perceptions on satisfaction with care issues, and (3) to identify differences and similarities in opinions on care issues between parents and NICU healthcare professionals, including ethnic differences.

METHODS

The exploratory and descriptive studies were designed as a 3-round Delphi method for nurses and physicians and an exploratory survey method for parents. The Delphi study was conducted first. The results of this study were then used for the survey study among parents. Both studies were completed between May 2007 and May 2008. The medical ethical review board of the Erasmus University Medical Center gave approval for the study.

The setting was a 30-bed level III NICU in the Netherlands. The yearly admission rate is around 700 patients, from low-birth-weight preterm infants (≥ 24 weeks gestational age) to 4-week-old term neonates. Approximately 250 very-low-birth-weight infants are admitted annually. Participants were nurses and physicians as well as parents of infants. Eighty-four nurses and 14 physicians consented to participate in the Delphi study. In total, 259 parents were invited to complete the questionnaire (Figure 1). Excluded from the study were parents of infants admitted for less than 48 hours and those whose child died during NICU admission.

The Delphi method allows for a systematic consultation of a large number of experts and the collection, evaluation, and tabulation of these experts' opinions.[16] Its strength lies in 4 specific characteristics: anonymity, iteration, controlled feedback, and statistical group response. Anonymity is guaranteed by the use of questionnaires. Iteration is achieved by presenting a topic over a certain number of rounds. Controlled feedback and statistical group response take place in between rounds, when individual experts are informed about the opinions of the total group. The Delphi method used in this study is outlined in Figure 2. The first step (Delphi round 1) was a questionnaire round to identify neonatal care issues among nurses and physicians. The questionnaire contained demographic characteristics and a single question: What do you think parents find important in the care for their child? Participants were asked to provide a maximum of 5 issues. The qualitative data of this first Delphi round were matched with a framework developed from a literature review of validated satisfaction-with-care instruments related to neonatal, pediatric and adult intensive care.[15] The framework contained 78 care issues. The written responses of the first Delphi round were independently reviewed and coded into the framework by 2 researchers (J.M.L. and K.v.N). If responses did not fit within the framework, they were incorporated into new statements. After completion of coding, outcomes for both researchers were compared until consensus was reached. A third researcher (J.A.H) functioned as an auditor to review the process. The result was a questionnaire with 92 neonatal care items. The second step (Delphi round 2) elicited opinions of the participants in a quantitative questionnaire in which the items were clustered in 5 domains: information (20 items), care and treatment (23 items), organization NICU (20 items), parental participation (14 items), and professional attitude (15 items). The participants were asked to rate each item on a 6 point scale ranging from "completely unimportant" to "extremely important". In the third step (Delphi round 3) the same questionnaire was used. This time, the results of round 2, in terms of the group mean rating of every item, were included in the questionnaire to attain consensus among participants. The participants were asked to review the annotated items again on importance.

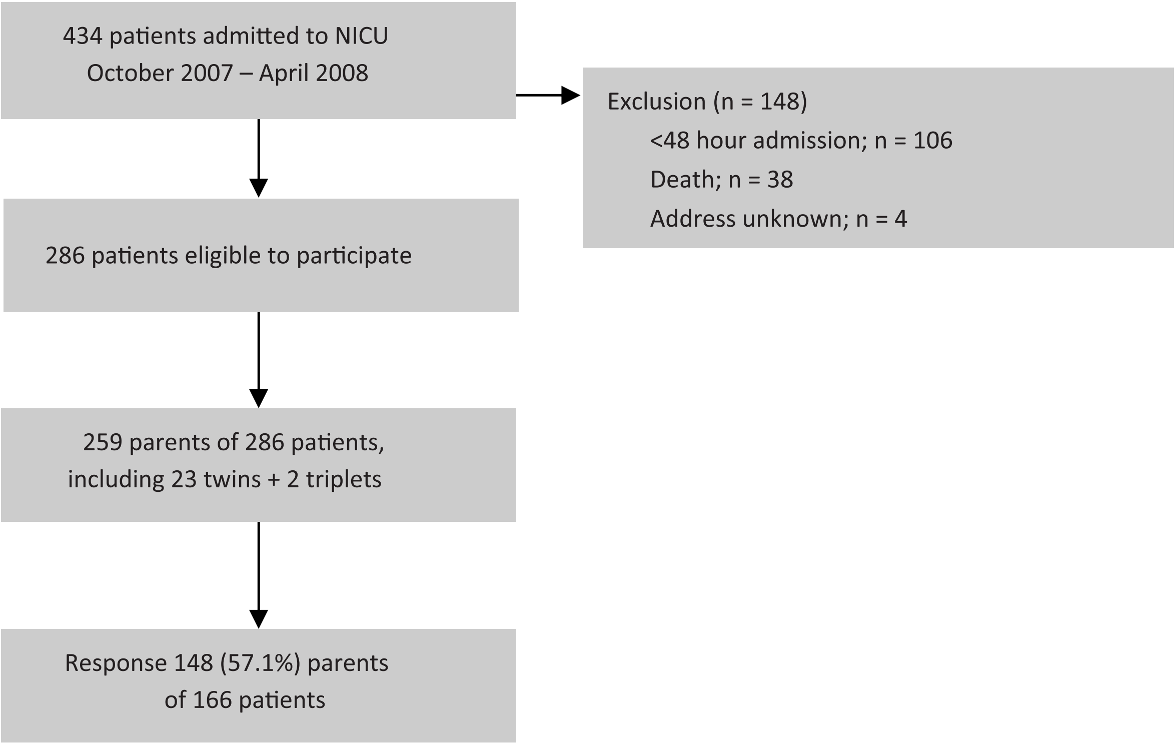

Figure 1 | Flowchart inclusion of parents

In the exploratory study among parents a self-administered questionnaire, including the 92 items regarding neonatal care issues, was used. Parents were sent a letter explaining the aim of the study 2 to 3 weeks after discharge of their child from the NICU. They were invited to rate each item's importance on a 6 point scale ranging from "completely unimportant" to "extremely important". Parents were also invited to suggest additional items they considered valuable.

The quantitative data were analyzed using SPSS (version 15, Chicago, Illinois). The demographic variables were analyzed by descriptive statistics. Significances between sex and type of profession of respondents and nonrespondents in the Delphi study were calculated with Fisher exact test. The *t* test for independent observations was used for the other demographic variables. Means and standard deviations were used for ranking the importance of the care items in both studies. The Cohen's d, standardized mean difference, was used to calculate the effect-size using the means and standard deviations of both the parents and the NICU professionals. The interpretation of the effect-size is small with a value of 0.2, medium with 0.5, and large > 0.8.[17] Guided by the interpretation of the Cohen's d, we used an effect-size of ≥ 0.30 or ≤ -0.30 as the cut off point for statistically meaningful differences which correspond to $P < 0.05$ (*t* test, 2-tailed). Related to the study aims, the *t* test for independent observations was used to calculate statistical differences of the importance of the items between the healthcare professionals and parents. All statistical testing took place at a 0.05 level of significance (2-tailed).

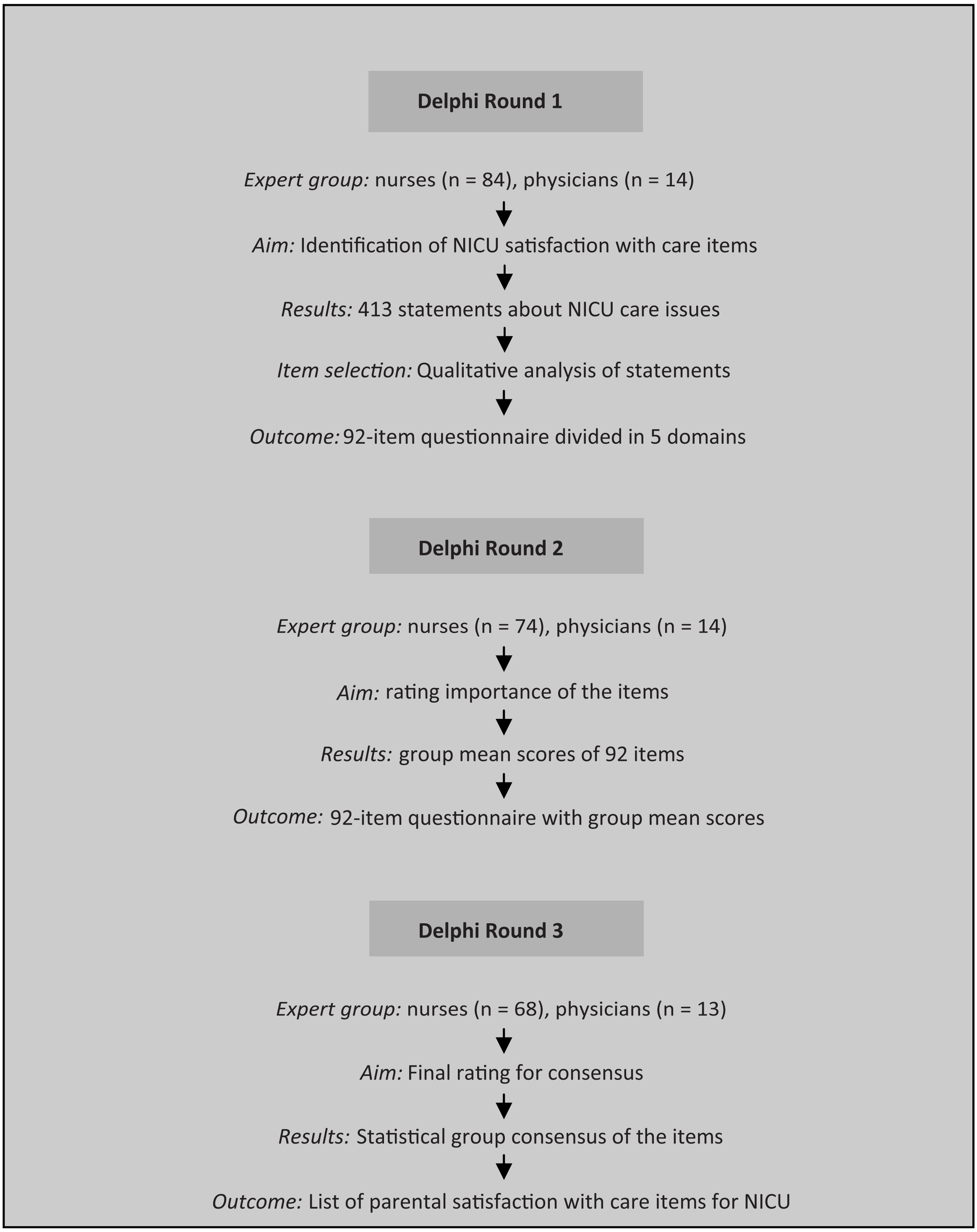

Figure 2 | Delphi study design

RESULTS

Of the 98 healthcare professionals who consented to participate in the Delphi study, 81 (83%) completed all three questionnaires (68 nurses and 13 physicians). Table 1 presents characteristics of the participants in each Delphi round. NICU experience ranged from 0.50 to 27 years and professional experience ranged from 1 to 35 years. The demographic variables for nonrespondents and respondents in round 3 did not differ significantly.

Table 1 | Characteristics of NICU professionals

			non-response		non-response	
	R1	R2	R2	R3	R3	
	n = 98	n = 89*	n = 9	n = 81	n = 8	*P*
Sex (F/M)	88/10	80/8	9/0	73/8	8/0	1.00 [1]
Age, years: mean (SD)	37.5 (8.78)	37.5 (8.92)	36.8 (7.69)	37.6 (9.07)	36.0 (7.58)	0.59 [2]
Profession (nurse/physician)	84/14	74/14	9/0	68/13	7/1	1.00 [1]
Experience NICU in years: mean (SD)	7.2 (6.39)	7.2 (6.55)	6.11 (4.68)	7.2 (6.57)	7.9 (6.70)	0.79 [2]
Experience overall profession in years: mean (SD	12.3 (8.91)	12.4 (9.11)	11.3 (7.70)	12.6 (9.38)	10.3 (5.78)	0.31 [2]
Working Hours per week: mean (SD)	32.3 (8.87)	32.7 (8.94)	28.1 (7.49)	33.1 (8.53)	28.1 (11.98)	0.29 [2]

*R indicates round; * one case missing; [1]Fisher exact test; [2]t test for independent observation.*

The first round yielded 419 short statements on neonatal care issues, an average of 4.3 statements per participant. The statements were clustered into 5 domains: (1) information (n = 104); (2) care and treatment (n = 64); (3) organization (n = 30); (4) parental participation (n = 98); and (5) professional attitude (n = 123). The following step was to match these statements into the framework derived from the literature. Most of the statements (n = 266) matched with 1 of the 78 items of the framework. The remaining 153 statements were condensed into 14 new issues, each supported by 1 to 42 statements. Thus, the first Delphi round resulted a list of 92 care related items distributed over 5 domains.

In the 7-month data collection period 434 children were discharged. Parents (n = 259) of 286 children were eligible to participate. A total of 148 parents (57.1%) completed the questionnaire (Figure 1). Most families were Dutch (n = 102, 68.9%). The other 46 (31.1%) families were mainly from a Moroccan (n = 10), Turkish (n = 6), or Surinamese (n = 5) cultural background. The characteristics are presented in Table 2.

Generally, mean item scores were fairly high. Nevertheless, ranking of the 92 items on importance was possible based on the definition: highest mean albeit the lowest standard deviation (Table 3). Finally, 78 (52.7%) parents wrote comments in the last section of the questionnaire. However, the narratives did not add additional items but rather described personal situations complementing the 92 items.

Table 2 | Characteristics of infants and parents

	Infants (n = 166)		**Parents (n = 148)**	
Male	98	(59%)		
Gestational age in weeks: median (min-max)	32	(24-42)		
Birth weight in grams: median (min-max)	1900	(630-4620)		
Length of stay NICU in days: median (min-max)	8.5	(2-109)		
Ventilation days: median (min-max)	1	(0-31)		
Questionnaire completed by*				
Mother			80	(54.4%)
Father			13	(8.8%)
Both			52	(35.4%)
Legal guardian			2	(1.4%)
Ethnicity				
Dutch			102	(68.9%)
Non-Dutch			46	(31.1%)

one case missing.

Table 3 | Similarities and differences of opinions of parents and healthcare professionals on neonatal care items

	Parents (n = 148)		Professionals (n = 81)			
	mean	**SD**	**mean**	**SD**	**Cohen's d**	***P***
Domain Information						
Parents are informed about the child's illness	5.81	0.47	5.60	0.59	0.40	0.008
Parents are informed about changes in the child's condition as soon as possible	5.79	0.42	5.57	0.57	0.44	0.002
Caregivers inform parents daily about the child's care and treatment	5.78	0.65	5.42	0.67	0.55	0.001
Caregivers provide honest information to parents	5.76	0.56	5.70	0.49	0.12	0.44
Parents are informed about tests and procedures	5.75	0.52	5.49	0.64	0.45	0.003
Caregivers answer parents' questions adequately	5.74	0.61	5.68	0.52	0.11	0.43
Caregivers inform the parents about the treatment consequences	5.68	0.71	5.44	0.65	0.35	0.02
Parents are informed about the child's future perspectives	5.57	0.73	5.36	0.70	0.29	0.04
Caregivers give no conflicting information to the parents	5.57	0.86	5.60	0.67	-0.04	0.75
Parents are informed about the (adverse) effects of the medication	5.52	0.79	4.74	0.85	0.95	0.001
Parents have easy access to information	5.44	0.74	5.21	0.67	0.33	0.02
Caregivers inform the parents in a way it is understandable for them	5.37	0.93	5.60	0.56	-0.31	0.04
Parents are informed about NICU rules	4.95	0.92	4.94	0.70	0.01	0.95
Caregivers inform the parents about breastfeeding	4.78	1.12	4.55	0.76	0.24	0.05
Caregivers provide not only oral but also written information	4.64	1.08	3.86	0.98	0.76	0.001
Caregivers inform the parents on the best moment for the parents	4.64	1.10	4.35	0.80	0.31	0.02
Caregivers' communication with non Dutch speaking parents is through an interpreter or the interpreter-telephone	4.64	1.56	5.31	0.75	-0.58	0.001
The way to the NICU is clearly signposted	4.60	1.10	4.86	0.82	-0.27	0.05
Parents are informed of visiting hours for other family members	4.34	1.26	4.25	1.00	0.08	0.55
Parents are informed about sanitary units	3.93	1.26	4.11	0.81	-0.17	0.19

	Parents (n = 148)		Professionals (n = 81)			
	mean	**SD**	**mean**	**SD**	**Cohen's d**	***P***
Domain Care and Treatment						
The correct medication is given at the right time	5.84	0.39	5.27	0.61	1.14	0.001
Caregivers know their profession	5.83	0.45	5.77	0.46	0.13	0.31
Pain is prevented and/or treated	5.81	0.43	5.75	0.46	0.13	0.38
Caregivers react promptly to changes in the child's condition	5.76	0.46	5.68	0.50	0.17	0.23
Caregivers jointly pursue one goal: adequate care and treatment of child and parents	5.70	0.61	5.56	0.57	0.24	0.08
Caregivers are aware of the child's medical history	5.63	0.75	5.26	0.63	0.54	0.001
A caregiver always advises parents during acute admission or an acute situation	5.53	0.65	5.04	0.77	0.69	0.001
Parents know which physician and nurse are responsible for the care of their child	5.51	0.72	5.12	0.64	0.57	0.001
At discharge, caregivers provide clear information to colleagues	5.50	0.76	5.32	0.63	0.26	0.06
Caregivers are alert to the child's developmental growth	5.49	0.70	4.94	0.71	0.78	0.001
Caregivers are alert to the child's comfort	5.49	0.73	5.56	0.52	-0.11	0.41
Caregivers display a caring attitude towards infant and parents	5.45	0.68	5.33	0.57	0.19	0.16
Caregivers are considerate to the infant's needs	5.45	0.74	5.00	0.76	0.60	0.001
Caregivers prepare the parents for a (planned) NICU admission	5.43	0.80	4.83	0.87	0.72	0.001
Caregivers take care of the infant to lay neatly and well-cared for in the incubator/bed	5.42	0.73	5.25	0.62	0.25	0.06
Parents are adequately prepared for the child's discharge	5.28	0.85	5.12	0.68	0.21	0.12
Caregivers provide emotional support	5.23	0.73	5.17	0.69	0.08	0.59
An assigned physician and nurse serve as contacts for parents during prolonged ICU-stay	5.21	1.02	5.49	0.53	-0.36	0.008
Caregivers work with a team spirit	5.18	0.78	5.01	0.73	0.22	0.10
Caregivers adequately meet the needs of the parents	5.10	0.78	4.89	0.73	0.28	0.04
Parents realize they cannot always have a caregiver's immediate attention	4.85	0.96	4.69	0.80	0.18	0.19
Nurses inform the parents of the availability of the NICU social worker for a meeting	4.73	1.09	4.90	0.64	-0.20	0.17
The lactation nurse is available to provide specific support to parents about breastfeeding	4.55	1.18	4.51	0.94	0.04	0.66

	Parents (n = 148)		Professionals (n = 81)			
	mean	SD	mean	SD	Cohen's d	*P*
Domain Organization						
Aggression by caregivers and parents is not tolerated in the NICU	5.62	0.75	5.64	0.56	-0.03	0.80
The infant's incubator/bed is clean	5.59	0.60	5.31	0.61	0.47	0.001
The NICU is clean	5.57	0.66	5.37	0.60	0.32	0.02
The NICU is well accessible by phone	5.51	0.78	5.53	0.53	-0.03	0.82
Moment of discharge is not influenced by bed capacity	5.38	0.90	4.67	0.89	0.79	0.001
The caregivers are efficiently organized	5.28	0.71	5.10	0.56	0.28	0.04
Visiting hours are flexible	5.28	0.86	5.12	0.68	0.21	0.14
Rooming-in near the NICU is possible	5.23	1.03	4.79	0.79	0.48	0.001
The NICU environment feels safe	5.20	0.88	5.10	0.63	0.13	0.30
Noise in the NICU is muffled as much as possible	5.11	0.89	5.05	0.71	0.08	0.56
Written information on unit rules, diseases and procedures are available in the NICU	5.03	0.94	5.09	0.62	-0.08	0.58
The infant's bed space is amply sufficient	5.01	1.01	5.15	0.73	-0.16	0.23
The NICU has comfortable furniture	4.76	1.04	4.75	0.75	0.01	0.94
The NICU has a special room for mothers to express milk	4.73	1.18	4.93	0.61	-0.22	0.16
The NICUs design is family-friendly	4.72	1.10	4.57	0.74	0.16	0.22
Every incubator has a camera to provide online contact between parents and infant	4.30	1.39	4.09	0.91	0.18	0.12
The waiting room is fitted comfortably	4.20	1.26	4.61	0.68	-0.42	0.002
Catering for parents is well taken care of	4.06	1.31	4.32	0.79	-0.25	0.08
A locker on the NICU is available for all parents	3.63	1.45	4.22	0.96	-0.49	0.001
The NICU have internet access for parents	3.22	1.55	3.18	1.20	0.03	0.64
Domain Parental Participation						
Parents trust the caregivers	5.72	0.48	5.58	0.55	0.27	0.07
Caregivers support the bonding between infant and parents	5.64	0.62	5.59	0.54	0.09	0.53
Caregivers and parents show respect to each other	5.61	0.63	5.15	0.57	0.77	0.001
Caregivers give instructions to the parents about care issues of the infant	5.56	0.72	5.58	0.50	-0.03	0.83
Caregivers stimulate parents to help in the care of the infant	5.52	0.74	5.48	0.53	0.06	0.65

	Parents (n = 148)		Professionals (n = 81)			
	mean	**SD**	**mean**	**SD**	**Cohen's d**	***P***
Caregivers stimulate and support parents in kangaroo care	5.52	0.85	5.59	0.49	-0.10	0.52
Caregivers stimulate parents to stay close to their child during procedures and tests	5.38	0.84	4.91	0.73	0.60	0.001
Caring aspects for home are discussed before discharged	5.36	0.84	5.04	0.58	0.45	0.001
Caregivers stimulate the parents to be close to their infant	5.32	0.85	5.36	0.58	-0.06	0.74
Parents share in the decision-making on the care and treatment of their child	5.03	1.04	4.95	0.71	0.09	0.44
Caregivers facilitate parents in expressing their feelings	4.85	0.90	4.83	0.65	0.03	0.85
Caregivers regularly inform after parental experiences during the course of admission	4.83	0.93	4.99	0.56	-0.22	0.11
Parents receive and are suggested to keep a diary	4.71	1.19	4.69	0.74	0.02	0.73
At admission, caregivers ask parents their expectations	4.63	1.05	4.39	0.77	0.26	0.05
Domain Professional Attitude						
Caregivers give the highest priority to the child's health	5.90	0.31	5.69	0.47	0.54	0.001
Caregivers adopt principles of hygiene	5.85	0.38	5.81	0.42	0.10	0.57
Caregivers provide equal care; irrespective of race, religion, sex, and education	5.75	0.51	5.64	0.53	0.21	0.14
Regardless the work pressure, the caregiver's attention towards infant and parents is not allowed to slacken	5.58	0.73	5.09	0.66	0.71	0.001
Parents feel welcome at admission	5.57	0.59	5.47	0.59	0.17	0.20
Caregivers respect the child and parents	5.56	0.58	5.54	0.53	0.04	0.79
Caregivers refrain from unnecessary discussions at the child's bedside	5.42	0.91	5.43	0.55	-0.01	0.87
Caregivers always work agreeably together	5.34	0.72	5.37	0.51	-0.05	0.72
Caregivers take time to listen to parents	5.30	0.74	5.23	0.55	0.11	0.46
Caregivers safeguard privacy of child and parents	5.28	0.78	5.37	0.58	-0.13	0.32
Caregivers show empathy to child and parents	5.11	0.89	4.98	0.55	0.18	0.16
Caregivers introduce themselves with name and position	5.03	0.96	4.89	0.67	0.17	0.18
Caregivers pay attention to siblings	4.57	1.18	4.64	0.70	-0.07	0.73
Caregivers are alert to the cultural background of the infant and parents	4.45	1.27	4.83	0.69	-0.39	0.008
Parents are offered religious / spiritual support	4.23	1.38	4.77	0.69	-0.52	0.001

Scores were rated on a 1 to 6-point scale from "completely unimportant" to "extremely important."

Parents rated 25 of the 92 items as significantly more important than did the NICU professionals (Cohen's d, 0.31 to 1.14 , $P \leq 0.02$). Most of these items were in 2 domains: "Information" and "Care and Treatment" (Table 4). The largest effect size rated as very important by parents was related to medication: "parents are informed about the (adverse) effects of the medication" (Cohen's d = 0.95, $P < 0.01$) and "the correct medication is given at the right time" (Cohen's d =1.14, $P < 0.01$). The professionals rated 7 items more important than the parents (Cohen's *d* between -0.31 and -0.58, $P \leq 0.04$) as listed in Table 5.

Table 4 | Care items (n = 25) parents find more important than NICU professionals

	Parents (n = 148)		Professionals (n = 81)			
	mean	**SD**	**mean**	**SD**	**Cohen's d**	***P***
Domain Information						
Parents are informed about the child's illness	5.81	0.47	5.60	0.59	0.40	0.008
Parents are informed about changes in the child's condition as soon as possible	5.79	0.42	5.57	0.57	0.44	0.002
Caregivers daily inform parents about the child's care and treatment	5.78	0.65	5.42	0.67	0.55	0.001
Parents are informed about tests and procedures	5.75	0.52	5.49	0.64	0.45	0.003
Caregivers inform the parents about the treatment consequences	5.68	0.71	5.44	0.65	0.35	0.02
Parents are informed about the (adverse) effects of the medication	5.52	0.79	4.74	0.85	0.95	0.001
Parents have easy access to information	5.44	0.74	5.21	0.67	0.33	0.02
Caregivers provide not only oral but also written information	4.64	1.08	3.86	0.98	0.76	0.001
Caregivers inform the parents on the best moment for the parents	4.64	1.10	4.35	0.80	0.31	0.02
Domain Care and Treatment						
The correct medication is given at the right time	5.84	0.39	5.27	0.61	1.14	0.001
Caregivers are aware of the child's medical history	5.63	0.75	5.26	0.63	0.54	0.001
A caregiver always advices parents during acute admission or an acute situation	5.53	0.65	5.04	0.77	0.69	0.001
Parents know which physician and nurse are responsible for the care of their child	5.51	0.72	5.12	0.64	0.57	0.001
Caregivers are alert to the child's developmental growth	5.49	0.70	4.94	0.71	0.78	0.001

	Parents (n = 148)		Professionals (n = 81)			
	mean	**SD**	**mean**	**SD**	**Cohen's d**	***P***
Caregivers are considerate to the infant's needs	5.45	0.74	5.00	0.76	0.60	0.001
Caregivers prepare the parents to a (planned) NICU admission	5.43	0.80	4.83	0.87	0.72	0.001
Domain Organization						
The infant's incubator/bed is clean	5.59	0.60	5.31	0.61	0.47	0.001
The NICU is clean	5.57	0.66	5.37	0.60	0.32	0.02
Moment of discharge is not influenced by bed capacity	5.38	0.90	4.67	0.89	0.79	0.001
Rooming-in near the NICU is possible	5.23	1.03	4.79	0.79	0.48	0.001
Domain Parental Participation						
Caregivers and parents show respect to each other	5.61	0.63	5.15	0.57	0.77	0.001
Caregivers stimulate parents to stay close to their child during procedures and tests	5.38	0.84	4.91	0.73	0.60	0.001
Caring aspects for home are discussed before discharged	5.36	0.84	5.04	0.58	0.45	0.001
Domain Professional Attitude						
Caregivers give the highest priority to the child's health	5.90	0.31	5.69	0.47	0.54	0.001
Regardless the work pressure, the caregiver's attention towards infant and parents is not allowed to slacken	5.58	0.73	5.09	0.66	0.71	0.001

Scores were rated on a 1 to 6-point scale from "completely unimportant" to "extremely important."

Table 5 | Care items (n = 7) NICU professionals find more important than parents

	Parents (n = 148)		**Professionals (n = 81)**			
	mean	**SD**	**mean**	**SD**	**Cohen's d**	***P***
Domain Information						
Caregivers inform the parents in a way it is understandable for them	5.37	0.93	5.60	0.56	-0.31	0.04
Caregivers' communication with non Dutch speaking parents is through an interpreter or the interpreter-telephone	4.64	1.56	5.31	0.75	-0.58	0.001
Domain Care and Treatment						
An assigned physician and nurse serve as contacts for parents during prolonged ICU-stay	5.21	1.02	5.49	0.53	-0.36	0.008
Domain Organization						
The waiting room is fitted out comfortably	4.20	1.26	4.61	0.68	-0.42	0.002
A locker on the NICU is available for all parents	3.63	1.45	4.22	0.96	-0.49	0.001
Domain Professional Attitude						
Caregivers are alert to the cultural background of the infant and parents	4.45	1.27	4.83	0.69	-0.39	0.008
Parents are offered religious / spiritual support	4.23	1.38	4.77	0.69	-0.52	0.001

Scores were rated on a 1 to 6-point scale from "completely unimportant" to "extremely important."

Three statements in the questionnaire might be considered of importance for multi-cultural care: alertness to family's cultural background, the use of interpreters in communication, and religious or spiritual support. Parents of Dutch origin rated these 3 statements as significantly less important than did the professionals. In contrast, differences between the non-Dutch parents and the professionals were less evident and not significant (Table 6).

Table 6 | Differences between professionals compared to Dutch parents and non-Dutch parents.

	Professionals (n = 81)	Dutch parents (n = 102)		Non-Dutch parents (n = 46)	
	Mean (SD)	Mean (SD)	Cohen's d	Mean (SD)	Cohen's d
Caregivers' communication with non Dutch speaking parents is through an interpreter or the interpreter-telephone	5.31 (0.75)	4.52 (1.56)	-0.68*	4.95 (1.53)	-0.32 (NS)
Caregivers are alert to the cultural background of the infant and parents	4.83 (0.69)	4.35 (1.27)	-0.49*	4.80 (1.31)	0.03(NS)
Parents are offered religious / spiritual support	4.77 (0.69)	4.18 (1.36)	-0.57*	4.44 (1.47)	-0.30(NS)

*Scores were rated on a 1- to 6-point scale from "completely unimportant" to "extremely important." * P (2-tailed) is <0.005; NS, not significant*

DISCUSSION

Being more aware of family-centered care, healthcare professionals today strive to empower parents in the care of their child in the NICU. Insight into parental perceptions is available[3,18,19], but there appears to be a gap between knowledge and practice.[20,21] This is remarkable because the impact of family-centered care initiatives has positive effects on parental stress, comfort and confidence.[4] Thus, assessments of parental experiences and needs are warranted to improve our services towards better outcomes for infants and the well-being of parents.

Good examples of the gap between knowledge and practice are the seven statements that professionals rated as more important than did parents. For one, providing lockers for the parents was more important for the professionals and rated among the least important issues by parents despite the fact that lockers are not available in our NICU. Another important issue is the assignment of a physician and a nurse to the parents. In some countries this is a governmental requirement for all hospitals. The Dutch healthcare system has no statutory regulations. However, having a first responsible nurse and physician for every child and parents has been promoted for the past decade. The importance attached to it by the professionals might indicate that this issue has not been fully integrated in daily practice and requires attention.

Perceptions of family needs were documented by 2 studies in adult Intensive Care Units (ICU).[22,23] Both studies used the Critical Care Family Needs Inventory (CCNFI) scale.[24] In a third study, the CCNFI was adapted to the NICU population.[21] Family members generally rated the items higher than did the professionals. In all 3 studies, family members and parents rated items such as "knowing the prognosis," "knowing the best possible care is given," and "have questions answered honestly" as most important. This was also observed among the parents in the present study. They rated the statement about highest priority given to their child's health as very important. The comparison is limited, however, by the fact that the instrument used in the present study differs from the CCNFI in number and concepts of the items and also measures another phenomenon.

Change in attitude of healthcare professionals toward provision of patient-driven care might be feasible when scientific evidence becomes available. A study among 292 parents and 197 neonatologists and nurses revealed that many parents (64%) would intervene to save infants regardless the condition or weight at birth, versus no more than 6% of the professionals.[25] In this respect, it appears that clinicians and parents do not always share the same values or beliefs in the care of their child.

Partnership between professionals and parents is being promoted, characterized by parental presence, involvement, open communication, and shared decision-making. These principles require a change in roles and attitudes of the NICU staff.[7,26] The results of the present study provide a scientific basis to share the expertise and needs of the parents with professionals. As an illustration, parents rated the items related to medication administration and information about the effect of medication significantly higher than did the professionals. This might demonstrate a changing attitude of parents to be more deeply involved in the care of their child. In this respect, the implication for the healthcare professionals is directed towards a reconsideration of the current parental wishes.

The political arena and communities in many countries are focusing on multicultural issues, integration of minority groups, and discrimination. Issues such as respect, violence, and equity have received increased attention in healthcare. For instance, the Netherlands is known for its multicultural society where pediatric departments in hospitals admit high proportions of infants and children from ethnic minority groups.[27] The assumption that parents of ethnic minorities have different preferences has been confirmed by studies from the United States.[28,29] In a large sample of parents of 36,238 children with special healthcare needs, satisfaction and the ease of using healthcare services was studied related to ethnic disparities.[29] Race and ethnicity were defined as white, black, and Hispanic. Parents with black and Hispanic race were significantly less satisfied with care than white parents. The authors noted that after multivariate adjustment for the interview language with parents, the difference disappeared. A more clinical question was addressed in a study examining ethnic differences between white, black, and Hispanic parents and their preferences to stay during their child's painful interventions.[28] Among the 300 parents, 2 ethnic differences were found: The English-speaking Hispanic parents were less likely inclined to attend resuscitation, and they also preferred to let the physician decide on attending or not. Differences between parents of diverse cultural backgrounds became clear from the results of the present study. The non-Dutch group rated the 3 care items related to cultural issues as more important than did the Dutch group. Therefore, future research could focus on satisfaction instruments that allow comparative analysis of various groups of parents.

Some discrepancies between perceptions of parents and professionals can easily be explained. The nurses and physicians have generally extensive experience with neonatal care, for parents this is often a once in a lifetime experience. Factors such as information provision by the media are bound to change parents' perceptions. Therefore, the recent media attention to aspects of patient safety, such as medication errors, might have caused parents to rate the issue on timely and correct medication administration as one of the highest priorities.

The results of the study are limited by the opinions of parents and NICU professionals on NICU care issues of 1 neonatology center. Outcomes might be different when studying this phenomenon on an (inter)national level. Nevertheless, the current results may stimulate a review among physicians and nurses of their professional practices in the light of the opinions of parents. Listening or reading parental narratives might provide a deeper understanding of the complexity of parental needs and desires.[30]

As a clinical implication of this study, physicians and nurses would do well to review the neonatal care issues identified and relate these to their own clinical practices. Furthermore, the results might also be important for future training of neonatal healthcare professionals. Translating the parental experiences into education programs might enhance the professionals' communication skills because communication competencies are often underrepresented in training programs.[31] Additionally, insight into parental experiences of a NICU admission could also help in counseling women with high risk pregnancy.[32]

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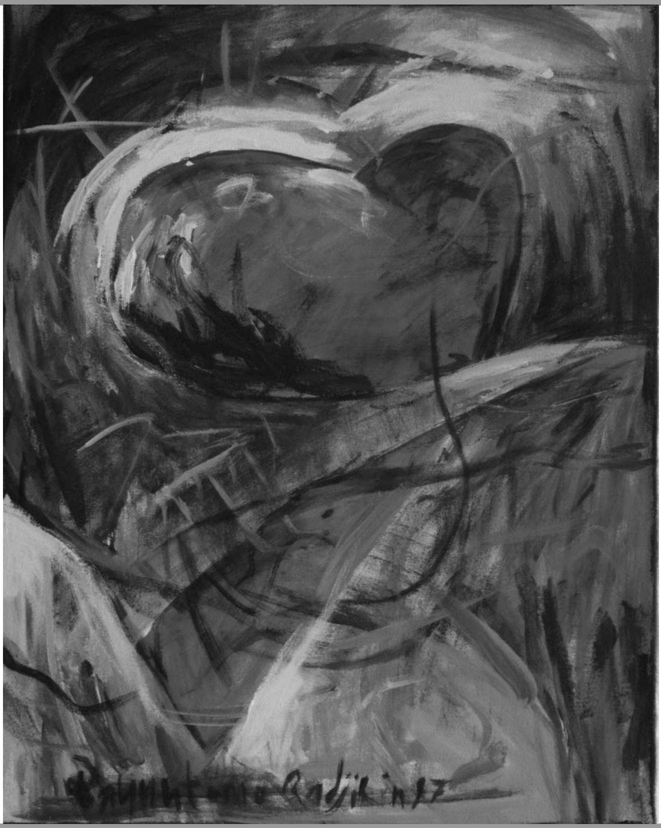

PART V

Validation

CHAPTER 12

Construction and psychometric testing of the EMPATHIC questionnaire measuring parent satisfaction in the pediatric intensive care unit

Jos M. Latour, Johannes B. van Goudoever, Hugo J. Duivenvoorden, Marcel J.I.J. Albers,
Nicolette A.M. van Dam, Eugenie Dullaart, Marc van Heerde, Marjorie de Neef,
Carin W.M. Verlaat, Elise M. van Vught, Jan A. Hazelzet

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ABSTRACT

Purpose: To construct and to test the reliability and validity of the EMpowerment of PArents in THe Intensive Care (EMPATHIC) questionnaire measuring parent satisfaction in the pediatric intensive care unit (PICU).

Methods: Structured development and psychometric testing of a parent satisfaction-with-care instrument with the results of two cohorts of parents (n=2046) from eight PICUs in the Netherlands.

Results: In the first cohort, 667/1055 (63%) parents participated followed by 551/991 (56%) parents in the second cohort. The empirical structure of the instrument was established by Confirmatory Factor Analysis with the first sample of parents confirming 65 statements within five theoretically conceptualized domains: Information, Care & Cure, Organization, Parental Participation, and Professional Attitude. The standardized factor loadings were greater than 0.40 in 63 statements. Cronbach's α, a measure of reliability, per domain ranged from 0.73 to 0.93 in both cohorts with no significant difference documenting the reliability over time. Beside rigorous content and face validity, the congruent validity of the instrument showed adequate correlation with four gold standard questions measuring overall satisfaction. The non-differential validity was confirmed with no significant differences between the population characteristics and the domains, except that parents with a child for a surgical admission were more satisfied on information issues.

Conclusions: The final EMPATHIC questionnaire incorporates 65 statements. The empirical structure of the satisfaction statements and domains was satisfactory. The reliability and validity proved to be adequate. The EMPATHIC questionnaire is a valid quality performance indicator to measure quality of care as perceived by parents.

INTRODUCTION

Performance measures of a pediatric intensive care unit (PICU) have traditionally been documented by clinical and physical parameters of critically ill children.[1-3] Others have focused on long-term outcomes of children after PICU treatment to evaluate pediatric intensive care, in particular health related quality of life.[4,5] Nevertheless, healthcare professionals are not only responsible for healthy outcomes of children. Parents too are part of the integrated care system and they have a right to receive the best care. Looking from a quality of care perspective, parent satisfaction is an important area to evaluate the desirable outcome of healthcare performances.[6] Given the increased awareness of consumer driven healthcare systems, it is not surprising that patient and family satisfaction is increasingly accepted as an important quality indicator in critical care.[7] It is expected that an increasing number of PICUs already use satisfaction surveys to document their quality of care. Whether these surveys are of an acceptable academic standard is unknown. The reality remains that only two parent satisfaction questionnaires for PICU services are documented in the literature.[8,9]

With respect to the empowerment of parents who experienced a PICU admission of their child, their knowledge is valuable for documenting and improving quality of care. Therefore, a large group of parents was consulted in developing a parent satisfaction instrument together with the Dutch PICU nurses and physicians.[10,11] Their views on satisfaction-with-care topics were the foundation to create a set of quality indicators measuring the perceived care by the parents. The next step and the aim of this study were to construct and to evaluate the reliability and validity of the EMpowerment of PArents in THe Intensive Care (EMPATHIC) questionnaire measuring parent satisfaction.

METHODS

This multicenter survey study was designed to assess the psychometric properties of the EMPATHIC questionnaire. All eight PICUs in the Netherlands participated in the study. Data was collected during two cohort periods of four months between February and September 2009. The medical ethical review board of the Erasmus Medical Center in Rotterdam approved the study followed by approval of the review boards of the participating medical centers.

Questionnaire construction

The item generation and selection of the questionnaire followed a structured process. The first steps concerned item generation. A literature review was performed to generate items from the existing satisfaction surveys.[12] The following step was a Delphi study to identify the importance of the items among 269 PICU nurses and physicians including the identification of possible new items.[10] This study resulted in 78 individual satisfaction-with-care items. Subsequently, a convenience sample of parents (n = 559) recruited from seven PICUs was asked to rate the importance of these 78 items.[11] Also, in-depth interviews with 41 parents were held to explore their experiences. Qualitative analysis revealed 63 subthemes divided into 6 themes. Following the item generation steps, item selection was based on the priorities of the opinions of parents and healthcare professionals. Of the generated items, 60 were found to be most relevant for measuring parent satisfaction with care. The items were rephrased into statements appealing to parents. Several items (n = 18) were considered important to differentiate between nurses and physicians. For example, the item about emotional support given to parents was rephrased into two statements; the first measuring the nurses' emotional support and the second measuring the physicians' emotional support. The draft questionnaire contained a demographic section to obtain characteristics of the child and its family, the 78 statements, four control questions about overall satisfaction-with-care, and free space was made available for the parents to write comments on their experiences. A 6-point scale, from 1 'certainly no' to 6 'certainly yes' was used for the statements. Parents could also tick a box if the statement was not applicable. This draft was introduced to eight nurses and eight physicians of the EMPATHIC study group and to ten parents. The aim was to investigate whether the statements were understandable and clearly formulated. The feedback resulted in some textual adjustments to the statements. The questionnaire was then translated into Arabic and Turkish by registered translators since a considerable number of parents might have difficulty in reading and understanding the Dutch questionnaire.

Statistical Analyses

Descriptive statistics were used to calculate mean scores and standard deviations of the statements. Before analyzing the psychometric properties of the instrument, four negatively formulated statements were deviated from the other statements. Two statements were deleted because more than > 75% of the parents scored these as not applicable leaving 72 statements for analysis. For each statement principal component analysis for the non-numerical data was performed to determine the scale value of the answer alternative 'not applicable'. Two-dimensional plots of the individual statements revealed that this value is closely related to the highest score on the 6-point scale. Therefore, it was justified to impute the answer alternative 'not applicable' to the highest value (in this case 6), meaning that parents who ticked the answer alternative 'not applicable' belong to the highest category of the 6-point scale.

Structural Equation Modeling is an advanced multivariate analysis technique using various analysis methods to identify, test, and estimate the relationship between study variables. Confirmatory Factor Analysis (CFA) is tailored to unraveling the empirical structure of the interrelationship of the 72 statements. The final model was based on both theoretical and statistical plausibility. The measures applied in this study were χ^2-Test of Model Fit, and the ratio of $\frac{\chi^2}{df} < 3$represents a good model fit. Other tests used for the model fit were: Comparative Fit Index (preferably CFI ≥ 0.95), Tucker-Lewis Index (preferably TLI ≥ 0.95), Root Mean Square Error of Approximation (preferably RMSEA < 0.08), and the Weighted Root Mean square Residual (preferably WRMR < 0.90).[13]

Reliability in this study refers to the internal consistency of the statements within the instrument. Internal consistency reliability measures were performed on the individual statements of the domains identified. On domain level the Cronbach's α was assumed to be satisfactory with values between 0.70 and 1.00. In order to get insight into the stability of the findings over time, the means of the domains at two measurement moments were tested for difference using the Levene's test for equality of variances and t-test for equality of means. If no statistical difference occurred, it was considered that the reliability across time was adequate.

Validity refers to the degree in which an instrument measures what it is intended to measure. Content validity and face validity were ensured as described by the questionnaire construction above. Congruent validity was assessed by using the Spearman's Rank correlation for estimating the relationship between the statements on domain level and four overall satisfaction-with-care scales. Furthermore, the non-differential validity referring to variables, which were assumed to have non-differential effects, was calculated by using the effect size of standardized mean difference (Cohen's d) between the demographic variables and the domains. The effect size is small with a value of 0.20, medium with 0.50, and large with greater than 0.80.[14]

All significance testing was set at $P \leq 0.05$ (two-tailed). SPSS (version 15, Chicago, USA) and the statistical modeling program M*plus* (version 5, 2007, Los Angeles, USA) were used for analysis.

Participants

The sample size was aimed at 600 parents at least for adequate psychometric analysis and a second cohort of 600 parents to test the stability of the instrument over time. Parents whose child was discharged alive from a PICU were recruited. If a child had one or more PICU admissions in the study period, the parents received only one questionnaire at the first admission. Parents whose child had died were excluded because in the Netherlands these parents receive an invitation to meet with the PICU physician and nurse six weeks after their child's death. During this meeting all aspects of treatment and care are being evaluated. Two to three weeks after PICU discharge parents received an invitation letter, including the information about the study, the EMPATHIC questionnaire, a consent form to be signed, and a prepaid reply envelope. One reminder was sent after three weeks if no response was received. Ethnicity of the parents was determined by asking the cultural background of the family in the demographic section of the questionnaire. In the analysis ethnicity was categorized into Dutch and non-Dutch.

RESULTS

In the first 4-month data collection period the questionnaire was mailed to 1,055 parents and 667 (63%) parents responded. In the second 4-month period 551/991 (56%) parents responded. Between both cohorts of parents, the questionnaire was completed by almost similar percentages of mothers (61.5% vs. 64.3%), fathers (11.9% vs. 11.4%), both mother and father (24.3% vs. 23.2%), and others (2.3% vs. 1.1%). The characteristics of the children and parents of the two cohorts are presented in Table 1 and they are not significantly different.

Table 1 | Characteristics of children and parents

	Cohort 1		**Cohort 2**		***P* value**
	n		**n**		
Age in months; median (P_{25-75})	660	30 (7-114)	539	36 (7-120)	0.59[a]
Length of Stay in days; median (P_{25-75})	656	3 (2-7)	537	3 (2-7)	0.42[a]
PICU admission	662		546		0.61[b]
Unplanned	365	55.1%	293	53.7%	
Planned	297	44.9%	253	46.3%	
Type of admission	652		534		0.65[b]
Surgical	359	55.1%	301	56.4%	
Medical	293	44.9%	233	43.6%	
Mechanical Ventilation required	661		541		0.77[b]
Yes	405	61.3%	336	62.1%	
No	256	38.7%	205	37.9%	
Family culture	664		551		0.33[b]
Dutch	576	86.7%	487	88.4%	
Other	88	13.3%	64	11.6%	

PICU, Pediatric Intensive Care Unit; [a] Mann-Whitney U test; [b] Chi Square test; Total numbers of respondents vary due to missing data

During the process of Structural Equation Modeling, the CFA showed that seven statements did not fit into the empirical structure of the domains. These statements where therefore removed from further analysis. Overall, the performance of the model fit of the remaining 65 statements in the five domains was adequate (Table 2). The standardized factor loadings of the statements were above 0.40 except for two statements (Table 3). The statement about the physician's knowledge of the child's medical history had a standardized factor loading of 0.39 and the statement about having an assigned physician during PICU stay had a standardized factor loading of 0.36.

Table 2 | Performance of the models

Domains	**No. of statements**	**n**	**Chi-Square test of Model Fit**						
			Value	***df***	***P* value**	**CFI**	**TLI**	**RMSEA**	**WRMR**
Information	9	667	83.60	17	< 0.01	0.97	0.99	0.08	0.82
Care & Cure	30	667	454.74	99	< 0.01	0.95	0.98	0.07	1.09
Parental Participation	8	667	55.64	12	< 0.01	0.99	0.99	0.07	0.75
Organization	6	655	18.50	8	0.02	0.99	1.00	0.05	0.46
Professional Attitude	12	667	141.26	27	< 0.01	0.98	0.99	0.08	0.94

Range of scoring scale was 1-6; df, degrees of freedom; CFI, Comparative Fit Index; TLI, Tucker-Lewis Index; RMSEA, root mean square error of approximation; WRMR, weighted root mean square residual

The reliability estimates of the individual statements and domains were sufficient. On the domain level the reliability estimates, Cronbach's α, were between 0.73 and 0.92 in the first cohort of parents. These estimates were also calculated among the second cohort of parents and showed similar outcomes from 0.73 to 0.93 (Table 4). At different time moments the two cohorts did not significantly differ on the equal variances for differences of the means on domain level and differences of variances (Table 4). Additionally, the standardized mean differences on domain level, Cohen's d, were calculated between the two cohorts: Information -0.02, Care & Cure -0.09, Parental Participation -0.12, Organization -0.12, and Professional Attitude -0.11. Overall, the reliability and stability of the EMPATHIC questionnaire over time provided empirical evidence that the reliability of the instrument was adequate.

Table 3 | Mean, standard deviation, and standardized factor loadings of satisfaction statements (n = 667)

	mean	SD	standardized factor loadings
Information			
We were always informed right away when our child's physical condition worsened	5.60	0.86	0.63
We had daily talks about our child's care and treatment with the nurses	5.50	0.95	0.69
Our questions were clearly answered by the nurses	5.48	0.88	0.72
Our questions were clearly answered by the doctors	5.42	1.00	0.78
The doctor clearly informed us about the consequences of our child's treatment	5.33	1.13	0.75
We received clear information about the examinations and tests	5.32	1.03	0.84
We were given clear information about our child's disease	5.30	1.20	0.61
We received understandable information about the effects of the drugs	5.06	1.29	0.66
We had daily talks about our child's care and treatment with the doctors	4.87	1.56	0.63
Care & Cure			
When our child's condition worsened, action was immediately taken by the doctors	5.79	0.56	0.65
When our child's condition worsened, action was immediately taken by the nurses	5.79	0.59	0.70
During acute situations there was always a nurse to support us	5.64	0.82	0.67
The team was alert to the prevention and treatment of pain in our child	5.60	0.76	0.73
The doctors and nurses are real professionals; they know what they are doing	5.59	0.72	0.78
Our child's comfort was taken into account by the nurses	5.58	0.81	0.80
The team had a common goal: the best care and treatment for our child and ourselves	5.56	0.76	0.91
Our child's needs were well responded to by the nurses	5.55	0.83	0.78
Attention was paid to our child's developmental level by the nurses	5.53	0.94	0.78
The team was helpful to our child and to us	5.52	0.88	0.89
Our own needs were well responded to by the nurses	5.49	0.86	0.80
Our child's needs were well responded to by the doctors	5.49	0.90	0.70
Attention was paid to our child's developmental level by the doctors	5.47	1.03	0.68

	mean	SD	standardized factor loadings
Every day we knew who was responsible for our child, regarding the nurses	5.46	1.10	0.58
Our child's comfort was taken into account by the doctors	5.44	0.91	0.71
The correct medication was always given on time	5.39	1.03	0.70
We were well supported emotionally by the nurses	5.38	1.07	0.69
Our own needs were well responded to by the doctors	5.37	1.00	0.71
At admission our child's medical history was known by the doctors	5.37	1.25	0.39
The doctors and nurses worked closely together	5.34	0.93	0.66
Transferral of care from the PICU staff to colleagues in the pediatric ward had gone well	5.17	1.30	0.58
We were well prepared for our child's discharge by the nurses	5.14	1.30	0.56
At admission our child's medical history was known by the nurses	5.12	1.41	0.41
We were well prepared for our child's admission by the nurses	5.11	1.47	0.41
We were well supported emotionally by the doctors	5.07	1.32	0.62
We were well prepared for our child's admission by the doctors	5.04	1.49	0.42
We were well prepared for our child's discharge by the doctors	4.87	1.53	0.50
During our child's stay we were assigned to a first responsible nurse	4.77	1.76	0.47
Every day we knew who was responsible for our child, regarding the doctors	4.62	1.72	0.53
During our child's stay we were assigned to one and the same doctor	4.25	1.96	0.36
Parental participation			
We had confidence in the doctors	5.63	0.75	0.63
We had confidence in the nurses	5.58	0.85	0.63
Even during intensive procedures we could always stay close to our child	5.57	0.94	0.65
We were encouraged to stay close to our child	5.35	1.09	0.77
Before discharge the care for our child was once more discussed with us by the nurses	5.15	1.29	0.62
We were actively involved in decision-making on care and treatment of our child	5.14	1.22	0.76
Before discharge the care for our child was once more discussed with us by the doctors	4.91	1.54	0.58
During our stay the staff regularly asked for our experiences	4.52	1.59	0.60

	mean	SD	standardized factor loadings
Organization			
The IC-unit could easily be reached by telephone	5.63	0.77	0.70
The visiting hours were flexible	5.60	0.96	0.50
The team worked efficiently	5.54	0.74	0.86
There was enough space around our child’s bed	5.39	0.99	0.80
The IC-unit was clean	5.39	1.00	0.73
Noise in the IC-unit was muffled as good as possible	4.95	1.37	0.64
Professional attitude			
Our child’s health always came first for the nurses	5.68	0.70	0.74
Our child’s health always came first for the doctors	5.68	0.72	0.71
At admission we felt welcome	5.61	0.83	0.74
The team showed respect for our child and for us	5.58	0.76	0.89
There was a pleasant atmosphere among the staff	5.54	0.73	0.86
The team worked hygienically	5.52	0.86	0.70
We received sympathy from the nurses	5.50	0.87	0.74
In spite of the workload, sufficient attention was paid to our child and to us by the nurses	5.49	0.87	0.78
The team respected the privacy of our child and of us	5.30	1.05	0.69
Nurses and doctors always introduced themselves by name and function	5.26	1.20	0.68
In spite of the workload, sufficient attention was paid to our child and to us by the doctors	5.25	1.05	0.66
We received sympathy from the doctors	5.21	1.18	0.58

Range of scoring scale was 1-6; SD, standard deviation

Table 4 | Descriptives, reliability estimates, and testing on domains of two cohorts

	Cohort 1 (n = 667)			Cohort 2 (n = 551)			Levene's test differences on variances		*t*-test differences on means
Domains (statements)	**mean**	**SD**	**α**	**mean**	**SD**	**α**	**F**	***P* value**	***P* value**
Information (9)	5.32	0.72	0.84	5.33	0.68	0.81	1.19	0.28	0.84
Care & Cure (30)	5.32	0.60	0.92	5.35	0.61	0.93	1.19	0.28	0.35
Parental Participation (8)	5.23	0.73	0.77	5.30	0.71	0.76	0.11	0.73	0.13
Organization (6)	5.42	0.63	0.73	5.47	0.61	0.73	1.56	0.21	0.19
Professional Attitude (12)	5.47	0.58	0.88	5.50	0.57	0.88	0.94	0.33	0.30

P value is two-tailed; Range of scoring scale was 1-6; SD, standard deviation; α Cronbach's alpha on standardized items

The EMPATHIC questionnaire showed sufficient correlation with the four statements of overall satisfaction as an indicator of congruent validity (Table 5). The non-differential validity of the instrument was assessed by calculating the effect size of domains and various population variables. The four tested variables of the five domains did not show significantly differences (Table 6). The parents of a child with a surgical procedure admission were more satisfied about the information statements than parents whose child had a medical PICU admission, Cohen's d 0.29, *P* <0.001.

Table 5 | Congruent Validity of Scales used Spearman's Rank correlation

	n	Would suggest PICU to others	Would come back again if needed	Overall satisfaction with physicians	Overall satisfaction with nurses
Information	650	0.435	0.422	0.504	0.364
Care & Cure	642	0.522	0.527	0.542	0.472
Parental Participation	651	0.478	0.475	0.465	0.423
Organization	651	0.523	0.508	0.392	0.401
Professional Attitude	651	0.588	0.583	0.575	0.519

Correlation is significant at 0.01 (two-tailed)

Table 6 | Non-differential validity, differences between domains and PICU characteristics

	Yes			No			Cohen's d	*P* value
	n	mean	SD	n	mean	SD		
Mechanical Ventilation								
Information	397	5.27	0.76	251	5.40	0.65	-0.18	0.07
Care & Cure	391	5.31	0.62	249	5.34	0.55	-0.05	0.83
Parental Participation	397	5.23	0.75	251	5.24	0.70	-0.02	0.91
Organization	396	5.41	0.67	252	5.42	0.57	-0.01	0.53
Professional attitude	397	5.48	0.60	251	5.45	0.56	0.05	0.32
Unplanned Admission								
Information	358	5.28	0.73	289	5.37	0.71	-0.13	0.06
Care & Cure	354	5.30	0.60	286	5.35	0.60	-0.07	0.24
Parental Participation	357	5.25	0.73	291	5.21	0.73	0.06	0.38
Organization	357	5.42	0.61	291	5.42	0.65	0.01	0.97
Professional attitude	357	5.49	0.57	291	5.45	0.59	0.08	0.46
Admission for Surgery								
Information	351	5.41	0.67	286	5.20	0.78	0.29	<0.001
Care & Cure	348	5.35	0.60	284	5.28	0.60	0.11	0.11
Parental Participation	351	5.24	0.75	287	5.21	0.71	0.03	0.44
Organization	352	5.42	0.64	287	5.42	0.62	0.00	0.92
Professional attitude	352	5.47	0.61	286	5.47	0.55	0.00	0.39
Dutch Culture								
Information	562	5.31	0.71	87	5.38	0.80	-0.09	0.11
Care & Cure	558	5.32	0.57	83	5.33	0.77	-0.01	0.09
Parental Participation	563	5.23	0.70	86	5.27	0.88	-0.06	0.07
Organization	564	5.42	0.62	85	5.39	0.69	0.05	0.97
Professional attitude	563	5.47	0.56	86	5.45	0.72	0.05	0.20

Range of scoring scale was 1-6; SD, standard deviation; Cohen's d, Standardized Mean Difference; P value, Mann-Whitney test (two-tailed)

DISCUSSION

The strength of this study lies in the rigorous development of the satisfaction instrument through a convenience sample of parents and PICU healthcare professionals. Psychometric testing of the EMPATHIC questionnaire revealed that this instrument is reliable and valid for measuring parent satisfaction of pediatric intensive care services. The 65 statements representing five domains provide a comprehensive conceptualization of parent satisfaction. The relevance of this study is not limited to the development of an acceptable and feasible quality performance indicator for PICUs. Healthcare departments are increasingly demanding satisfaction outcomes of individual healthcare services above and beyond general hospital satisfaction measures.[15-17] Besides, healthcare insurance companies increasingly demand patient satisfaction data to fund hospitals.[18] This study provides a valuable contribution towards PICU colleagues in other countries and cultures. The increased need for validated instruments to collect data of patient or family experiences is evident. The challenge is to construct and design research instruments for use in study populations with different cultural backgrounds. The EMPATHIC questionnaire showed that there were no significant differences between Dutch parents and parents with a non-Dutch background. However, these results can not be generalized when using the EMPATHIC questionnaire in other countries with other languages. Although its reliability and validity has been proven, thorough translation of the instrument is needed to provide evidence that the meaning of the translated statements is equivalent to the original statements.[19] For this translation process, a framework has been described of 10 consecutive steps, based on a review of 12 guidelines for translation and cultural adaptation, to ensure principles of good practice.[20]

Only two validated parent satisfaction instruments have been documented in the literature for PICU settings.[8,9] The instrument developed in the UK assessed the face and content validity although no reliability testing was performed.[8] Despite the proper testing of the reliability and validity of the 23-item instrument developed in the USA, the authors stated that a limitation of this instrument is its restricted number of items.[9] The authors stated that their instrument was not intended to be 'all-inclusive' but that it was rather directed to PICU care only. However, it is debatable whether 23 statements are sufficient to reflect PICU services. In contrast, after its validation process the EMPATHIC questionnaire included 65 statements. In this perspective, two issues are important to address: the number of statements needed to measure the complexity of PICU services and the length of the questionnaire related to the response rates. The latter is addressed in a review of 210 patient satisfaction studies. In 125 studies the number of items used in the survey were reported and ranged from 1 to 361 items.[21] Of these, there was a weak negative correlation between the number of items and the response rate. A similar effect occurred between the Picker Patient Experience (PPE-15) questionnaire embedded in a four page survey with 31 questions including demographic details and a 12-page survey with 108 questions.[22]

The analyses revealed that the length of the questionnaire did not lead to reduced response rates and there was no effect on the quality of data in terms of percentages of items completed. Therefore, the 65-statement EMPATHIC questionnaire seems feasible as it resulted in response rates of 63% and 56% in the two measurement periods. Incidentally, these response rates can be considered acceptable to satisfaction surveys because the mean initial response rate was 72.1% (SD = 19.8) in 124 satisfaction studies.[21] The other issue to be addressed is the question of how many statements are needed to measure parent satisfaction for PICU services. Basically, an instrument should include items on all factors of importance to the trait under study. This refers to the content validity of an instrument. A review of ten satisfaction instruments designed for PICU, neonatal ICU, adult ICU, and pediatric wards documented a range of 15 to 45 items.[12] The strength of the EMPATHIC questionnaire lies in the item generation and item selection phase where a large number of parents and healthcare professionals were consulted to identify the most important items.[10,11] The items were converted into statements and theoretically conceptualized in domains related to family centered care concepts.[23] It is, therefore, recognized that the 65 statements of the EMPATHIC questionnaire reflect the most important issues of the PICU care.

Two limitations of the psychometric testing of the EMPATIC questionnaire need to be addressed. The first concern is the test-retest reliability. This refers to administering the same instrument to the same respondents at two different moments in time to estimate its stability over time. A high correlation between the two measurement periods refers to a good test-retest reliability. It was decided not to burden the parents with two questionnaires in a short period of time. Therefore, as it was assumed that neither the care and the treatment nor the population of parents would change within eight months, two cohorts of parents were included to test the stability of the findings across time.

The second limitation is the lack of criterion validity testing of the instrument. This validity refers to association of the results between the tested instrument and another validated instrument measuring the related concept. Although one parent satisfaction instrument for the PICU was tested to be valid[9], its limitations to use it as the gold standard were based on a single center study, the limited items of the instrument, and the validity tested on a small group of 40 parents of which 27 responded. For that reason, congruent validity was chosen to examine part of the validity of the EMPATHIC questionnaire by testing the statements on four generally accepted gold standard questions measuring overall satisfaction.

Despite the recognition that satisfaction outcome measures are increasingly used as quality performance indicators[24,25], the reality is that there is a paucity of PICU parent satisfaction instruments in the literature. However, it is expected that many PICUs have developed and carry out their own unit-based satisfaction survey. Therefore, and in conclusion, this study provides a reliable and valid parent satisfaction instrument that is feasible to administer to parents. The found empirical structure of the satisfaction-with-care statements can be considered adequate. The proven statistical evidence of the statements is of importance in order to be able to apply the EMPATHIC questionnaire in other PICUs. Nevertheless, including statements of clinical relevance specific to local PICU settings might be considered. Ultimately, using a validated instrument contributes to the empowerment of parents to work collaboratively with nurses and physicians on PICU quality of care.

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CHAPTER 13

Development and validation of a neonatal intensive care parent satisfaction instrument

Jos M. Latour, Hugo J. Duivenvoorden, Jan A. Hazelzet, Johannes B. van Goudoever

Submitted

ABSTRACT

Objective: To develop and test the psychometric properties of the EMPATHIC-N (EMpowerment of PArents in THe Intensive Care-Neonatology) questionnaire measuring parent satisfaction.

Patients and Methods: A prospective cohort survey testing the reliability and validity of a parent satisfaction questionnaire among 441 parents in a 30-bed Neonatal Intensive Care Unit.

Results: In the first cohort, 220/339 (65%) parents responded, in the second cohort 59/102 (58%) parents responded. Structural Equation Modeling and Confirmatory Factor Analysis resulted in an adequate model fit of 57 statements within five domains: Information, Care & Cure, Organization, Parental Participation, and Professional Attitude. Standardized factor loading of these statements were between 0.58 and 0.91. Reliability measures, Cronbach's α, of the domains ranged from 0.82 to 0.95. Reliability across time showed no significant differences between the domains and population characteristics of both cohorts. Congruent validity was confirmed by a good correlation (*P* = 0.01) between the domains and four general satisfaction questions. Non-differential validity showed no significant effect sizes between the infants' characteristics and the domains, except between ventilated infants and parent participation statements, and infants ≥30 week gestational age and organizational statements.

Conclusions: The EMPATHIC-N questionnaire is a valid quality performance indicator to measure the delivered care as perceived by parents. Using the EMPATHIC-N questionnaire in clinical practice empowers parents to partner with healthcare professionals to work collaboratively on quality of care improvement.

INTRODUCTION

Progression of medical technology in neonatology has led to increased survival of premature infants, including improved long-term outcomes. At the same time, non-pharmacological interventions such as the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) seems to improve, despite contrasting findings, short and long term outcomes.[1-3] Evenly important might be the changes in the roles of parents. Historical developments have led healthcare professionals towards accepting an increased involvement of parents in the care of their child.[4] Today's most important parental needs concern issues of assurance such as the best care provided and accurate information[5], while the Neonatal Intensive Care Unit (NICU) staffs' behavior seems to direct towards emotional support, parent empowerment, supportive unit policies, and parent education.[6] Therefore, assessment of parental experiences and satisfaction with care necessitate ongoing attention to improve parental care and possibly resulting in positive outcomes in premature infants.

The increasing demand for consumer-driven care and the acceptance of patient satisfaction as a quality performance measure justify the development of rigorous parent satisfaction instruments. Although a few neonatal parent satisfaction questionnaires are reported in the literature, a widespread adoption of these instruments was not suggested due to limitations in validity, reliability, and covering the full scope of parent satisfaction measures.[7] Nevertheless, at the same time it was recommended to continue measuring parent satisfaction with selective use of the available instruments until more evidence becomes available on parental experiences. Indeed, parental experiences have been investigated extensively over the past decade. Recent studies provide insight in factors contributing to parent's satisfaction. Comprehensive factors are the caregivers' communication skills and providing individual care.[8-10] Besides these attitudes, family-centered care issues need to be identified and integrated in satisfaction surveys to improve clinical practice based on the experiences of the parents.[11]

The empowerment of the parents and partnership with the staff is beneficial in building a family-centered care environment. In this respect, parents and neonatal staff were consulted to identify satisfaction with neonatal intensive care items.[12] These studies formed the basis of the present study. The objectives of this study were to develop and to test the psychometric properties of the EMPATHIC-N questionnaire measuring parent satisfaction.

PATIENTS AND METHODS

The survey study was conducted in a 30-bed NICU in the Netherlands. Yearly admission rate is around 750 infants, including approximately 300 very-low-birth-weight infants. Data collection was assembled during two cohort periods. The first nine-month period was from January till September 2009, followed by a three-month period from October until December 2009. The medical ethical review board of the Erasmus Medical Center in Rotterdam approved the study.

Participants of the study were parents whose child had been admitted to the NICU. Excluded were parents whose child's admission was less than 48 hours or whose child died. Parents with multiple births received only one questionnaire. In the first cohort, 339 parents of 360 children were invited to participate and in the second cohort, in order to test the stability of the instrument over time, 102 parents of 111 children were invited. The self-administered questionnaire was mailed to the parents three to four weeks after NICU discharge. One reminder was sent after three weeks if no response was received.

The development of the EMPATHIC-N questionnaire was a structured process. The process started with reviewing previously developed satisfaction surveys in critical care units and general pediatrics.[7,13] Secondly, satisfaction with care items were identified in a 3-round Delphi study among 81 NICU staff members and a survey study completed by 148 parents, published previously.[12] The results of these studies were 92 neonatal care-related items prioritized by parents, nurses and physicians. The third step consisted of generating the satisfaction with care items and drafting the questionnaire. The 67 care items rated most importantly were rephrased into statements appealing to parents. The rating scale was a 6-point scale, from 1 'certainly no' to 6 'certainly yes'. An alternative box, 'not applicable', was added. Furthermore, four control questions measuring overall satisfaction and a demographic section were added. The questionnaire was concluded with free space to allow parents to write their experiences or give comments. The last step of the questionnaire development related to content and face validity. The draft questionnaire was distributed to five parents and five NICU staff members to review the understandability and clarity of the formulated statements. Minor textual changes were needed.

Statistical analyses of the psychometric testing of the EMPATHIC-N questionnaire were performed via sequential procedures: Structural Equation Modeling (SEM) tailored to Confirmatory Factor Analysis (CFA), reliability, and validity testing.

SEM is a priori a technique with advanced multivariate analysis. Predetermined models need to be specified to conduct the analysis. The specification of the model needs a theoretical basis preferably based on results of previous studies.[14] The defined model tested in this study related to the statements within five predefined domains; Information, Care & Cure, Organization, Parental Participation, and Professional Attitude. Depending on the complexity of the tested model, a sample size exceeding 200 cases could be considered large.[14]

CFA was performed to unravel the empirical structure of the interrelationship of the statements. The χ^2-Test of Model Fit was applied in this study and the ratio of $\frac{\chi^2}{df} < 3$ represents a good model fit. Furthermore, the Comparative Fit Index (preferably ≥ 0.95), the Tucker-Lewis

Index (preferably ≥ 0.95), the Root Mean Square Error of Approximation (preferably < 0.08), and the Weighted Root Mean square Residual (preferably < 0.90) were used to test the model fit.[15]

Reliability refers to the internal consistency of the statements within an instrument. Internal consistency reliability measures, the standardized factor loadings, were performed on the individual statements within the domains. The Cronbach's α on domain level was considered satisfactory with values between 0.70 and 1.00. To obtain insight into the stability of the findings across time, the means of the domains of the two cohort periods were tested in difference using the Levene's test for equality of variances and t-test for equality of means. The reliability across time was considered adequate when no statistical difference occurred.

Validity is the degree in which an instrument measures what it is intended to measure. During the development of the questionnaire, the content and face validity were assessed as described above. Congruent validity was performed using the Spearman's Rank correlation to estimate the relationship between the statements on domain level and the four overall satisfaction with care scales. In addition, the non-differential validity referring to variables of which was assumed that they have non-differential effects was analyzed using the effect size of standardized mean difference (Cohen's d) between demographic variables and the domains. The effect size is small with a value of 0.20, medium with 0.50, and large with > 0.80.[16]

The data were analyzed using SPSS (version 15, Chicago, Illinois) and the statistical modeling program M*plus* (version 5, 2007, Los Angeles, USA). The level of significance was set at 0.05 (two-tailed).

RESULTS

In the first 9-month cohort period 220 of 339 (64.9%) parents responded to the questionnaire. In the second cohort, a 3-month period, the response rate was 59 of 102 (57.8%) parents. Both study populations were representative of the NICU. The characteristics of the infants and parents are presented in Table 1. There were no significant differences between both cohorts.

During the SEM technique, the structure of the questionnaire was theoretically specified in five domains including the statements. The domains were: Information (14 statements); Care and Cure (20 statements); Parental Participation (9 statements); Organization (11 statements), and Professional Attitude (13 statements). Prior to the analyses, two negatively formulated statements and one statement with a 91% 'not applicable' score were removed. On the remaining 64 statements, principal component analysis for non-numerical data was performed to determine the scale value of the alternative answer 'not applicable'. Two dimensional plots of each statement confirmed that this value was strongly related to the highest score on the 6-point scale, justifying to impute the 'not applicable' answer to the highest value.

Table 1 | Characteristics of infants and parents

	Cohort 1	Cohort 2	*P*
Infants	n = 234	n = 66	
Gender: boy (%)	140 (60%)	38 (58%)	0.74[2]
Gestational age in weeks: median (min;max)	33 (24;42)	33 (24;42)	0.77[1]
Birth weight in grams: median (min;max)	1725 (558;5300)	1980 (535;4440)	0.60[1]
Length of stay NICU in days: median (min;max)	7 (2;148)	7 (2;78)	0.99[1]
Ventilation days: median (min;max)	4 (1;46)	4 (1;53)	0.33[1]
Parents	n = 220	n = 59	
Cultural background			0.37[2]
Dutch	171 (78%)	49 (83%)	
non-Dutch	49 (22%)	10 (17%)	
Education level mothers			0.44[1]
Low	17 (8%)	4 (7%)	
Medium	95 (43%)	23 (39%)	
High	83 (38%)	24 (41%)	
University	25 (11%)	8 (13%)	
Education level fathers[3]			0.51[1]
Low	22 (11%)	5 (10%)	
Medium	95 (50%)	22 (42%)	
High	50 (26%)	21 (40%)	
University	25 (13%)	4 (8%)	

[1] Mann-Whitney U test; [2] Chi Square test; [3] first cohort 28 missing and second cohort seven missing

The CFA confirmed that seven statements did not fit into the empirical structure of the domains and were therefore omitted from further analysis. The remaining 57 statements within the five domains showed an adequate model-fit (Table 2).

Table 2 | Performance of the models

Domains	Items no.	n	Chi-Square test of Model Fit						
			Value	*df*	*P*	CFI	TLI	RMSEA	WRMR
Information	12	214	58.14	21	<0.001	0.97	0.98	0.09	0.92
Care & Cure	17	214	113.96	28	<0.001	0.97	0.99	0.12	1.11
Parental Participation	8	214	52.78	12	<0.001	0.96	0.98	0.13	0.86
Organization	8	215	51.96	12	<0.001	0.96	0.97	0.12	0.97
Professional Attitude	12	215	67.13	27	<0.001	0.98	0.99	0.08	0.70

Item scoring range 1-6; df degrees of freedom; CFI Comparative Fit Index; TLI Tucker-Lewis Index; RMSEA root mean square error of approximation; WRMR weighted root mean square residual.

The standardized factor loadings of the statements within the domains were moderate to high: Information, 0.61 to 0.87; Care and Cure, 0.64 to 0.91; Parental Participation, 0.74 to 0.88; Organization, 0.58 to 0.87; Professional Attitude, 0.59 to 0.91 (Table 3).

Table 3 | Means, standard deviations, standardized factor loadings of the statements

	mean	SD	standardized-factor loadings
Information			
The doctors and nurses gave honest information to us	5.60	0.73	0.80
We were always informed right away when our child’s physical condition worsened	5.55	0.97	0.61
The information provided by the doctors and nurses was understandable	5.47	0.87	0.73
Our questions were clearly answered	5.44	0.86	0.79
The doctor clearly informed us about the consequences of our child’s treatment	5.43	1.05	0.83
We were given clear information about our child’s disease	5.37	1.05	0.78
We received clear information about the examinations and tests	5.33	1.06	0.87
The information brochure we received was complete and clear	5.22	1.43	0.70
We received understandable information about the effects of the drugs	5.18	1.11	0.73
We had daily talks about our child’s care and treatment with the doctors and the nurses	5.08	1.31	0.61
The doctor informed us about the expected health outcomes of our child	4.82	1.54	0.61
The information given by the doctors and nurses was always the same	4.53	1.70	0.61

	mean	SD	standardized-factor loadings
Care & Cure			
When our child's condition worsened, action was immediately taken by the doctors and nurses	5.71	0.58	0.86
The doctors and nurses are real professionals; they know what they are doing	5.63	0.62	0.80
At admission our child's medical history was known by the doctors and nurses	5.61	0.91	0.74
Our child was always well taken care of by the nurses while in the incubator/bed	5.60	0.72	0.74
During acute situations there was always a nurse to support us	5.59	0.83	0.86
Our child's comfort was taken into account by the doctors and nurses	5.56	0.71	0.86
The team was alert to the prevention and treatment of pain in our child	5.56	0.77	0.86
The correct medication was always given on time	5.55	0.80	0.75
Our child's needs were well taken care of	5.52	0.76	0.82
Attention was paid to our child's developmental by the doctors and nurses	5.52	0.87	0.86
The team had a common goal: the best care and treatment for our child and ourselves	5.50	0.85	0.89
The team was caring to our child and to us	5.42	0.90	0.91
The doctors and nurses worked closely together	5.38	0.92	0.78
Transferral of care from the NICU staff to colleagues in the High Care unit or pediatric ward had gone well	5.31	1.20	0.64
The doctors and nurses responded well on our own needs	5.17	1.13	0.86
We were emotionally supported	5.02	1.32	0.86
Every day we knew who of the doctors and nurses was responsible for our child	4.92	1.53	0.64
Parental Participation			
We had confidence in the team	5.64	0.70	0.80
Even during intensive procedures we could always stay close to our child	5.59	0.82	0.84
The nurses stimulated us to help in the care of our child	5.55	0.97	0.88
The nurses helped us in the bonding with our child	5.51	0.97	0.87
We were encouraged to stay close to our child	5.39	1.12	0.80
The nurses had trained us the specific aspects of newborn care	5.25	1.30	0.80
We were actively involved in decision-making on care and treatment of our child	4.84	1.54	0.74
Before discharge the care for our child was once more discussed with us	4.79	1.61	0.74

	mean	SD	standardized-factor loadings
Organization			
The unit could easily be reached by telephone	5.74	0.61	0.80
Our child's incubator or bed was clean	5.69	0.65	0.80
The team worked efficiently	5.62	0.65	0.87
There was a warm atmosphere in the Neonatology unit without hostility	5.62	0.82	0.80
The Neonatology unit made us feel safe	5.57	0.83	0.80
The Neonatology unit was clean	5.26	1.07	0.68
Noise in the unit was muffled as good as possible	4.93	1.30	0.65
There was enough space around our child's incubator/bed	4.56	1.57	0.58
Professional Attitude			
Our cultural background was taken into account	5.76	0.76	0.76
Our child's health always came first for the doctors and nurses	5.75	0.55	0.88
The team worked hygienically	5.62	0.67	0.91
The team showed respect for our child and for us	5.62	0.72	0.91
The team respected the privacy of our child's and of us	5.61	0.66	0.85
There was a pleasant atmosphere among the staff	5.59	0.68	0.91
We felt welcome by the team	5.50	0.88	0.91
The doctors and nurses always took time to listen to us	5.43	0.87	0.84
In spite of the workload, sufficient attention was paid to our child and to us by the team	5.42	0.87	0.87
We received sympathy from the doctors and nurses	5.37	0.97	0.80
Nurses and doctors always introduced themselves by name and function	5.29	1.11	0.65
At our bedside, the discussion between the doctors and nurses was only about our child	5.02	1.57	0.59

Item scoring range 1-6.

The internal consistency reliability estimates, the Cronbach's α, of the domains were high. These estimates were calculated in both cohorts. In the first cohort the Cronbach's α was between 0.82 and 0.91 and in the second cohort these values were between 0.84 and 0.95. Between the two time moments, the two cohorts did not significantly differ on the equal differences on variances and the differences on means on domain level (Table 4). Generally, empirical evidence proved that the reliability and stability of the EMPATHIC-N questionnaire across time was adequate.

Table 4 | Descriptives, reliability estimates, and testing on domains of two cohorts

Domains (statements)	Cohort 1 (n = 220)			Cohort 2 (n = 59)			Levene's test differences on variances		*T* test differences on means	
	mean	SD	α	mean	SD	α	F	*P*	t	*P*
Information (12)	5.26	0.69	0.86	5.22	0.68	0.85	0.18	0.67	0.28	0.78
Care & Cure (17)	5.45	0.57	0.91	5.53	0.60	0.95	0.12	0.73	-0.97	0.33
Parental Participation (8)	5.32	0.78	0.85	5.36	0.85	0.91	0.02	0.90	-0.33	0.74
Organization (6)	5.37	0.61	0.82	5.45	0.57	0.84	0.52	0.47	-0.90	0.37
Professional Attitude (12)	5.50	0.58	0.90	5.57	0.55	0.92	0.36	0.55	-0.80	0.43

P value is two-tailed; Item scoring range 1-6; α Cronbach's alpha on standardized items as a measure of consistency.

Congruent validity was obtained by correlating the domains of the questionnaire with the four overall satisfaction indicators. The Spearman's Rank correlations were sufficient and significantly positive. The correlations ranged from r_s, 0.37 to r_s, 0.51 (Table 5). The non-differential validity of the EMPATHIC-N questionnaire was assessed by calculating the standardized mean difference, Cohen's d, between the domains and four population variables (Table 6). The characteristics tested on the five domains showed no significant differences except for parents whose infant was ventilated and the domain Parental Participation (Cohen's d 0.42, $P < 0.004$), and parents whose infant was above 30 weeks of gestational age and the domain Organization (Cohen's d -0.47, $P < 0.001$).

Table 5 | Congruent Validity of Scales used Spearman's Rank correlation

	n	Suggest NICU to others	Come back again if needed	Overall satisfaction physicians	Overall satisfaction nurses
Information	212	0.44	0.41	0.51	0.41
Care & Cure	210	0.48	0.48	0.49	0.48
Parental Participation	211	0.44	0.49	0.46	0.37
Organization	213	0.41	0.45	0.43	0.42
Professional Attitude	215	0.39	0.45	0.42	0.45

All correlations are significant at 0.01 (two-tailed).

Table 6 | Non-differential validity, differences between domains and characteristics

	Yes			No				
	n	**mean**	**SD**	**n**	**mean**	**SD**	**Cohen's d**	***P***
Mechanical Ventilation								
Information	100	5.37	0.56	115	5.16	0.77	0.31	0.08
Care & Cure	100	5.52	0.52	113	5.38	0.61	0.26	0.06
Parental Participation	100	5.49	0.63	114	5.17	0.86	0.42	0.004
Organization	98	5.43	0.57	116	5.32	0.65	0.18	0.27
Professional Attitude	100	5.57	0.54	116	5.44	0.60	0.22	0.19
Length of stay ≤ 7 days								
Information	108	5.17	0.78	106	5.34	0.57	-0.24	0.25
Care & Cure	107	5.38	0.61	105	5.51	0.53	-0.23	0.11
Parental Participation	108	5.20	0.87	105	5.44	0.65	-0.31	0.07
Organization	106	5.39	0.65	107	5.36	0.58	0.05	0.29
Professional Attitude	108	5.42	0.61	107	5.57	0.53	-0.25	0.17
Gestational age < 30 weeks								
Information	50	5.32	0.57	164	5.23	0.72	0.13	0.76
Care & Cure	50	5.48	0.55	162	5.43	0.58	0.08	0.73
Parental Participation	50	5.47	0.64	163	5.27	0.81	0.25	0.21
Organization	51	5.15	0.65	162	5.44	0.59	-0.47	0.001
Professional Attitude	51	5.50	0.62	164	5.49	0.56	0.01	0.94
Dutch Culture								
Information	166	5.26	0.63	49	5.23	0.86	0.04	0.48
Care & Cure	164	5.46	0.56	49	5.40	0.62	0.10	0.54
Parental Participation	165	5.32	0.69	49	5.31	1.01	0.02	0.29
Organization	167	5.37	0.58	47	5.38	0.72	-0.01	0.54
Professional Attitude	169	5.50	0.54	47	5.49	0.69	0.02	0.50

Item scoring range 1-6; Cohen's d, Standardized Mean Difference; P value, Mann-Whitney test (two-tailed).

DISCUSSION

Hospitals are increasingly being pressured to document patient satisfaction outcomes.[17,18] At the same time, patient satisfaction data are becoming an important tool for healthcare insurance corporations to fund hospitals.[19] The relevance of this study is not limited to managerial or financial decisions, but rather presents a profound identification of NICU care aspects translated in a validated parent satisfaction instrument. The 57 statements divided in five domains provide a conceptualization of parent satisfaction within the NICU from a family-centered care perspective. Although various definitions of family-centered care are available[20,21], the most influential factors of family-centered care are related to communication, continuity of care and the parent-nurse/physician relationship.[22] In the development phase of the EMPATHIC-N questionnaires these factors were recognized but not limited to. The statements in the five domains represent a wider perspective of the parental views believed to be important.[12] Statements about medication administration, pain management, and safety might not directly relate to family-centered care according to the literature; parents have scored these issues as important. Thus, from the parent's perspective the EMPATHIC-N questionnaire seems a more complete reflection of a renewed family-centered care concept.

The psychometric tests of the EMPATHIC-N questionnaire were carefully chosen to document its reliability and validity. Unlike the published validated NICU parent satisfaction questionnaires[7,13], the process of developing and testing the EMPATHIC-N questionnaire started with SEM. The theoretically defined statements in the five domains provided a model that could be tested by CFA. The fit indices indicated that seven statements did not fit to the model, in casu the domains. Indeed, it is recognized that the good model fit did not guarantee the inclusion of all of the tested statements in the domains of the model.[23] However, this does not indicate that the statistically omitted statements have no clinical importance. Careful assessment of the performance of a local NICU setting might result in adding statements as 'fillers' to the validated questionnaire when the questionnaire is used for ongoing assessment of parental satisfaction or as a quality control instrument.

Reliability and validity testing of the existing NICU satisfaction instruments generally was weak. The Parent Feedback Questionnaire was not tested for reliability and only content validity was evaluated.[24] A few years later, the Neonatal Index of Parent Satisfaction was only tested for test-retest reliability, with an intraclass correlation of 0.71, and the construct validity, with a moderate correlation of 0.61 between the questionnaire and a global rating of general satisfaction.[25] Finally, the NICU-Parent Satisfaction Form documented internal consistency reliability estimates, content validity, and discriminant validity.[7] Of the nine scales, five scales showed reliability estimates ≥0.70 while the discriminant validity was limited described for correct interpretation of the results. In contrast, the systematical and rigorous construction of the

EMPATHIC-N questionnaire provided a scientific basis for psychometric testing. The reliabilities measures on domain level were above the recommended standard. The validity, including the performance of the questionnaire over time, was satisfactory. Thus, the development and the psychometric testing of the EMPATHIC-N questionnaire proved to be an acceptable and feasible quality performance indicator for neonatal intensive care services. Although the questionnaire was tested on a large group of parents, the empirical data originate from a single center. Transferring the instrument to other settings with other languages might require further testing for its generalizability and acceptability. Thorough translation of the statements is, therefore, required to assure that the meaning of the translated statements is equivalent to the original statements.[26]

Two limitations of the psychometric testing need to be addressed. First, the test-retest reliability among the same group of parents at two different time moments was not performed. We did not want to burden parents with two questionnaires in a short time period due to the experienced stress and anxiety of a NICU admission of their infant.[27] A control group was approached to participate in the study to test the stability of the questionnaire across time. The results provided sufficient reliability. The second limitation of the psychometric testing concerned the validity. The criterion validity, predicting how well the questionnaire correlates to another validated instrument, i.e. the gold standard, was not tested. Although few validated parent satisfaction instruments are available, most of them were developed over a decade ago before family-centered care was implemented in NICUs.[7] Besides, many statements in the EMPATHIC-N questionnaire did not occur in these instruments. With respect of the available instruments, congruent validity was chosen to test the EMPATHIC-N questionnaire on four generally accepted overall satisfaction questions.

Other validated instruments have been used to document parental experiences and the staff’s support to parents such as the NICU Family Needs Inventory and the parental stress scale NICU.[6,28,29] But the concept of satisfaction is not synonymous to the assessment of stress and needs.[30] Having met the needs of parents does not guarantee satisfaction. In addition, the assessment of stress factors provides insight into care issues related to parental stress, but these measurements do not provide evidence of the actual performance of the NICU team. Therefore, this study presents a comprehensive parent satisfaction questionnaire measuring a wide range of today’s important NICU care practices and proves to be reliable and valid with an adequate empirical structure of the statements in the five domains. The relevance for clinical practice is that the use of the EMPATHIC-N questionnaire empowers parents to partner with NICU healthcare professionals to work collaboratively on quality of care improvement.

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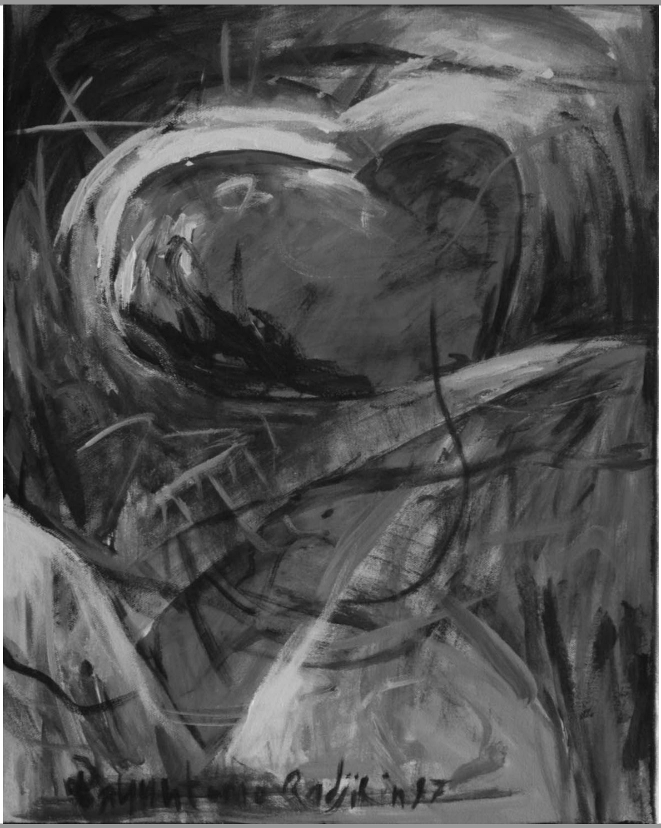

PART VI

Discussion

CHAPTER 14

General discussion and future directions

GENERAL DISCUSSION AND FUTURE DIRECTIONS

In search of destiny, you will often find yourself obliged to change direction.
Paulo Coelho, 2008

The journey of the EMPATHIC study has taught us to change our direction towards a better understanding of parents' experiences about our PICU and NICU services. Although we may not have fully captured the expectations of the parents, we certainly have learned more about their knowledge and experiences with regard to their child's intensive care admission.

Starting-point

This thesis includes a series of studies – collectively named the EMPHATIC study – aimed at developing and implementing validated parent satisfaction questionnaires in the PICU and NICU. The study became a national voyage taking on board parents and professionals in the eight PICUs and a NICU in the Netherlands.

The available scientific evidence about parent satisfaction in pediatric and neonatal intensive care was diminutive. Therefore we needed to explore related concepts such as family-centered care, parental needs and experiences. Based on scientific assumptions, a framework for action was designed to serve as a firm foundation of the study. The rigorous explorative period was devoted to understanding the current opinions of parents and healthcare professionals about the PICU and NICU services. Differences in those opinions were explored and on the basis of the findings we constructed and validated the EMPATHIC and EMPATHIC-N questionnaires. In this chapter, the general findings are discussed and future research perspectives are suggested.

Definition

Patient satisfaction in healthcare has been studied widely over the past 50 years. Various definitions have been proposed by leaders in the field. Within the nursing domain, one of the earliest definitions is the one by Hinshaw and Atwood (1981): Patient satisfaction is the expression of a patient's judgment on the quality of care in all its aspects.[1] Almost the same time, Donabedian (1982) advocated that, within the domain of quality assessment, the individual patients and healthcare professionals need to come to an agreement.[2] In this respect, patient satisfaction became one of the quality outcome measures.[3] Attributes to measure quality preferably include the patients' knowledge, attitudes, and behaviors. An interactive model of client health behavior described elements of client singularity, client-professional interaction, and health outcomes.[4] This model supports the vision that patients act according to their perceptions, but that these perceptions may not be congruent with reality. Therefore, patient satisfaction has become one of the five health outcome indicators of the key concepts of affective support, health information, decisional control, and professional/technical competencies.[5] The concept of satisfaction-with-care also has been linked to the degree of congruence between patients' expectations and their actual experiences of the perceived care.[6,7] However, it is debatable whether this is a sound association. Particularly in emergency admissions, parents might not have had time to imagine expectations beyond hoping for the survival of their child. Besides, the media might be responsible for negative or wrong expectations of healthcare services. An example is the overestimation of survival following resuscitation. The lay public is influenced by unrealistic expectations aroused in popular television programs.[8,9] Therefore, and based on the EMPATHIC study outcomes, it is suggested to define parent satisfaction within the intensive care as the parents' opinion of their experiences of the perceived care in terms of information, care and treatment, parental participation, organization, and professional attitude.

Model

Today's challenge for healthcare professionals is putting the patient and his family in the center of care. In pediatric critical care, the children and parents are increasingly recognized as one family system.[10] Because most infants and children are unable to express their needs, parents are important partners to collaborate with the healthcare professionals and thus improve quality of care continuously.

Family-centered care has gained much attention since the American Institute of Medicine (IOM) identified patient-centered care as one of the six areas that are still below standard in today's healthcare systems.[11] In response to this omission, the American Academy of Critical Care labeled 43 evidenced-based guidelines classified into ten domains to support family members and parents in intensive care units (Box 1).[12]

Box 1 | Ten domains of family support in the ICUs

- decision making
- family coping
- staff stress related to family interactions
- cultural support
- spiritual/religious support
- family visitation
- family presence on rounds
- family presence at resuscitation
- family environment of care
- palliative care

Others have defined domains of family-centered care, of which the most commonly accepted are the following six: respect, information and education, coordination of care, physical support, emotional support, and involvement of parents.[11,13] The framework for action of the EMPATHIC study was built on these domains. Parent satisfaction – recognized as an important quality of care performance indicator – was placed in the inner circle. The outer circle listed the above six domains of family-centered care. The middle circle defined the parental needs and experiences assumed to be the influencing factors for patient satisfaction.[14] This framework for action proved useful and, in our view, remains a valuable framework for future studies on the impact of family-centered care in pediatrics, and related sub-specialties.

The series of studies in this thesis provided evidence to develop a theoretical model of parental satisfaction with intensive care (Figure 1). The aim of this model is to explain the relationships between family-centered care aspects and parent satisfaction outcomes. The emphasis of the model is the *structure* of the care delivery as defined in family-centered care domains. The *process* of the model consists of the parental experiences of the delivered care and the interaction with the healthcare professionals. The *outcome* indicators are the satisfaction-with-care measures that, consequently, need to provide valuable input for quality improvement. By ratifying the outcome indicators, intensive care units can clearly show the level of performance and quality of their services related to family-centered care. Fundamental to this model is the assumption that parents are competent of providing informed feedback on the aspects of family-centered care and intensive care services.

Family-centered care principles are the paramount issues of today's intensive care delivery systems. These principles aim to establish the collaboration between parents and healthcare professionals. In the model the family-centered care domains are defined as information, care and cure, organization, parental participation, and professional attitude. These domains emerged from three explorative EMPATHIC studies identifying the most important intensive care issues among parents and healthcare professionals.[15-17] The domain on information encompasses various elements of information provision, content, and timing. The domain care and cure includes aspects of pain and comfort, medication, and treatment, but also relates to the professional knowledge levels, and admission and discharge processes. The organization domain concerns environmental issues and general regulations of an intensive care unit. The domain parental participation has been conceptualized towards parent autonomy and involvement in care. Finally, the professional attitude domain concerns equity, teamwork, and empathic behavior. The operational definitions of the family-centered care domains are assumed to form the structure of family-centered care delivery.

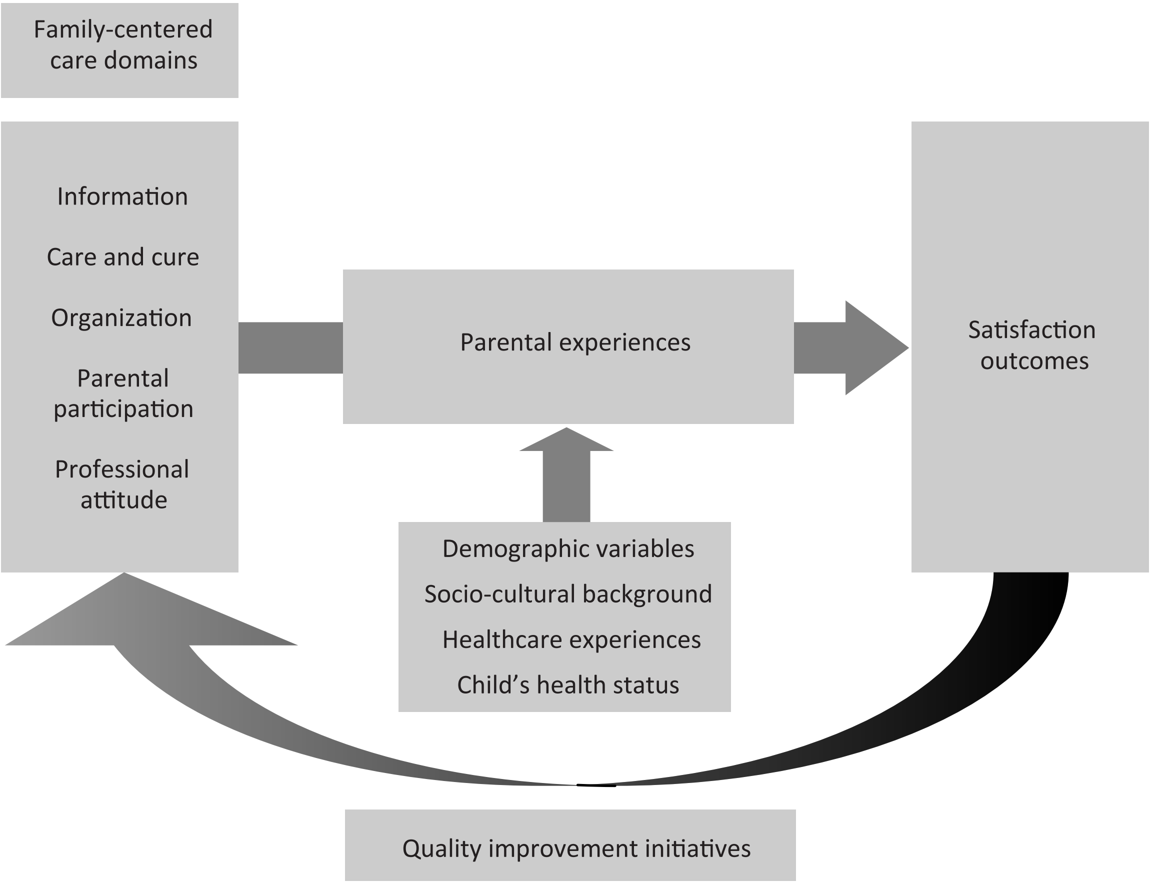

Figure 1 | Parent satisfaction model for intensive care quality performance

Parental experiences are related to the process indicators and are located in the center of the model because parents are the primary assessors. The studies in this thesis have documented that parents are capable of communicating their intensive care experiences.[17,18] However, intrinsic variables might influence these experiences, such as demographic status, socio-cultural background, previous hospital experiences, or the child's health status during and after intensive care admission. Based on the validation studies of the EMPATHIC and EMPATHIC-N questionnaires it can be assumed that these variables result in different satisfaction outcomes among various groups of parents.

Satisfaction outcomes are related to the quality indicators that provide evidence of the care delivery processes as experienced by the parents. In this model, and based on the results of this thesis, the satisfaction-with-care indicators are defined in 65 statements for the PICU services and 57 statements for the NICU services. Although the following was beyond the scope of this thesis, it is believed that satisfaction outcomes are needed to develop *quality improvement initiatives*.[19-21] This part of the model needs further testing.

Learning to use and understand a new set of statistical procedures is like making a long journey through a strange land.
Rex B. Kline, 2005, Principles and practice of structural equation modeling, p. 8

The EMPATHIC studies created and tested a new set of parent satisfaction statements. The process of modeling was long and complex. One question remains: are the validated questionnaires the gold standard to measure parent satisfaction in the intensive care unit? The three “Ms” of Measures, Meanings, and Memories might guide PICU and NICU professionals towards accepting children and parents as partners in quality of care improvement.

Measures

Satisfaction with healthcare services has been widely discussed in the medical and nursing literature. Many patient satisfaction instruments are predominantly constructed in domains of nursing and medical care. Numbers of items vary widely, which may be due to the fact that most instruments were developed with input of expert opinions.[22] No more than 13 of the 54 different instruments have used patient input in the developmental phase. Patients’ perspectives provide valuable information related to patient-staff communication, patient’s needs, and organization.[23,24] It would seem imperative, therefore, to consult patients or family members when developing a satisfaction instrument. In the development of the EMPATHIC questionnaires, it was suggested to start using the domains of patient- and family-centered care.[11,22]

Parents or the child’s caretakers are often the proxies of the critically ill child in the communication with healthcare professionals. In this perspective, the family-centered care domains provide a comprehensive framework for the development of satisfaction instruments. Although roles and preferences of parents in pediatric care have been identified, in reality the health professionals’ knowledge of family-centered care principles does not match that of the parents.[25] Therefore, a structured approach was the basis of the EMPATHIC study. We did not aim to reinvent the wheel because many general satisfaction instruments were already available. However, most instruments originate from other healthcare areas and often lack rigorous validated approaches.[26,27]

In the exploratory phase of the EMPATHIC study, we conducted several studies to identify intensive care issues of importance to parents and professionals. These proved plentiful. The validated EMPATHIC and EMPATHIC-N questionnaires eventually included 65 and 57 statements, respectively. In comparison, other published parent or family satisfaction surveys in pediatrics and critical care units contain between 15 and 43 items.[27] Although skeptics might debate the effectiveness of a time-consuming satisfaction instrument, a study revealed no significant differences in response rates between a short and long version of a hospital satisfaction survey.[28] A review has confirmed this finding: regarding 125 satisfaction surveys with 1 to 361 items, a median of 14, there was a weak negative correlation between the number of items and the response rate (r = -0.29).[29] Besides, the response rates in all EMPATHIC survey studies remained stable between 54% and 65%, thus equaling response rates published in medical and nursing journals.[30,31]

Meanings

Measurement of satisfaction-with-care has been given an impetus with the promotion of patient-driven care. The concept of patient satisfaction itself has been studied widely. As a result it has been introduced as a valuable quality performance measure in many hospitals.[32-36] However, critics have questioned the meaning of high satisfaction outcomes and their relevance to clinical practice.[37,38] Indeed, high satisfaction-with-care ratings have been reported in intensive care[39], in line with the explorative and validation studies in this thesis.[16-18] The challenge, however, is to capture not only quantitative measures but also quantitative findings, for example by including open-ended questions or providing space for written comments. The exploration of parents' narratives in satisfaction surveys might provide a valuable in-depth meaning of the quantitative measures.[40-42] Analyzing the combination of both types of measures has been of benefit to quality improvement projects.[19,43] The currently used EMPATHIC questionnaires also provide space for comments, and over 70% of parents used this to communicate their experiences. Most of these experiences give detailed information related to the quantitative statements, but otherwise provide as well a wealth of information to improve clinical practice.

It is still being debated whether measuring patient satisfaction is the gold standard to capture the concerns of an individual patient. A recent book by Fred Lee about things that would be different if Disney should be running a hospital has stimulated many hospital directors to concentrate on patient perspectives.[44] Lee had been advocating patient satisfaction for many years. However, he changed his mind and now refers to it as tinsel because satisfaction measures seem to be important but become useless if patients seem to prefer the next treatment in another hospital. The new trend seems to focus on the so-called loyalty factor. Without doubt, caring with empathy and an extra dimension of attention might satisfy patients to the extent that they become loyal to a hospital. However, the number of hospitals with a pediatric or neonatal intensive care unit is limited due to the centralization of these centers. But this does not mean that pediatric and neonatal intensive care staff has a wild card. Providing care to the child and parents with an extra touch remains of utmost importance. Obviously this relates to the much applauded individual care delivery concept. Indeed, investigating the parents' wishes should be on the agenda of regular evaluation meetings between parents and healthcare professionals. Or even better, inquiring from parents at admission what their care preferences are coupled with regular evaluation of compliance with these preferences. It would be wise to have various strategies available. In this respect, satisfaction surveys might not be the gold standard but rather form part of a wider evaluation system. Other approaches, such as focus group meetings, discharge meetings with the parents, or follow-up (telephone) interviews have been documented to be successful and to add to the meaning of the evaluation of care.[45-48] However, the importance of validated satisfaction instruments stretches beyond the evaluation of care only. In scientific research, satisfaction-with-care has been proven to be a valuable outcome measure for family and parental support interventions.[21,49,50] Therefore, the validated parent satisfaction instruments resulting from our studies as well as the validated instruments to measure the impact of PICU and NICU care remain of importance for pediatric and neonatal intensive care services. Not only to assess quality of care or the parents' perspectives, but also as primary outcome measures in future interventional studies.

Memories

Parents are recognized partners in the evaluation of their child's intensive care period. For NICUs this is obvious. However, giving the child its own empowerment to evaluate the intensive care experience is not often acknowledged. It might be considered as an omission to exclude the children's perspectives in establishing satisfaction-with-care strategies in a PICU. Children from a certain age seem to be capable of defining the concepts of satisfaction. A qualitative study conducted recently among 40 children aged between 10 and 15 years identified three themes to determine satisfaction.[51] The findings of three focus group meetings with these children identified that satisfaction was related to comparison, evaluation of the experienced emotion, and positive external feedback. It was suggested also that one should be aware that children might interpret questions on satisfaction-with-care differently.

The techniques used to identify a child's experience of a hospital stay vary from interviews to standardized questionnaires.[52-54] It seems feasible to include children in evaluation studies, provided they are in stable condition and without cognitive disabilities.[55] After all, children from the age of eight are able to recall an intensive care experience up to 12 months after discharge.[56]

Knowing is not enough; we must apply. Willing is not enough; we must do.
Johann Wolfgang von Goethe (1749-1832)

At the end of our EMPATHIC journey we cannot but conclude that we have gained extensive knowledge about parental intensive care experiences in the Netherlands – which we have processed into two validated satisfaction instruments. The challenge now is having parent satisfaction accepted as a quality performance indicator. Its use will even raise the level of excellence in care.

Utilization

Various issues concerning the use of parent satisfaction measures should be addressed. First, the primary aim should be the documentation of the parental experiences and to identify and test necessary quality improvement projects. Second, the validated satisfaction questionnaires can be used for benchmarking among PICUs and NICUs and might be widely applicable in many countries. Although colleagues might hesitate to present their satisfaction outcomes for benchmarking with others, such initiatives can lead to recognition of pitfalls in care delivery systems and subsequently to establishing best practices.[57] Significant differences in the quality of care between centers might come to the fore and this indeed has already been documented.[58] Establishing a positive and learning environment among participating centers in a benchmark program would certainly be of value to the individual healthcare professionals. Third, there is the issue of the relation between the length of a satisfaction questionnaire and response rate. As discussed previously, such a relation does not seem to exist. However, a few important issues related to the utilization of such instruments remain: selection of the rating scale, timing of administering the questionnaires, and administering mode. Various rating scales are being used in satisfaction surveys such as emotional icons (smiley's) or visual analog scales. A study comparing a 5-point satisfaction scale, from dissatisfied to very satisfied, with a 10-point evaluation scale, from very poor to excellent, yielded no different satisfaction outcomes.[59] Timing of administering a satisfaction questionnaire is important because it might influence the response rate. Few studies have documented a reduction in response rates when satisfaction questionnaires were mailed 3 months after discharge from the hospital; the period between 1 and 5 weeks after discharge was recommended.[60,61] Whether online satisfaction questionnaires have a positive influence on the response rate has, within critical care units, not been tested. In one of our EMPATHIC surveys, the questionnaire was mailed between 2 and 4 weeks and was also made available online.[17] No more than 3% of parents choose to complete the online survey. Thus, although various innovative information technologies have become available, it might be considered to use a paper version in combination with online options.

Finally, satisfaction-with-care should be measured over time to provide continuous quality outcomes of the delivered care. In order to have satisfaction measures embedded in the PICU and NICU quality measures, it is suggested to incorporate parent satisfaction in the Dutch PICU and NICU registries. Consequently, periodical assessment of parent satisfaction outcome makes it possible to collaboratively work on quality improvement.

Ultimately

Measuring and analyzing parent satisfaction supports healthcare professionals in their efforts to improve the care of the critically ill infants, children, and their families.

Future directions

The topic of measuring satisfaction in healthcare requires basic knowledge of the patient satisfaction literature combined with the clinical expertise. We celebrate, with due pride, the construction and validation of two parent satisfaction questionnaires for PICU and NICU services. However, the journey of discovering parents' experiences and satisfaction-with-care has not come to an end. Several issues that can influence satisfaction outcomes – and consequently have an effect on the quality of nursing and medical care – have not yet been explored. The following areas deserve priority:

- Testing the validated satisfaction instruments on their ability to document changes in clinical practice implemented via quality improvement initiatives;
- Investigating the characteristics of non-responders and their experiences of care;
- Exploring the influences of family culture and context on perceptions of care;
- Developing instruments to assess children's views on their intensive care period;
- Conducting research on the experiences and satisfaction of parents of deceased children in the intensive care unit.

Exciting times lie ahead of us in which the public is going to play an important role in monitoring healthcare services. In this respect, parents might become our 'auditors' monitoring the intensive care services. It is our duty to collaboratively and continuously work on quality of care.

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CHAPTER 15

Summary

SUMMARY

This thesis addresses the empowerment of parents in the intensive care unit. Giving parents a voice in the evaluation and quality assessment of intensive care services does not only benefit parents and children, but also allows healthcare professionals to reflect upon their care.

The aim of the EMPATHIC study was to develop and implement validated parent satisfaction questionnaires for the eight PICUs and one NICU in the Netherlands. The different parts of this thesis address the following research questions:

1. Which methodology and concepts of parent satisfaction measures related to pediatric critical care are described in the literature?
2. What do nurses and physicians find important in the care for the critically ill infant/child and the parents?
3. What are the perceptions of the parents who had experienced a PICU or NICU admission of their child on satisfaction-with-care issues?
4. Do parents and healthcare professionals have different perspectives on the importance of intensive care practices?
5. Are the constructed parent satisfaction questionnaires reliable and valid to measure satisfaction-with-care?

PART I | INTRODUCTION

Part I provides a justification to focus on parent satisfaction measures in the intensive care unit. In ***Chapter 1*** the growing interest in healthcare satisfaction research is addressed. Patient satisfaction has been advocated by governments, patient organizations, and healthcare insurance companies while hospitals have started to integrate patients' perspectives in their policy documents. However, patient satisfaction outcomes must not exclusively be used as a benchmark tool but should drive healthcare professionals towards quality improvements. Parent satisfaction and its relationship to family-centered care are discussed in ***Chapter 2***. The debate continues by touching upon the family needs and the way healthcare professionals take these needs into consideration in their daily practice. This debate is further explored in ***Chapter 3***. The needs of family members in the ICU have often been conceptualized by communication, information, assurance, and proximity. It is argued that meeting these needs does not always guarantee satisfaction. The aims and research questions of the separate EMPATHIC studies are based on this debate and recognize the partnership between parents and professionals in quality improvement, and they are presented in ***Chapter 4***.

PART II | FRAMEWORK

This part is devoted to reviewing the scientific evidence and designing a framework for action. First, we conducted a literature review to assess the content and characteristics of the available validated parent and family satisfaction instruments (***Chapter 5***). It appeared that only one validated parent satisfaction instrument for PICU services had been published and two for NICU services. Nine other instruments had been designed for adult ICUs and general pediatrics. Reviewing the instruments provided 95 unique satisfaction topics. Most instruments had been tested on validity and reliability. However, the strength of the psychometric properties varied and in some cases the family members or parents had not been involved in the development of the instrument. The recommendations in this chapter are related to the use of the identified satisfaction topics, to incorporating parents' experiences in the development phase, and to thorough statistical testing. Second, in ***Chapter 6*** we discuss the concepts of family-centered care, experiences, needs, and parent satisfaction and describe a framework for action. It was assumed that this framework would be valuable for future studies on the impact of satisfaction and family-centered care in pediatrics and related sub-specialties. This framework became the theoretical basis of the EMPATHIC studies.

PART III | EXPLORATIONS

We conducted three explorative studies to identify the experiences of parents and healthcare professionals related to the importance of pediatric intensive care services. ***Chapter 7*** starts with a qualitative study of in-depth interviews with parents of 41 children. The interviews were analyzed using thematic analysis and revealed 63 sub-themes in six major themes: attitude of the professionals; coordination of care; emotional intensity; information management; environmental factors; parent participation. These proved valuable in the construction of a parent satisfaction instrument. In addition, the findings also documented associations between the themes. It turned out that parental emotional impact was associated with all other themes.

At the same time, we conducted two quantitative studies. In ***Chapter 8***, a two-round Delphi study among PICU professionals is presented. A total of 302 nurses and 62 physicians identified and prioritized 78 meaningful parent satisfaction items divided into five domains. The same questionnaire was presented to 1042 parents, of whom 559 (54%) responded, as described in ***Chapter 9***. Parents were asked to rate the items on importance. The highest scores were assigned to aspects on information provision, care and cure, and attitude of the professionals. The questionnaires were found of great importance for future research in other countries and were, therefore, tested on reliability of the dimensional structure and on the impact of the individual items within that structure.

PART IV | PERCEPTIONS

A comparison of the explorative studies described in Chapters 8 and 9 is presented in ***Chapter 10***. Parents rated 31 items more important than the professionals. Ten of these were related to information provision, such as on the effects of medication, and to the correct administration of medication. In contrast, the PICU professionals rated 12 items more important than the parents. We concluded that these findings may reflect a gap in the professionals' understanding of parental experiences.

Chapter 11 describes two similar studies among parents and NICU professionals. First, a 3-round Delphi study was performed among 81 professionals to identify and to reach consensus on a priority list of NICU care items. Second, this list with 92 care items was then used in a survey study among 148 parents. They were asked to rate these items on their importance. Here, too, we encountered differences between parents and professionals. Parents rated 25 of 92 care items significantly higher than the professionals. The largest effect sizes were found for two items related to medication administration. The NICU professionals rated seven items significantly higher than the parents. One of these involved the desirability of assigning a single physician and a single nurse to the parents and three items were related to multicultural care. As a clinical implication of these studies we think that physicians and nurses need to review the identified care items and relate these to their own clinical practices. In addition, these findings might also be important for training and education.

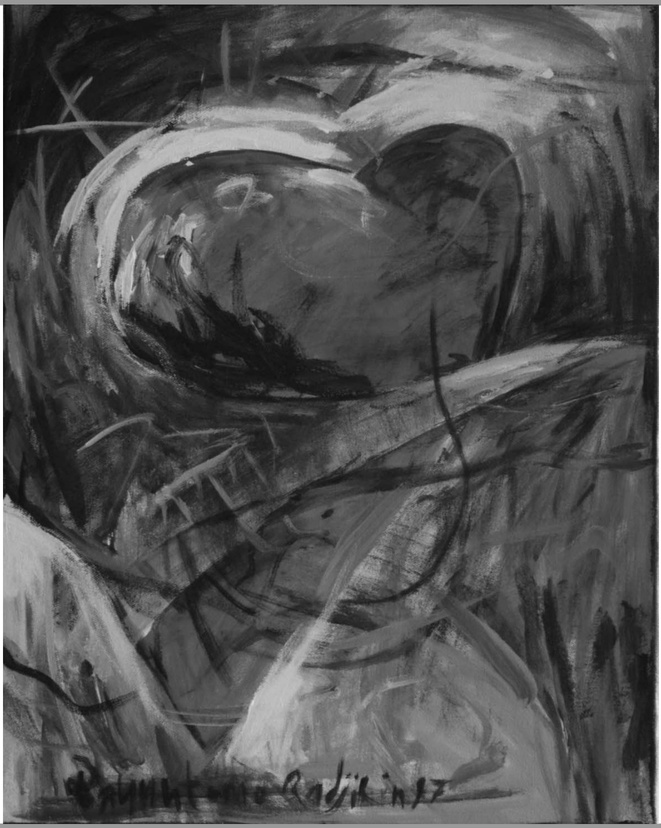
PART V | VALIDATION

In ***Chapter 12*** the validation study of the EMPATHIC questionnaire is presented. The outcomes of the explorative studies served as a basis for the construction of the questionnaire. The psychometric properties were tested by using the empirical data of 1218 respondents divided into two cohorts: 667/1055 (63%) parents in the first cohort and 551/991 (56%) parents in the second. The data of the first cohort were used for the Confirmatory Factor Analysis (CFA) to unravel the structure of the 72 statements under five domains: Information, Care & Cure, Organization, Parental Participation, and Professional Attitude. Seven statements did not fit into the domains resulting in 65 statements. Further reliability testing showed good outcomes. The data of the second cohort were used to test the non-differential validity. It appeared that parents whose child had undergone surgery were more satisfied with the statements in the domain of information. Several statements were below acceptable standards, for example, daily talks with the physician about the child's care and treatment, the way in which physicians prepared the child's discharge, and the noise levels in the ICU units. We concluded that the EMPATHIC questionnaire can be accepted as a valid quality performance indicator for PICUs.

Chapter 13 presents the psychometric testing of the EMPATHIC-N questionnaire. The statements of this questionnaire were derived from the explorative studies as described in Chapter 11. Sixty-seven of the 92 items listed in these studies were found to be of importance and were translated into statements in the EMPATHIC-N questionnaire. This study also used two cohorts: 220/339 (65%) parents in the first cohort and 59/102 (58%) parents in the second. Two negatively formulated statements and one statement with a 91% 'not applicable' score were removed before the analyses. Seven statements did not fit into the empirical structure of the domains and were removed. The remaining 57 statements within the five domains showed an adequate model fit. Non-differential validity showed no significant effect sizes between the infants' characteristics and the domains, except between ventilated infants and statements related to parental participation, and infants ≥30 weeks gestational age and organizational statements. The statements found to be below standard were related to information given by physicians about expected health outcomes of the child and about identical information provided by physicians and nurses. Also, parents were dissatisfied about their level of active involvement in decision-making processes and the received guidance about the child's care after discharge. The noise levels in the NICU and the space around the incubator were also found below standard. The conclusion of this study was that the EMPATHIC-N questionnaire is a reliable and valid instrument that enables healthcare professionals to identify areas of improvement.

PART VI | DISCUSSION

In ***Chapter 14*** the EMPATHIC studies in this thesis are discussed. The measures, meanings, and memories of satisfaction outcomes are highlighted as well the best possible ways to utilize parent satisfaction questionnaires. Finally, the proposed research directives provide a road map for an ongoing journey in discovering the experiences and satisfaction of children and parents in the intensive care unit.



PART VII

Appendices

NEDERLANDSE SAMENVATTING

Ouders een stem geven in de kwaliteit van zorg op de intensive care is goed voor ouders en kinderen, en zorgt er voor dat de zorgverleners nadenken over de manier waarop zij de zorg verlenen.
Dit proefschrift gaat over de inspraak van ouders in de intensive care unit.

Het doel van de EMPATHIC studie was het ontwikkelen en implementeren van oudertevredenheidsvragenlijsten voor de acht kinder intensive care afdelingen (ICK) en een neonatologie intensive care afdeling (NICU) in Nederland.
Dit proefschrift beantwoordt de volgende onderzoeksvragen:

1. Welke methodologie en concepten van oudertevredenheid met betrekking tot intensive care zorg worden in de literatuur beschreven?
2. Wat is voor verpleegkundigen en artsen belangrijk in de zorg voor het ernstig zieke kind en de ouders op een ICK en NICU?
3. Wat zijn de ervaringen van ouders die een opname van hun kind op een ICK of NICU hebben meegemaakt?
4. Hebben ouders en zorgverleners verschillende meningen over de zorg op de ICK en NICU?
5. Zijn de ontwikkelde oudertevredenheidsvragenlijsten voor de ICK en NICU betrouwbaar en valide?

DEEL I | INLEIDING

Deel I is de inleiding van het proefschrift en legt uit waarom hier is gekozen voor het meten van oudertevredenheid op de intensive care.

In ***Hoofdstuk 1*** wordt de groeiende belangstelling in onderzoek naar de patiënttevredenheid besproken. Het meten van patiënttevredenheid wordt inmiddels aanbevolen door de regering, patiëntenorganisaties en zorgverzekeraars terwijl ziekenhuizen zijn begonnen met het integreren van de ervaringen van patiënten in hun beleidsdocumenten. Resultaten van patiënttevredenheid moeten echter niet exclusief worden gebruikt als vergelijkingsmateriaal, maar zorgverleners stimuleren tot kwaliteitsverbeteringen.

Oudertevredenheid en de relatie daarvan met gezinsgerichte zorg worden besproken in ***Hoofdstuk 2***. De discussie spitst zich vervolgens toe op de behoeften van familieleden en de manier waarop zorgverleners in hun dagelijkse praktijk rekening houden met deze behoeften. Deze discussie wordt nader besproken in ***Hoofdstuk 3***. De behoeften en ervaringen van familieleden op de intensive care afdelingen zijn vaak globaal omschreven in concepten zoals communicatie, informatie, geruststelling en nabijheid. Gesteld wordt dat het voldoen aan de behoeften van familieleden niet altijd tevredenheid garandeert.

Het doel en de onderzoeksvragen van de EMPATHIC studies worden gepresenteerd in ***Hoofdstuk 4*** en zijn gebaseerd op de erkenning van de samenwerking tussen ouders en zorgverleners met het oog op kwaliteitsverbetering.

DEEL II | KADER

Dit deel is gewijd aan het ontwikkelen van een kader voor de EMPATHIC studies, gebaseerd op de wetenschappelijke bewijslast.

In ***Hoofdstuk 5*** hebben we eerst een literatuurstudie verricht om de betekenis en kenmerken van de beschikbare gevalideerde vragenlijsten over tevredenheid te beoordelen. In de literatuur is maar één gevalideerde vragenlijst over oudertevredenheid gepubliceerd voor de ICK en twee voor de NICU. De resterende negen gepubliceerde tevredenheidlijsten hadden betrekking op de volwassenen intensive care afdelingen en algemene kindergeneeskunde. De beoordeling van de vragenlijsten leverde 95 unieke onderwerpen met betrekking tot tevredenheid op.

De psychometrische eigenschappen van de gevalideerde vragenlijsten varieerden echter en soms werden de familieleden of ouders niet betrokken bij de ontwikkeling van het instrument. De aanbevelingen in dit hoofdstuk hebben betrekking op het gebruik van de geïdentificeerde tevredenheidonderwerpen, het meenemen van de ervaringen van de ouders in de ontwikkelfase, en grondige statistische toetsing.

Vervolgens bespreken we in ***Hoofdstuk 6*** de concepten van gezinsgerichte zorg, ervaringen, behoeften en oudertevredenheid en wordt een kader beschreven. Dit kader is waardevol voor toekomstig onderzoek naar de invloed van tevredenheid en gezinsgerichte zorg in de kindergeneeskunde en gerelateerde deelspecialismen. Het kader vormt de theoretische basis van de EMPATHIC studies.

DEEL III | EXPLORATIES

In dit deel van het proefschrift hebben we drie exploratieve studies uitgevoerd om de ervaringen van ouders en zorgverleners te identificeren met betrekking tot het belang van de zorg op de intensive care.

Hoofdstuk 7 begint met een kwalitatieve studie met diepte-interviews met ouders van 41 kinderen die op een ICK waren opgenomen. De interviews werden geanalyseerd met behulp van thematische analyse en onthulden 63 subthema’s verdeeld over zes hoofdthema’s:

- Attitude van de zorgverleners
- Coördinatie van de zorg
- Emotionele intensiteit
- Informatie management
- Omgevingsfactoren
- Ouderparticipatie

De subthema's en thema's leverden waardevolle informatie voor het ontwikkelen van een oudertevredenheidvragenlijst. Bovendien toonden de bevindingen ook een verband tussen de hoofdthema's waarbij de emotionele intensiteit van de ouders geassocieerd is met alle andere hoofdthema's.

Tegelijkertijd werden twee kwantitatieve studies uitgevoerd. In ***Hoofdstuk 8***, wordt een Delphi studie van twee vragenrondes met de zorgverleners van alle ICKs omschreven om onderwerpen over oudertevredenheid te identificeren. In totaal hebben 302 verpleegkundigen en 62 artsen 78 onderwerpen over oudertevredenheid, verdeeld in vijf domeinen, vastgesteld.

Deze onderwerpen werden ook aan 1042 ouders voorgelegd, zoals beschreven in ***Hoofdstuk 9***. Van deze groep hebben 559 (54%) ouders gereageerd. Aan de ouders werd gevraagd de onderwerpen van tevredenheid naar belangrijkheid te waarderen. Kwesties met betrekking tot informatieverstrekking, zorg en behandeling, en de attitude van de zorgverleners kregen de hoogste scores. Deze vragenlijst is, gezien het belang voor toekomstig onderzoek in andere landen, getest op betrouwbaarheid. Vier items zijn verwijderd en dit resulteerde in een valide vragenlijst met 74 onderwerpen die het belang van de zorg op de ICK meten.

DEEL IV | INZICHTEN

Deel IV richt zich op de verschillen en overeenkomsten van meningen over de zorg tussen de ouders en zorgverleners.

De vergelijking van de in Hoofdstuk 8 en 9 beschreven exploratieve studies wordt gepresenteerd in ***Hoofdstuk 10***. Ouders vonden 31 onderwerpen significant belangrijker dan de zorgverleners. Tien onderwerpen hadden betrekking op informatieverstrekking zoals informatie over de effecten van medicatie en de correcte toediening van medicatie. Daarentegen vonden de zorgverleners van de ICK 12 onderwerpen significant belangrijker dan de ouders. We concludeerden dat de inzichten van de zorgverleners niet geheel overeenkomen met de percepties van de ouder over de zorgonderwerpen.

In ***Hoofdstuk 11*** worden vergelijkbare resultaten onder ouders en zorgverleners van de NICU gepresenteerd. Dit hoofdstuk beschrijft twee studies. Eerst werd een Delphi studie van drie rondes uitgevoerd onder 81 zorgverleners om een prioriteitenlijst van zorgonderwerpen op de NICU op te stellen en consensus hierover te bereiken. Vervolgens werd deze lijst met 92 onderwerpen gebruikt in een onderzoek onder ouders (n = 148). Aan hen werd gevraagd om de zorgonderwerpen naar belangrijkheid te waarderen. Ten slotte werden de gegevens van beide studies vergeleken.

Ouders waardeerden 25 van de 92 zorgonderwerpen significant hoger dan de zorgverleners. Het grootste verschil werd geconstateerd bij twee onderwerpen met betrekking tot medicatie. De zorgverleners waardeerden zeven onderwerpen significant hoger dan de ouders. Een van deze onderwerpen had betrekking op het toewijzen van een vaste arts en een vaste verpleegkundige aan de ouders en drie onderwerpen gingen over multiculturele zorg. Als klinische implicatie van deze studies denken we dat artsen en verpleegkundigen de zorgonderwerpen kritisch moeten bekijken en toepassen in hun dagelijkse praktijkvoering. Bovendien kunnen deze bevindingen ook belangrijk zijn voor toekomstige training en opleiding van de zorgverleners.

DEEL V | VALIDATIE

Dit deel bespreekt de ontwikkeling en de psychometrische testen van de EMPATHIC en de EMPATHIC-N vragenlijst voor de ICKs en de NICU.

In ***Hoofdstuk 12*** wordt de studie van de EMPATHIC vragenlijst gepresenteerd. De ontwikkeling van de samenstelling van de vragenlijst was gebaseerd op de resultaten van de exploratieve studies. De psychometrische eigenschappen van de vragenlijst werden getest met behulp van de empirische gegevens van 1218 ouders verdeeld in twee groepen: 667/1055 (63%) ouders in de eerste groep en 551/991 (56%) ouders in de tweede. De gegevens van de eerste groep werden gebruikt voor de betrouwbaarheidstesten zoals de Confirmatory Factor Analysis (CFA). De CFA is uitgevoerd om de structuur te bepalen van de 72 stellingen verdeeld in de vijf domeinen:

- Informatie
- Zorg & Behandeling
- Organisatie
- Ouderparticipatie
- Professionele Attitude

CFA bevestigde dat zeven stellingen niet pasten in de domeinen. De gegevens van de tweede groep ouders werden gebruikt om de niet-differentiële validiteit te testen. Het bleek dat ouders van een kind dat voor een operatie werd opgenomen meer tevreden waren over de stellingen in het domein Informatie. Verscheidene stellingen lagen onder de aanvaardbare norm zoals een dagelijks gesprek met de arts over de zorg en behandeling van het kind, de informatie van de arts over het ontslag van het kind, en het geluidsniveau op de afdeling.

We concludeerden dat de EMPATHIC vragenlijst kan worden geaccepteerd als een valide prestatie-indicator voor de kwaliteit op de ICKs.

Hoofdstuk 13 bespreekt de ontwikkeling en de psychometrische testen van de EMPATHIC-N vragenlijst. De stellingen van deze vragenlijst werden verkregen uit de in Hoofdstuk 11 beschreven exploratieve studies. Van de 92 in deze studies opgenomen zorgonderwerpen waren er 67 belangrijk en deze werden vertaald in stellingen voor de EMPATHIC-N vragenlijst. Deze studie gebruikte ook twee groepen ouders: 220/339 (65%) ouders in de eerste groep en 59/102 (58%) ouders in de tweede groep. Voor de analyses werden twee negatief geformuleerde stellingen en een stelling met een 91% ‘niet van toepassing’ score geschrapt. De CFA bevestigde dat zeven stellingen niet pasten in de structuur van de domeinen en deze werden verwijderd. De resterende 57 stellingen in de vijf domeinen hadden een adequate samenhang. Niet-differentiële validiteit toonde geen significante verschillen tussen de kenmerken van de pasgeborenen en de domeinen, behalve tussen beademde pasgeborene en stellingen in het domein Ouderparticipatie, en pasgeborenen ≥ 30 weken en stellingen in het domein Organisatie. De stellingen die beneden de norm waren, hadden betrekking op de informatie door artsen over de gezondheidsverwachtingen van het kind en over eenduidige informatievoorziening door de artsen en verpleegkundigen. Ouders waren ontevreden over hun mogelijkheid voor actieve betrokkenheid bij besluitvormingsprocessen en de ontvangen begeleiding bij de zorg voor het kind voorafgaande aan zijn ontslag. De geluidsniveaus in de NICU en de ruimte rondom de couveuse waren beneden de norm.

De conclusie van deze studie was dat de EMPATHIC-N vragenlijst een betrouwbaar en valide instrument is waarmee de zorgverleners verbeterprojecten kunnen identificeren en implementeren.

DEEL VI | DISCUSSIE

In ***Hoofdstuk 14*** worden de EMPATHIC studies in dit proefschrift besproken. Drie thema’s over oudertevredenheid worden benadrukt:

- de metingen
- de betekenis
- de herinnering

Daarnaast worden methoden over het gebruik van de oudertevredenheidsvragenlijsten beschreven. Tot slot nemen we de voorstellen voor toekomstig onderzoek mee op de ontdekkingsreis naar de ervaringen en tevredenheid van kind en ouders op de intensive care.

LIST OF ABBREVIATIONS

AICU, Adult Intensive Care Unit
ANZICS, Australian New Zealand Intensive Care Society
CCNFI: Critical Care Family Needs Inventory
CCFS, Critical Care Family Survey
CFA, Confirmatory Factor Analysis
CFI, Comparative Fit Index
COPE, Creating Opportunities for Parent Empowerment
df, degrees of freedom
EMPATHIC, EMpowerment of PArents in THe Intensive Care
EMPATHIC-N, EMpowerment of PArents in THe Intensive Care – Neonatology
ICU, Intensive Care Unit
IOM, Institute Of Medicine
NICU, Neonatal Intensive Care Unit
NICU-PSF, Neonatal Intensive Care Unit - Parental Satisfaction Form
NIDCAP, Newborn Individualized Developmental Care and Assessment Program
NIPS, Neonatal Inventory Parent Satisfaction
NS, Not Significant
PICE, Pediatrische Intensive Care Evaluatie
PICU, Pediatric Intensive Care Unit
PFQ, Parent Feedback Questionnaire
PFSQ, Parent Family Satisfaction Questionnaire
PPE, Picker Patient Experience
RMSEA, Root Mean Square Error of Approximation
SD: Standard Deviation
SEM, Structural Equation Modeling
SPSS, Statistical Package for Social Science
TLI, Tucker Lewis Index
WRMR, Weighted Root Mean square Residual

MEMBERS OF THE EMPATHIC STUDY GROUP

Erasmus MC – Sophia Children's Hospital, Rotterdam:
T. van Eijk, B. Elink Schuurman, H.J. Duivenvoorden, J.B. van Goudoever, J.A. Hazelzet, J.M. Latour, C. van Leeuwen

AMC – Emma Children's Hospital, Amsterdam:
A.P. Bos, M. de Neef, K. van Roest, D. Tol

Leiden University Medical Center, Leiden:
N.A.M. van Dam, B.J. Geesink – van der Veer, S.A. de Groot, K. Ommering

Maastricht University Medical Center, Maastricht:
E. Dullaart, G. Vos

Radboud University Nijmegen Medical Center, Nijmegen:
C.W.M. Verlaat, A. van der Zande

University Medical Center Groningen – Beatrix Children's Hospital, Groningen:
M.J.I.J. Albers, S. Dijkstra

University Medical Center Utrecht – Wilhelmina Children's Hospital, Utrecht:
M. Berckmans – de Jonge, K. Jansen, A.J. van Vught, E.M. van Vught

VU University Medical Center, Amsterdam:
A. Esmeijer, B. de Graauw, M. van Heerde , F.B. Plötz

AFFILIATION CO-AUTHORS EMPATHIC STUDY

Author	**Affiliation**
M.J.I.J. Albers, MD, PhD	– Pediatric Intensive Care Unit, University Medical Center Groningen – Beatrix Children's Hospital, Groningen
N.A.M. van Dam, MD	– Pediatric Intensive Care Unit, Leiden University Medical Center, Leiden
E. Dullaart, RN	– Pediatric Intensive Care Unit, Maastricht University Medical Center, Maastricht
H.J. Duivenvoorden, PhD	– Department of Medical Psychology and Psychotherapy, Netherlands Institute for Health Science, Erasmus University Medical Center, Rotterdam
B. Elink Schuurman, RN, MScN	– Department of Pediatrics, Erasmus MC – Sophia Children's Hospital, Rotterdam
J.B. van Goudoever, MD, PhD	– Department of Pediatrics, Division of Neonatology, Erasmus MC – Sophia Children's Hospital, Rotterdam – Department of Pediatrics, AMC – Emma Children's Hospital, Amsterdam – Department of Pediatrics, VU University Medical Center, Amsterdam
C. Haines, MSc, BSc(Hons), PGDE, RNT, RGN, RSCN, PCC Cert.	– Pediatric Intensive Care Unit, Bristol Royal Hospital for Children, United Bristol Healthcare Trust, Bristol, UK
J.A. Hazelzet, MD, PhD, FCCM	– Department of Pediatrics, Division of Pediatric Intensive Care, Erasmus MC – Sophia Children's Hospital, Rotterdam
M. van Heerde, MD	– Department of Pediatric Intensive Care, VU University Medical Center, Amsterdam
A.J. van der Heijden, MD, PhD	– Department of Pediatrics, Erasmus MC – Sophia Children's Hospital, Rotterdam
M. de Neef, RN, MSc	– Pediatric Intensive Care Unit, AMC – Emma Children's Hospital, Amsterdam
C.W.M. Verlaat, MD	– Pediatric Intensive Care Unit, Radboud University Nijmegen Medical Center, Nijmegen
E.M. van Vught, RN, BScN	– Pediatric Intensive Care Unit, University Medical Center Utrecht – Wilhelmina Children's Hospital, Utrecht

CURRICULUM VITAE

Personal

Name : Jos M. Latour
Address : Burg. Hogguerstraat 377; 1064 CS Amsterdam, the Netherlands
E-mail : jos.latour@planet.nl
Date of Birth : 29 July 1960
Place of Birth : Hoensbroek, the Netherlands
BIG registry number : 69011991530

Education and Qualifications

1995 Master of Science in Nursing, Cardiff University, Wales, United Kingdom, September 1992 - January 1995
1995 Certificate of Advanced Life Support, Institution Venti-Care (under the auspices of the European Resuscitation Council) in Utrecht, October 1995.
1988 Certificate of Pediatric Intensive Care Nursing, Wilhelmina Children's Hospital in Utrecht, January 1988 - December 1988
1987 Certificate of sports massage, 'Maastrichtse Opleiding voor Sportmassage' in Maastricht, January 1986 - May 1987
1986 Certificate of Pediatric Nursing, No 169826, University Hospital Maastricht in Maastricht, September 1985 - November 1986.
1985 Management for non-profit organizations, 'Institute for Social Science' in Leiden, September 1984 - May 1985
1982 Certificate of General Nurse, No 169826, De Wever Hospital in Heerlen, September 1978 - February 1982.
1978 MAVO-4, advanced elementary school, school "De Ravensberg" in Valkenburg, August 1973 - June 1978

Courses

2007 Methodology of patient-oriented research and preparation of grant applications, Erasmus Medical Center, Rotterdam
2005 Act Medical Research and Good Clinical Practice Course, Erasmus MC – Sophia, Rotterdam
2005 Advanced Course ATLAS.ti 5, Kwalon, University of Humanistics, Utrecht
2004 Qualitative Research; Interview Techniques, Kwalon, University of Humanistics, Utrecht
2004 Quality of Qualitative Research, Kwalon, University of Humanistics, Utrecht
2004 Introduction to Qualitative Research, Kwalon, University of Humanistics, Utrecht

Work experience

2003 – to date	Erasmus MC – Sophia Children’s Hospital, Rotterdam; Nurse scientist
1997 – 2003	VU University Medical Center, Amsterdam; Nurse manager PICU, Nurse manager NICU a.i. (2000 – 2001)
1992 – 1997	Wilhelmina Children’s Hospital, Utrecht; Pediatric Intensive Care nurse, nurse researcher
1990 – 1991	VU University Medical Center, Amsterdam; Pediatric Intensive Care nurse
1990 – 1990	Wilhelmina Children’s Hospital, Utrecht; Pediatric Intensive Care nurse
1989 – 1990	Wenchi Methodist Hospital, Wenchi, Ghana; Research nurse
1986 – 1989	Wilhelmina Children’s Hospital, Utrecht; Pediatric Intensive Care nurse
1982 – 1986	University Hospital Maastricht, Maastricht; Pediatric nurse, deputy nurse manager
1978 – 1982	De Wever Hospital, Heerlen; Nurse student, registered nurse

Professional experiences and skills

2008	Rater in the McMaster Online Rating of Evidence System, McMaster University, Hamilton, Ontario, Canada (2008 – to date).
2008	Co-chair 3rd EfCCNa Congress, 9-11 October 2008, Florence, Italy.
2007	Co-chair 5th World Congress Pediatric Critical Care, 24-29 June 2007, Geneva, Switzerland.
2005	Chairman 2nd EfCCNa Congress, 10-12 November 2005, Amsterdam, the Netherlands.
2005	Treasurer of the World Federation Pediatric Intensive and Critical Care Societies, WFPICCS (2005 – to date).
2004	Course Developer and faculty of the Clinical Nurse Educator Course, Papageorgiou Hospital, Thessaloniki, Greece.
2004	Expert appointed by Court of Justice, The Hague, the Netherlands; Case in High Court of a nurse accused of murder of several patients (children and adults).
2003	Vice-President of the World Federation Pediatric Intensive and Critical Care Societies, WFPICCS (2003 – 2005).
2003	Expert appointed by the Court of Justice, Assen, the Netherlands; Civil Court case about suspected medical and nursing malpractice in a hospital.

2002 Member of Fraction 3 ‘Child and Maternity Care’ of the AVVV, the Dutch National Nursing Council (2002 – 2004).

2001 Consultant for the Public Prosecutors, The Hague, the Netherlands; Case of a nurse accused of murder of several patients (children and adults) (2001 – 2002).

2001 Coordinator of the emergency services (disaster plan) in the VU University Medical Center during the Volendam fire disaster, 1 January 2001.

1999 CBO, Dutch Institute of Quality Improvement in Health Care. Expert in two Breakthrough Series of Adult Intensive Care (1999 – 2002).

1996 President of European Society of Pediatric Neonatal Intensive Care, ESPNIC (1996 – 2000).

1996 Nursing Project Team, nurse consultant for a new nursing organizational structure in the Wilhelmina Children’s Hospital, Utrecht, the Netherlands (1996 - 1997).

1993 Implementation of a nursing research program in the Wilhelmina Children’s Hospital, Utrecht, the Netherlands (1993 – 1997).

Research Projects

2009 Devictor D, Latour JM: *EURYDICE II Study: How children die in European Pediatric Intensive Care Units* (2009-2010).

2007 Blackwood, Albarran JW, Latour JM: *Research priorities of adult intensive care nurses in 20 European countries: a Delphi Study* (2007-2009).

2005 Latour JM, Hazelzet JA, van Goudoever JB: *Empowerment of Parents in the Intensive Care: the EMPATHIC Study.* PhD research project (2005 – 2010).

2005 Latour JM, Albarran J, Fulbrook P: *Views of European Nurses in the Intensive Care on End-of-life-care: the VENICE study.* (2005 – 2006)

2004 van Staa AL, Latour JM, Jedeloo, S: *‘Op Eigen Benen’: Preferences and competences of adolescents with a chronic illness in the transition of care process from pediatric health care to adult health care* (2004 – 2007).

2002 Latour JM, Albarran J, Fulbrook P: *A European survey of pediatric intensive care nurses’ attitudes and experiences of parental presence during cardiopulmonary resuscitation.*

2002 Fulbrook P, Albarran J, Latour JM: *A European Survey of critical care nurses’ attitudes and experience of family presence during cardiopulmonary resuscitation*.

1997 Latour JM and Rodenburg J: *Development of a general framework of standards of the nursing care and a quality measuring instrument for the pediatric intensive care unit.* Wilhelmina Children’s Hospital, Utrecht.

1995 Latour JM: *Development of a general framework of standards of the nursing care and a quality measuring instrument for the Emergency Department.* Wilhelmina Children’s Hospital, Utrecht.

1994 Latour JM: *A Delphi study to establish nursing research priorities in the Wilhelmina Children's Hospital Utrecht.* Master's thesis at the University of Wales to obtain the degree of Master of Science in Nursing.

Editorial board member & Reviewer journals

2007 – to date, *Pediatric Critical Care Medicine*, International Editorial Board
2006 – to date, *Journal of Child Health Care*, International Editorial Board
2004 – to date, *Nursing in Critical Care*, International Editorial Board
2001 – to date, *CONNECT: World of Critical Care Nursing*, International Editorial Board
2001 – to date, *Pediatric Intensive Care Nursing*, International Editorial Board
1996 – 2000, *KRITIEK, tijdschrift voor intensive care medewerkers*, Editorial Board
2008 – to date, *American Journal of Critical Care*, ad hoc reviewer
2007 – to date, *Intensive Care Medicine*, ad hoc reviewer
2006 – to date, *Pediatrics*, ad hoc reviewer

Honors & Awards

2010 Society of Critical Care Medicine (SCCM): Presidential Citation for outstanding contributions to the SCCM.
2009 European Society Paediatric and Neonatal Intensive Care (ESPNIC): Life Time Achievement Award.
2008 Fellow of the European Federation Critical Care Nursing associations (EfCCNa)
2006 Society of Critical Care Medicine (SCCM): Presidential Citation for outstanding contributions to the SCCM.

Membership professional organizations

1. Sigma Theta Tau International, Honor Society of Nursing, Rho Chi Chapter
2. Society of Critical Care Medicine, SCCM
3. European Society of Intensive Care Medicine, ESICM
4. European Society of Paediatric and Neonatal Intensive Care Nursing; ESPNIC
5. American Association Critical-care Nurses; AACN
6. Vereniging Voor Kinder Verpleegkundigen; VVKV
7. Nederlandse Vereniging voor Intensive Care Verpleegkundigen; NVICV

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PhD PORTFOLIO

Name PhD student: drs. J.M. Latour	PhD period: 2004-2010
Erasmus MC Department: Pediatrics	Promotor: Prof.dr. J.B. van Goudoever
	Co-promotor: Dr. J.A. Hazelzet

1. PhD training

	Year	Workload	
		Hours	ECTS
General PhD courses			
Introduction to Qualitative Research, Kwalon, University of Humanistics, Utrecht	2004	8	0.3
Quality of Qualitative Research, Kwalon, University of Humanistics, Utrecht	2004	8	0.3
Qualitative Research; Interview Techniques, Kwalon, University of Humanistics, Utrecht	2004	16	0.6
Advanced Course ATLAS.ti 5, Kwalon, University of Humanistics, Utrecht	2005	16	0.6
Act Medical Research and Good Clinical Practice Course, Erasmus MC – Sophia, Rotterdam	2005	8	0.3
Methodology of patient-oriented research and preparation of grant applications, Erasmus Medical Center, Rotterdam	2007	8	
Presentations			
– *A new quality indicator for PICU: Parent Satisfaction.* International Symposium on Pediatric Critical Care, 2-4 September 2010, Changsha, China	2010	28	
– *Parents in the NICU: Do we know what they think?* 50th Annual Meeting of the European Society for Paediatric Research. 9-12 October 2009, Hamburg, Germany	2009	28	
– *Satisfaction with the health care system: State of practice and future trends to patients, families, and nurses.* 2nd International Symposium on Pediatric & Neonatal Intensive Care, 12-14 November 2008, Sao Paulo, Brazil	2008	28	

– *Family-centered care and family satisfaction in PICU.* 9th Latin-American Congress on Pediatric Intensive Care, 2-5 April 2008, Vina del Mar, Chile	2008	28	
– *Measuring patient satisfaction in pediatric population.* 5th World Congress Pediatric Critical Care, 24-28 June 2007, Geneva, Switzerland	2007	28	

International conferences and seminars

– *22nd Annual Congress of the European Society of Intensive Care Medicine (ESICM), 11-14 October 2009, Vienna, Austria*	2009	18	0.6
– *3rd Congress European federation of Critical Care Nursing associations (EfCCNa) Congress, 9-11 October 2008, Florence, Italy*	2008	28	
– *Critical Care & Thoracic Society Conference, 5-8 August 2008, Cape Town, South Africa*	2008	28	1
– *5th World Congress Pediatric Critical Care, 24-28 June 2007, Geneva, Switzerland*	2007	32	1.1
– *36th Critical Care Congress of the Society of Critical Care Medicine,* – *17-21 February 2007, Orlando, USA*	2006	28	1

Review manuscripts for peer-reviewed journals

– *Pediatric Critical Care Medicine (17 manuscripts)*	2006-2010	136
– *Intensive Care Medicine (5 manuscripts)*	2007-2010	40
– *Nursing in Critical Care (11 manuscripts)*	2007-2009	88
– *Pediatrics (2 manuscripts)*	2006-2008	16
– *American Journal of Critical Care (1 manuscript)*	2008	8
– *Journal of Child Health Care (1 manuscript)*	2007	8
– *Rater Evidence-Based Nursing , McMaster University, Canada*	2006-2010	20

2. Teaching

	Year	Workload	
		hours	ECTS
Lecturing			
– IPOKRaTES Pediatric Critical Care Nursing Seminar, 6-9 November 2006, Shanghai, China. (11 lectures and bed-side teaching)	2006	32	
Tutoring			
– Evidenced-Based Nursing Lunches (9 tutorials)	2004-2010	72	
– Evidenced-Based Nursing Courses at the Zorgacademie – (teacher and supervisor of 58 literature review projects)	2004-2010	348	
Supervising Master's and Bachelor's theses			
– iBMG – project: Needs of parents and family members on the ICU	2004	36	
– iBMG – project: Patient classification for the pediatric ward	2004	36	
– Hogeschool Rotterdam – Nursing Bachelor project: Pilot study of the experiences of adolescents during transition fro, pediatrics to adult care	2004	36	
– Hogeschool Rotterdam – Nursing Bachelor project: Sudden Infant Death Syndrome	2008	36	
– Hogeschool Rotterdam – Nursing Bachelor project: Nursing history taking at a child's admission	2009	36	

ONCE UPON A TIME…

… there was a swan lake with many beautiful swans taking care of sick swanlings. This place was called the Sophia Children's Hospital. The swans in this lake had great visions to promote nursing science. One day, I landed as a novice swan on this lake because Wil de Groot-Bolluijt and Prof Hans Büller decided to give me the opportunity to become a nurse scientist. Thank you, Wil and Hans, for giving me the opportunity to glide along. But, as a typical Dutch standard, a novice nurse scientist swan is not fully grown until he completes his PhD. So, this novice discussed his future research directives with Prof Bert van der Heijden and Dr Jan Hazelzet. We agreed that my clinical skills were closely related to the wild waters of pediatric and neonatal intensive care. I was allowed to start a new research line on parental experiences and satisfaction in the intensive care unit. Bert and Jan, thank you for giving me a plan to swim and to fly forward. I enjoyed doing it.

After one year of drafting a research protocol and publishing a review, Prof Hans van Goudoever became my promoter and Dr Jan Hazelzet my supervisor. Birds like swans are heavy lifters to take off into the sky. Hans and Jan provided me the best airflow that kept me flying high towards my destiny. Thank you, Hans and Jan, for blowing the wind in the right direction. And frankly spoken, I have not landed yet.

In order to fly higher, help was needed from a statistical swan. Luckily, I met Hugo Duivenvoorden. Hugo, you taught me the complex mathematics of flying, allowing me to reach blues skies. With your bird's eye view I learned to navigate through the clouds; thanks for the instructions.

Often, swans congregate in herds. Grouping is safe, and above all, fun. From all over the country, many swans came and joined us in the so-called EMPATHIC study group pond. More than five years we have been together, connecting the eight different university lakes. It is simply too much to list all my colleagues. So, please turn back a few pages and you can see our group listed in the section "Members of the EMPATHIC study group". The success of our project is your unconditional participation in constructing our nest.

Over the years, the nest grew bigger and bigger. Two highly motivated swans saw me struggling with the piles of files. Beatrix Elink Schuurman and Arianne Jacobse became my counterparts in

collecting and positioning the nest in the correct files. Thank you for the help and I enjoyed sitting offshore with you.

Doing research you need a guard. I guess I am a privileged swan having many guardian swans overlooking my progress. Some were very visible; others guarded me from a distance like Prof Dick Tibboel. Thank you, Dick, for showing trust and faith in my flying skills.

To the invisible foreign swans from many countries, the reviewers of our manuscripts: we acknowledge that you have put a lot of time and energy to increase the quality of our work. Thank you very much and you are most welcome to stop by at our lovely lake when migrating to pleasant climates.

Some years ago, around this almost 150-year old lake, a new group of swans joined. Gradually, the nursing science swans appeared. They formed a strong group with a mission. Drs Coby de Boer, Anneke Boerlage MScN, Dr Monique van Dijk, Onno Helder MScN, Corry van den Hoed – Heerschop MScN, and Dr Erwin Ista; thanks a lot, mates, for your feedback and ongoing support.

Many parents of the swanlings have contributed to our work. Without doubt, all your trumpeting sounds were heard and incorporated into our studies. We all thank you for letting us know how you experienced the care in the eight university swan lakes.

Swans love swans and they mingle around to create tranquility and uproar on the lake. Many of them have supported me in quiet and busy times. Patricia was the senior swan providing me wise directions of life and Natascha pushed me to the edge to focus on one flying route only. Thanks for the wise instructions towards the final stages.

Although most swan species live in the northern hemisphere, we do have far away friends. In my journey I met many colleagues and friends. Particularly, the leading swans from WFPICCS, ESPNIC, and EfCCNa. You all have given me joy and pleasure and it is a privilege flying with you towards a common aim: to provide excellent care to critically ill swanlings and their parents.

The party swans of the “Beestenclub” from the Utrecht lake are meanwhile fully grown and spread out over the country. Yes, we are flying alone but we are still together.

To my close friends; together we are the elements of our ongoing swan lake ballet performance. Thanks a lot for being around.

Family swans are important, and so are Marjo, Jean-Pierre, and Pauline. You and your families witnessed many turning points of my journey. I am sure we keep sharing our stories helping younger generations to adapt the changing world.
Mum, Dad… how proud would you have been sitting on the first row and listening to my PhD defend. You always have given me unrestricted support in my life and let me explore all the lakes of the world. I say it again: “thanks for being my parents”.

To my close friends Hans and Emmy: The wind blew you to higher directions where humans can not fly. Remembrance is what I do.

This is a story of a white male swan swimming both in calm and wild waters. Indeed, you rarely see a black and a white male swan comfortably swimming together in a lake. Cedric, you made this happen. Let’s continue flying together, a journey full of inspirations, so we carry on… Happily ever after.