Parental Involvement in Pediatric Hospital Care

- Implications for Clinical Practice and Quality of Care

BY

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Abstract

The overall aim of this thesis was to gain a deeper understanding about parents’ perceptions of quality of care and their own involvement in pediatric hospital care.

Parental involvement in the care of hospitalized children has gained increased attention in recent years. The aim of this thesis was to study parental involvement in pediatric hospital care and investigate its association to the work conditions of pediatric hospital staff.

The first study validated a parent questionnaire that measured parents’ views of the quality of care. The questionnaire measures quality of care by means of eight indices and an overall quality grade. Results showed that the questionnaire demonstrated satisfactory validity and reliability.

Study 2 examined whether there were differences in quality ratings between respondents and non-respondents to the parent questionnaire. The main parent questionnaire was distributed in hospital and a follow-up questionnaire was sent home to a random sample of parents three week after the hospital visit. This study pinpointed a number of difficulties that need to be considered when conducting investigations of non-response.

The third study aimed at gaining a deeper understanding of factors that influence parents’ views of their own involvement in pediatric care. Semi-structured interviews were conducted with parents of chronically ill children. Four themes emerged from the interviews: support, professionalism, work environment and responsibility. Underlying these four themes is a need for a clear communication between staff and parents.

The fourth study examined hospital staff’s perceptions of parental involvement and possible consequences for staff work environment. A questionnaire was sent out to hospital staff at oncology, neurology and surgery units at three university children’s hospitals. Hospital staff on oncology units gave higher ratings to their workplace routines for involving parents in the child’s care, and experienced less work strain from parental demands, compared to staff on the other units.

The results of this thesis indicate a clear association between parental involvement in pediatric care and the work conditions of pediatric hospital staff.

Keywords: pediatric care, parent questionnaire, parental involvement, quality of care, non-response

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Table of contents

INTRODUCTION .................................................................................................................................................. 3
BACKGROUND .................................................................................................................................................. 3
AIMS OF THE THESIS ..................................................................................................................................... 4
PEDIATRIC HOSPITAL CARE: HISTORICAL PERSPECTIVES ........................................................................ 4
PARENTS IN THE HOSPITAL ......................................................................................................................... 6
PARTICIPATION AND INVOLVEMENT IN PEDIATRIC CARE .......................................................................... 6
EMPOWERMENT ............................................................................................................................................. 7
FAMILY-CENTERED CARE ............................................................................................................................. 8
HOSPITAL STAFF’S PERCEPTIONS OF PARENTAL INVOLVEMENT ............................................................. 8
QUALITY OF CARE .......................................................................................................................................... 10
WHY MEASURE QUALITY OF CARE? ........................................................................................................... 10
THE CONCEPT OF SATISFACTION WITH HEALTH CARE ............................................................................. 10
MEASURING SATISFACTION ....................................................................................................................... 11
QUALITY OF CARE INSTRUMENTS FROM THE PARENTS’ PERSPECTIVE .................................................... 12
THEORETICAL FRAMEWORK ...................................................................................................................... 13
PRESENTATION OF THE STUDIES ............................................................................................................... 15
MATERIAL AND METHODS ....................................................................................................................... 16
SETTINGS .................................................................................................................................................... 16
SAMPLING AND DATA COLLECTION ......................................................................................................... 16
DATA ANALYSIS .......................................................................................................................................... 18
ETHICAL CONSIDERATIONS ....................................................................................................................... 20
RESULTS ...................................................................................................................................................... 21
STUDY 1 ....................................................................................................................................................... 21
STUDY 2 ....................................................................................................................................................... 21
STUDY 3 ....................................................................................................................................................... 21
STUDY 4 ....................................................................................................................................................... 22
DISCUSSION .................................................................................................................................................. 23
PRIMARY FINDINGS ....................................................................................................................................... 23
METHODOLOGICAL ISSUES IN QUESTIONNAIRE STUDIES .................................................................... 25
METHODOLOGICAL ISSUES IN QUALITATIVE STUDIES ........................................................................... 27
CONCLUSIONS AND FURTHER STUDIES ................................................................................................. 29
SAMMANFATTNING (IN SWEDISH) ........................................................................................................... 31
ACKNOWLEDGEMENTS ............................................................................................................................. 33
REFERENCES ................................................................................................................................................. 35
INTRODUCTION

Background

Approximately 100,000 children (0-19 years) are hospitalized every year in Sweden. These children correspond to about 150,000 care episodes where the youngest children are in majority (41%; fig. 1). These children who are too young to express their own views, need to have parents or other close relatives to interpret their needs. The expectations of the parents of hospitalized children have changed enormously over the past thirty years. While parents previously were expected to remain separated from the children, they are now expected to stay with them in the hospital and be involved in the child’s care.

Fig. 1. Diagram showing the number of care episodes (in percent) in four different age groups in Sweden. Figures are based on the total amount of care episodes in Sweden during the years 1999-2002 (n=584,363). Note that the majority of care episodes in children during these years occurs in children between 0 and 4 years of age. Ref: The Centre for Epidemiology, The National Board of Health and Welfare, Stockholm 2003.

The hospital is an unknown and unfamiliar place for both the child and the parents. The parents’ anxiety, due to the fact that the child is ill and the family is away from their home where privacy and control can be exercised, puts them in a vulnerable situation. Hospital staff, on the other hand, are in their occupational role and usually wearing uniforms, which puts them in a more dominant position (Callery and Smith 1991).
Hospital management, responsible for quality improvement, has begun to recognize that patients’ and parents’ perceptions of quality of care should be a part of the process of delivering a high quality of care.

To be a “magnet hospital” and attract patients and hospital staff, the views of patients, parents, and relatives is one key factor for success (Scott et al., 1999, Aiken et al., 2000). Without satisfied patients, parents, and relatives, health care has not achieved its goal (Vouri 1991).

The research studies presented in this thesis were prompted by the relatively limited knowledge available about parents’ perceptions of and experience with pediatric care. The lack of valid, reliable instruments for measuring parents’ views of the quality of pediatric care was reason enough to start the present research process.

**Aims of the thesis**
The overall aim of the studies upon which this thesis is based was to gain a deeper understanding about parents’ perceptions of quality of care and their own involvement in pediatric hospital care:

-- To focus on the application and validation of an instrument for measuring parents’ satisfaction with pediatric hospital care (Study 1).
-- To examine whether there were differences in quality ratings between respondents and non-respondents to the parent questionnaire, the instrument that was used in the first study (Study 2).
-- To gain a deeper understanding of factors that influence parents’ views of their own involvement in pediatric care, in order to be able to develop clinical routines and staff guidelines for parental involvement. (Study 3).
-- To examine hospital staff perceptions of parental involvement and possible consequences for staff work environment. (Study 4)

**Pediatric hospital care: Historical perspectives**
Hospitals for children were first opened in the mid-nineteenth century. One of the first was The Hospital for Sick Children at Great Ormond Street in London, which opened in 1852. The Crown Princess Lovisa Nursing Institution for Sick Children, opened in 1854, was the first children's hospital in Sweden. Hospital care was mostly for children from families with difficult social backgrounds, where families were unable to treat their child at home. The most common diseases were chronic diarrhea, pertussis, and rickets. Mortality was 16% and the average length of stay was 66 days (Zetterström 2000). The atmosphere was quite home-like, and mothers were permitted to stay with their child and even encouraged to spend time there (Zetterström 1985).

Toward the end of the 19th century, however, attitudes towards parents underwent a drastic change. Infectious diseases were a threat to children and infant mortality was high. The routines in hospitals began to focus on hygiene, which affected contact between children and their families, and mothers were no longer allowed to spend time there. Children were only allowed to have a few hours of visits a day. Hygiene routines did not allow children to play...
with other children in the hospital. Even toys had to be cleaned in between children, and this resulted in toys being rarely used.

It was not until the 1950s that any changes really occurred. Reports published around this time showed evidence that separation from parents could be harmful to a child, with symptoms of protest at first, then despair and denial (Bakwin 1949, Blom 1958). Separation from the family was reported to harm the child’s character and mental development. Some children even developed depression.

As a result, the Ministry of Health in London published the Platt Report (1959), which stated that children should be admitted to special children’s hospitals, that parents should be allowed to stay with their child at the ward, and that nurses should undergo special training in pediatric care. One of the report’s major recommendations was that parents should be allowed to visit at any reasonable time of day or night. The Committee not only recommended daily visiting of children, but strongly urged that hospitals should introduce open visiting hours and encourage the admission of mothers with their children.

The recommendations of the Platt Report were widely published but the implementation was slow. Three main reasons for the slow implementation and continued limitation of visiting were identified. One was fear of introducing infections, another reason was relatively poor understanding of children’s development, and a third reason was the expected increase in nurses’ workloads. (Connell and Bradley 2000).

Another explanation for the slow implementation may have been the fact that the Committee had only considered psychological theory, i.e. mother-child separation, and not the wider sociological impact the report had on hospital organization (Darbyshire 1994). Even as late as 1970, when a new children’s hospital in Stockholm, S:t Görans Children’s Hospital, was built, there were no facilities for parents, and no space for them to stay with their child on the ward.

In 1975 the Swedish Board of Health and Welfare established guidelines for hospitalized children in Sweden and emphasized the importance of increased parental participation in care (SOU 1975: 87).

During the next decade an awareness of children’s reactions to illness and hospitalization resulted in several studies (Visintainer and Wolfer 1975, Perrin and Gerrity 1981, Brewster 1982). Hospitalization was reported to pose a series of threats to the child, including fear of being hurt physically, being separated from the parents, and also the unknown environment with unfamiliar persons. Brewster (1982) concluded that information and effective communication is an essential element in treating children. Children may also be more upset if their parents are anxious (Davies 1984). Edwinson et al. (1988) demonstrated that parents who were well-informed and well-prepared were less anxious, a fact that was found to decrease the child’s level of stress.

In 1989 the United Nations formulated the Convention on the Rights of the Child, and according to Article 12, “children are entitled to participate in all decisions that affect them” with their views “given due weight” according to their age and maturity (UN 1989).
Two years later, in 1991, in London, The Department of Health’s “Welfare of Children and Young People in Hospital” stressed that:

…it is now generally accepted that the care and comfort of parents for a child is fundamental to the care and treatment of children in hospital. The care provided by a hospital has to centre firmly on the recognition of the child as a member of a family—a family whose support during the hospital stay is essential to the child’s wellbeing (Ministry of Health 1991).

The Swedish Board of Health and Welfare guidelines for hospitalized children from 1975 remain the current regulations in Sweden.

Parents in the hospital

Participation and involvement in pediatric care

One of the first studies to recognize parents’ views of their child’s hospitalization was performed in 1957 by Gofman et al. They interviewed 100 parents, both at the time of the child’s admission to the hospital and at discharge. At this time parents were not allowed to stay with the child in the hospital. These parents expressed the greatest anxiety at separation from the child. In an effort to determine how to reduce this anxiety, parents expressed a desire to know why their child was hospitalized, what the visiting hours were, and whether the child could bring any of his own possessions. They also wanted an admission procedure that allowed a more gradual separation of parent and child.

Today the views of close relatives take on increased importance, especially for patients with difficulties expressing their own views, like small children and elderly individuals (Conner and Nelson 1999, Mitchell-Dicenso et al. 1996). In pediatric hospital care the role of parents has been more closely examined by researchers, although different expressions are used, such as participation, involvement, or family-centered care.

The Webster’s Ninth New College Dictionary (1990) defines “participate” thus: “to take part or share in something” and “involve”, “to engage as a participant or to commit emotionally”. Participation can be used when describing the performance of routine physical care, and also for the practical functions of parents in care. In one study participation is described as “a deeper sense of being an integral and essential part of their child’s hospital experience” (Darbyshire 1994). In another study, participation is described as one’s right to be listened to and have one’s views taken seriously and treated with respect, and does not mean having the right to make the decision or determine the outcome (Cashmore 2001).

Several researchers have studied parental participation. Researchers agree that parents’ presence in the hospital is beneficial for the family; the child feels more secure and emotional stress is reduced. For the parents, however, this is a dual experience. They want to support the child and at the same time their role for participation is quite unclear (Palmer 1993, Kristensson-Hallström and Elander 1994, Coyne 1995, Callery 1997, Connell and Bradley 2000). Parents choose to participate in care to optimize the child’s emotional welfare, but they experience lack of information, non-negotiation of roles, feelings of anxiety, and loneliness, according to Coyne (1995).
Other studies have shown that health care professionals were sometimes unwilling to share their power, rejecting the mothers’ input and suggestions. Conversely, when hospital staff recognize the mothers’ competence, hospital staff were reported to place too much responsibility on the mothers (Darbyshire 1993). In a study by Neill (1996) parents wanted to participate in decisions about their degree of involvement in the child’s care. Problems of communication between parents and hospital staff were identified in this study as well.

In a study by Hallström et al. (2002) the purpose was to examine the extent to which parents participate in decisions during the hospitalization. Thirty-four parents of 24 children were observed. The results showed that parents have varying abilities to be involved in decision-making, and that hospital staff need to communicate more openly with them, since some parents are unable or unwilling to express their needs.

Marino and Marino (2000) demonstrated that the more problems parents experienced with communication or with partnership, the less satisfied they were with care. A recently published study by Nobile and Drotar (2003) reviewed thirty-one articles that focused on parent-provider communication in the context of pediatric care. An effective parent-provider communication is associated with parent satisfaction with care and adherence to treatment recommendations. According to the authors, previous research has been limited by the lack of theory. This limited the generalizability of the research findings and the ability to evaluate in interventions aimed at enhancing parent-provider communication on pediatric outcomes (Nobile and Drotar 2003).

Parents’ needs during their child’s hospitalization was investigated by Hallström and Runesson (2001), by using non-participant observation of and interviews with 26 parents. In the analysis of observations nine themes were identified: needs for security, mediating security to their child, communication, control, parental competence, fitting in, family, relief, and satisfying practical needs. In the interviews four groups of needs were identified: the needs for competent caregivers, communication, confirmation, and participation. The authors concluded in their study that routines should be established and evaluated in an ongoing process to ensure that both children and parents are cared for in an individualized way, based on evidence-based care.

Parents and staff’s perceptions of the needs of parents of hospitalized children is examined in a study by Shields et al. (2003). The “needs of parents of hospitalized children” questionnaire (NPQ) was used, it contained 51 statements comprising a panorama of needs that parents may experience during their hospital stay. A total of 132 (48%) parents and 115 (60%) staff answered the questionnaire. In 30 statements staff and parents gave similar responses about the importance of those needs. In all other needs statements, staff were more likely to think that parents would require help in having those needs met, while parents were more likely to think they could meet these needs without assistance. The authors concluded that this could be due to the fact that parents are more independent than staff believe, or that parents are not aware of the assistance they can receive from staff.

**Empowerment**

Empowerment in patients is defined by Baksi and Cradock (1998) as follows: “patients are empowered when they have the knowledge, skills, attitudes and self-awareness necessary to influence their own behaviour and that of others in order to improve the quality of their lives.”
In a study by Gibson (1995) the word empowerment is used to describe situations in which mothers of chronically ill children were full participants in their children’s care. In this study, empowerment is described as a process in which the first step was to accept the reality that the child was chronically ill. Frustration was a powerful force that permeated the process. Frustration evoked ongoing cycles of critical reflection, the second step in this process, which led the mothers to take charge and finally to hold on to their sense of power. Keys to a successful partnership were mutual respect and a common goal between the mother and the health care professional. What these mothers needed most was to be listened to by health professionals.

**Family-centered care**

Family-centered care within the nursing profession is not a new trend, having roots that date back to the early 1950s. The visions for family-centered care encompass increasing support for the emotional and developmental needs of the child (Darbyshire 1993). Family-centered care is a concept that is often based on intuition and untested assumptions with few clinical guidelines, according to Rushton (1990).

In a study by Connell and Bradley (2000) family-centered care is described as power sharing, information giving, facilitation, and empowerment. The authors conclude that practitioners need to strive to deliver true family-centered care and to avoid becoming complacent. Another study dated the same year concluded that the family-centered care approach still carries with it a myriad of challenges related to parental participation, including issues of role stress, negotiation failure, and power struggles (Newton 2000).

In a review article from 2002 (Irlam and Bruce 2002), family-centered care was defined as care that is patient-led with the nurse acting as a consultant or counselor, fostering open, honest dialogue with the family. The authors also conclude that a definition of family-centered care is difficult to formulate, mainly due to lack of consensus about its meaning. Alshop-Shields (2002) suggested a parent-staff interaction model, where communication is a linking factor between family and hospital staff. This model provides an educational framework for raising consciousness about roles and interactions of parents in the hospital. Various models involving parents and family in the hospitalized child’s care have evolved within nursing, but research indicates that it is not yet widely practiced (Alshop-Shields 2002).

**Hospital staff’s perceptions of parental involvement**

Few studies have examined hospital staff’s perceptions of parental involvement in pediatric hospital care. Brown and Ritchie (1990) examined nurses’ interaction with parents. The study was performed in a children’s hospital in Canada. Twenty-five nurses were interviewed and asked to describe their perceptions of parents’ and nurses’ roles in caring for hospitalized children. The nurses described six major roles that parents and/or nurses play in caring for hospitalized children. These include assisting with activities of daily living, providing technical or medical care, acting as gatekeeper by exerting control over parents and children, being an advocate by defending the rights of the child, providing psychosocial care, and providing general care related to the child’s care. The nurses indicated that they fulfilled all
six roles and that parents fulfilled all of the roles except gatekeeping. However, none of the
nurses in that study explained or reviewed the rooming-in guidelines with the parents; they
assumed that parents already knew about this routine. Fifty percent of the nurses indicated
that they relied upon the parents to make general observations of their children’s condition
and to report any changes to them, but is quite unclear how they inform parents about their

In a study by Callery and Smith (1991), the role negotiation between nurses and parents was
examined, and 64 nurses took part in the study. The authors used the critical incident
technique where nurses described different situations and how they handled them. The results
indicated that the nurses had expectations concerning how parents should behave, but did not
voice this expectations to parents. However, the current knowledge about nurses’ attitudes
towards parental involvement is still limited (Callery and Smith 1991).

Even less has been documented regarding attitudes of other hospital staff towards parental
involvement. Gill (1993), explored the relation of personal and professional characteristics to
the attitudes of health professionals toward parent participation. Gill used a questionnaire
where the identified constructs were: parental visiting, homelike atmosphere, parental
adjustment, parental support- child negative condition, parental comforting, emotional support
child, accompaniment and emotional support parent. The study was performed in the United
States, were members of an association that worked for supporting care of children, Care of
Children’s Health (ACCH), were randomly selected from their mailing list. The response rate
was 80 % (n= 810). Results of the study showed that the more accepting the head nurse was
of parents’ participation, the more accepting the staff was as well. In addition, registered
nurses were more accepting than hospital staff with less education. There were no differences
in attitudes between health professionals. However, among all health professionals the
attitudes were slightly more accepting as the number of years of experience increased.

In Australia, Johnson and Lindschau (1996) investigated hospital staff’s attitudes towards
parent participation. Two questionnaires were used; one was for measuring hospital staff’s
attitudes towards parents’ participation. The second instrument was to obtain demographic
data regarding professional and personal characteristics of the participants, such as age, years
of employment working with children, educational level, marital status, and parental status.
The questionnaire items in the first questionnaire concerned parents’ practical task-oriented
participation, such as permitting parents to feed their baby or accompany their child to the
treatment room. A random sample of 155 hospital staff who cared for children on four
pediatric wards were invited to participate in the study. Forty percent (n=62) completed the
questionnaire. Results of this study showed that nurses had a more accepting attitude towards
parent participation than did any other professional group. No differences were determined by
age of participant or how many years of working experience they had. These results contrast
with the results found by Gill (1993), which could reflect differences in education programs
for nurses or the culture in the hospital setting, i.e. how different professionals work together.
Quality of Care

Why measure quality of care?
Quality is a concept not easily defined. Webster’s Ninth New Collegiate Dictionary (1990) describes quality as “degree or grade of excellence”.

During the last few decades there has been a growing interest in defining and measuring quality of care. Avedis Donabedian, one of the forerunners of research in this area, described a three-part approach to assessing quality of care, based on an analysis of structure, process and outcomes (Donabedian 1988). Structure refers to the settings in which care is offered, including manpower, material resources, and organizational structure. The process describes what is involved in the patient’s seeking care and what occurs during the care exchange. Outcomes refer to the effects of the care on the receivers. Donabedian (1988, p. 1747) also describes two elements in the performance of practitioners, the technical and the interpersonal; “The interpersonal process is the vehicle by which technical care is implemented and on which its success depends”.

The patient’s judgement of the quality of care in all its aspects, but particularly concerning the interpersonal process, is defined by Donabedian (1980) as one outcome of care. According to (Kitson 1989), quality of care in the nursing profession begins and ends with the patient’s experience with health care services.

The concept of satisfaction with health care
When measuring patients’ judgements of care, the concept of patient satisfaction is often used. Korsch et al. (1968) launched the hypothesis that a relationship existed between the nature of the verbal communication between the doctor and the patient and the outcome in terms of patient satisfaction. Larsen and Rootman had a hypothesis that satisfaction with medical care is influenced by the degree to which a doctor’s role performance corresponds to the patient’s expectations. A questionnaire was sent out to a random sample of 1000 households, 91% (n = 907) answered the questionnaire. The findings strongly support their hypothesis that patients who are more involved in their care feel more satisfied with care and are more likely to comply with treatment, and as a consequence have better outcomes (Larsen and Rootman 1976).

Donabedian (p. 25, 1980) stated that:
“Client satisfaction is of fundamental importance as a measure of quality of care since it gives us information about the provider’s success at meeting those client’s values and expectations on which the client is the ultimate authority. The measurement of satisfaction is, therefore, an important tool for research, administration and planning.”

In a study by Carr-Hill, human satisfaction is defined as a complex concept that is related to a number of factors including lifestyle, past experiences, future expectations, and the values of both individual and society (Carr-Hill 1992).

Today patient satisfaction is considered an important indicator of care quality. Patients can play an important role in defining what constitutes quality by determining what values should be associated with different outcomes. Vuori (1991) states that patient satisfaction is more than an indicator or a measure of the quality of care. If health is a desired outcome of care,
patient satisfaction is an essential part of the quality of care. It does not matter whether satisfaction reflects the competence of the physician or the nursing care. If patients are dissatisfied, health care has not achieved its goal (Vouri 1991).

In a recently published study, Cleary (2003) examined a case of a patient admitted for surgery. The surgery was successful, but the hospital stay was marked by inefficiency and inconveniences. These problems could seriously compromise the quality of clinical care. Relatively easy and inexpensive ways to avoid many of these problems are discussed in this study, such as reducing variability in non-urgent procedures and routinely asking patients about their experiences and suggestions for improvement.

**Measuring satisfaction**

In order to evaluate quality improvement efforts, it is necessary to measure quality of care. A review of the literature revealed a wealth of studies that aimed to measure the quality of care from the patient perspective. Measurements of patient satisfaction have been criticized from different aspects; one of these is that patients should be allowed to define their own criteria for quality of care. This presupposes a willingness from providers to see to the patient’s interest, although this willingness may not, in fact, exist. Providers of health care contend that their expertise gives them greater competence, compared to the non-expert consumer, in making decisions involving health care quality (Locker and Dunt 1978). One practical reason for measuring patients’ views is that medical diagnoses and treatment depend, to a great extent, on communication and active patient involvement in the treatment process (Cleary and McNeil 1988).

Rubin (1990) published a thorough review of 59 studies that attempted to define and measure patient satisfaction. The increased interest in measuring patient satisfaction has also resulted in varying quality in the studies. Aharony and Strasser (1993) pointed out some of the specific problems with these studies, such as a lack of clarity and consistency in understanding the determinants of patient satisfaction, as well as a lack of a conceptual or theoretical model of the patient satisfaction process.

Some years later, Sitzia and Wood (1997) published a review study with over 100 papers on patient satisfaction. The review highlighted the complexity and breadth of the literature in this field. A major weakness identified in all proposed schemes was that they are based upon criteria from management and professionals rather than from the consumers. One trend is to ask patients to report on the interpersonal aspects of care, rather than to respond about their level of satisfaction, though the varying expectations of patients often confound the use of patient satisfaction measures for evaluating quality of care, according to Darby (2002).
Quality of care instruments from the parents' perspective.

A thorough review of the literature revealed a lack of studies that examined parents’ views of quality of pediatric care. Existing studies have been narrow in focus, investigating only parent satisfaction with certain parameters, like inpatient care (Homer et al. 1999, Lanford et al. 2001), primary care (Seid et al. 2001, Seid et al. 2003), medical encounters (Lewis et al. 1986, Wells et al. 1998), pain management (Watt-Wattson et al. 1990, Reid et al. 1997) or certain diagnoses, such as cancer (Sobo et al. 2002) and bleeding disorders (Cygan et al. 2002).

Homer et al. (1999) reported on a study where parent satisfaction with inpatient care was examined with the Picker instrument. In a survey from 1991 to 1995, parents of children were contacted by telephone two weeks after the children’s discharge from hospital during specific months. The study is based on 3622 (77%) of 4724 participants answering 122 questions. Six broad dimensions of care were reported. These included information to parents, information to the patient, partnership in care, pain management, surgical issues and preparation for discharge from the hospital. Conclusions from this study mainly concerned communication between clinician and parent. Parental assessment of inpatient pediatric care rested heavily on the quality of communication between the clinician and the parent (Homer et al. 1999).

Lanford et al. (2001) used the Picker instrument in a survey of 22 hospitals’ inpatient care. The Picker Score is a problem score, where lower scores indicate better ratings. Dimensions with high scores, i.e. areas that could be improved, were given to “partnership” and “information to child”.

Findings similar to those of Homer et al. (1999), where communication is an important aspect, were the results of a study by Lewis et al. (1986), who examined parent satisfaction with pediatric medical care. Three factors in parent satisfaction were identified; these included relief of distress, physician’s communication with the child, and the physician’s communication with the parent.

A questionnaire for assessing parent satisfaction with inpatient end outpatient care was developed by Mountzoglou et al (2001) and applied in a pediatric hospital in Athens, Greece. The questionnaire consisted of 22 questions. A total of 240 parents (62%) answered the questionnaire and main results from the study demonstrated a low satisfaction with care. The general mean of satisfaction observed, 45 on a scale of 100, is not close to the mean, 76, derived from a systematic review of 221 satisfaction studies, according to the authors. Type of appointment was the only predictor of parent satisfaction.

In studies concerning specific diagnoses, like the one by Cygan et al. (2002), 54 parents of children with bleeding disorders completed a questionnaire that examined the importance of 33 indicators of quality of care. The most important indicators for quality of care for parents were being included in decisions about their child’s care and having competent and caring providers with whom they could communicate. Waiting time was the least important indicator for quality of care in this study. In another study by Sobo et al. (2002) interviews were conducted with 20 parents in a pediatric cancer unit. Parents in this study called for communication improvements, standardization of all nursing procedures and techniques, and a guide providing clear understanding of what to expect from whom.

Other studies have focused on health care quality and nursing care; one of these was Oerman et al. (2000), who reported that parents expect nurses to be up-to-date, well-informed and easy
to communicate with. In another study, one that focused on different aspects of nursing practices that were predictive of parent satisfaction, the authors reported that overall satisfaction was strongly associated with collaboration between nurses and parents (Marino and Marino 2000).

Schaffer et al (2000) used a questionnaire with open-ended questions for evaluate nursing care. A total of 1405 (14%) self-reported parent surveys were collected. Using content analysis a group of nurses reviewed the parents’ comments to determine major themes. The themes were caring, communication, safety, environment and appreciation. Caring was defined as being treated with respect and to be involved in their child’s care. Communication concerned information about the child’s treatment, but also that they want to know what was expected from them. Safety is defined as absence of fear, one example is that parents felt afraid of leaving their child. Environment is physical comfort for both the child and themselves. Appreciation is described as parents level of overall satisfaction with nursing care.

A literature review by Conner and Nelson (1999) investigated 55 studies relevant to parent satisfaction with pediatric and neonatal health care services. Nine categories of health care services in pediatric care were identified to be important enough to impact satisfaction reports. These included access to provider, long-term care of chronically ill children, communication, competency of medical and nursing care, continuity of care, environment, pain management, and participation in care. Five parent satisfaction questionnaires were critically reviewed and the authors concluded that few questionnaires were available, and none was comprehensive in its measurement of parent satisfaction. These instruments had not been tested and validated fully, and more importantly, they measured parent satisfaction in isolation from the care- delivery process (Conner and Nelson 1999).

Theoretical framework

It seems logical that there would be a relationship between hospital staff work environment and the quality of care they provide to patients. This thesis is based on the theory that work environment is one part of structure and process that is essential for delivering high quality of care from the parents’ perspective. There are certainly other factors that are important for quality of care, like management and competence, but these factors have not been in focus in these studies.

Studies of the nature of the causal relationship between employee attitudes about their jobs and the potential impact of these attitudes on patient satisfaction attitudes are needed, according to Aharony and Strasser (1993). Job satisfaction is one aspect of organizational effectiveness and can also be linked to client outcomes. Staff who are more satisfied with their working conditions may interact more effectively with patients (Weisman and Nathanson 1985). Similar results were seen by Shortell et al. (1995), who found that quality improvement work and overall organizational well-being impacted favorably on both staff and client satisfaction.
A questionnaire that measures hospital patients’ views of quality of care was developed in Sweden. This instrument, Pyramid, includes measures of the patient’s view of staff work environment (Arnetz and Arnetz 1996). The theory behind this method is that staff work environment has an impact on health care performance, thereby affecting how patients judge the quality of care.

Parental involvement is part of the process for achieving high quality of care, but results in the literature indicate that the concept is defined in a myriad of ways. Lack of clear communication between parents and staff is the underlying theme in many studies (Darbyshire 1993, Palmer 1993, Coyne 1995, Callery 1997, Connell and Bradley 2000). Parents’ role ambiguity and experience, unexpressed expectations of parents, and sometimes non-negotiation of roles contribute to the lack of clear communication between parents and staff.

This is the first attempt at developing a theory about quality of care from the parents’ perspective and the factors that influence the outcome. For this purpose Donabedian’s model with its three components of structure, process, and outcome could be used. In this model the care-delivery process of the child and parents is described, with quality of care as an outcome. Here parental involvement is part of the process, but it is also connected with all necessary organizational attributes like a structure for information about routines and examinations and treatment, as well as staff guidelines for parental involvement. Parental involvement is not isolated from the rest of the caring process, where medical treatment, care processes, staff attitudes, and communication all aim at the child’s well-being.

(See Figure 2.)
PRESENTATION OF THE STUDIES

Parental involvement in pediatric hospital care
- implications for clinical practice and quality of care

I. Quality of pediatric care: application and validation of an instrument for measuring parent satisfaction with hospital care.
   -- 912 questionnaires (63 questions)
   -- distributed to parents in hospital
   -- 68% response rate (n=624)

II. A study of non-response in a questionnaire survey of parents' views of pediatric care.
   -- 1094 questionnaires (58 questions)
   -- distributed to parents in hospital
   -- 63% response rate (n=693)
   -- three weeks later
   -- 140 follow-up questionnaires (16 questions)
   -- sent home to parents
   -- 50% response rate (n=70)

III. A study of parental involvement in pediatric hospital care: implications for clinical practice.
   -- 14 parents interviewed (semi-structured)

IV. Hospital staff's perceptions of parental involvement in pediatric hospital care.
   -- 338 questionnaires (26 questions)
   -- distributed to hospital staff at work
   -- 61% response rate (n=207)
MATERIAL AND METHODS

Settings

The setting for the first three studies was a university children’s hospital, the Astrid Lindgren Children’s Hospital, a division of Karolinska Hospital in Stockholm, Sweden. The hospital is a center for pediatric care in Stockholm. Each department consists of different units for both in-patient and out-patient care. The hospital has 180 beds, more than 100,000 outpatient visits, 10,000 admissions and 5000 operations annually. Approximately 1500 staff are employed by the hospital.

Three units at the university children’s hospitals in Gothenburg, Stockholm and Uppsala participated in Study 4. The three inpatient units were oncology, neurology/neuropediatrics, and pediatric surgery.

Sampling and data collection

In Study 1, the first aim was to apply and validate an adapted version of an existing patient questionnaire in a study of parental satisfaction with pediatric care in a university hospital. The second aim of this study was to evaluate how parents rated the quality of care at this university hospital.

The parent questionnaire that was used in the study had been piloted one year earlier in two pediatric departments in two other cities. The parent questionnaire is a version of the patient questionnaire developed by Arnetz and Arnetz (1996), the Quality of Care Patient Questionnaire, also called the Pyramid Questionnaire, which measures quality of care from the patient perspective.

The parent questionnaire consists of 63 questions categorized into eight domains. These include Information about illness, Information about routines, Accessibility, Medical treatment, Care processes, Staff attitudes, Participation, and Staff work environment. Parents were also asked to give their overall rating of the quality of care on a modified Visual Analogue Scale (VAS) from 1(very negative) to 10 (very positive). Together all these categories aim to achieve a total picture of the quality of care.

A total of 912 questionnaires were distributed in 17 inpatient and outpatient units at the children’s university hospital during a two-week period. Three units were excluded — emergency, radiology, and the operation theatre. These exclusions were made in order to diminish the risk that parents would receive more than one questionnaire during their visit to the hospital. The number of questionnaires was in proportion to the number of patient visits to the units during a two-week period. The total number of questionnaires corresponded to approximately 50% of all visits and in-patient stays at the hospital during a two-week period. The questionnaires were distributed to parents by hospital staff upon arrival to the unit. Boxes for depositing the completed questionnaires in sealed post-paid envelopes were available in each unit.

Questionnaire responses were anonymous. Parents were also given the option of completing the questionnaire at home and sending it directly to the research institute by prepaid mail. All
units had one or two contact persons who were responsible for the distribution and collection of the questionnaires. These contact persons, usually registered nurses, were chosen by management because of their interest in quality issues, and they were given both written and oral information about the questionnaire in advance.

In Study 2, the Pyramid parent questionnaire was used a second time in the same setting. This time the questionnaire consisted of 58 questions, since five questions concerning waiting times had been omitted. This was done in an effort to shorten the questionnaire. Also, parents’ ratings of specific waiting times had shown no association to ratings of the other measurement areas. A total of 1094 questionnaires were distributed. The response rate this time was 63% with 693 questionnaires returned.

Three weeks later a follow-up questionnaire was sent home to a random sample of parents (n=140) who had visited the hospital during the same two weeks during which the main questionnaire was distributed. These parents were identified by the hospital’s central database. The sampling strategy used was the same as in the main study, i.e. the number of questionnaires mailed out to parents on each unit was in proportion to the total number of patients receiving care during the two-week period for the main study. Each questionnaire was accompanied by a letter explaining the purpose of the follow-up questionnaire, along with a prepaid envelope for returning the completed questionnaire.

The follow-up questionnaire consisted of 16 questions. Of these, seven questions measured two of the domains that were part of the main questionnaires — Information about illness and Participation. A number of additional questions asked parents if they had received the main questionnaire in the hospital, whether or not they had answered it, and possible reasons for not answering it. Parents also had the opportunity to give an overall quality rating on a scale from one to ten.

In Study 3, the aim was to gain a deeper understanding of factors that influence parental involvement and to clarify the parental role in hospital care. Fourteen parents were interviewed about their experience with involvement in pediatric hospital care. These parents were recruited with help from the Parents’ Council at the hospital. The Parents’ Council is comprised of parents with long-term experiences with pediatric care. Parents in the Parents’ Council were asked to suggest possible study participants. This technique is called snowball sampling, where the logic is that those who have the targeted characteristics, in this case, parents of children with chronic illness, are likely to know others with the same profile (Bowling 2002). Their children had different kinds of chronic illnesses, requiring care from units including neurology, endocrinology, orthopedics, and oncology. Many children with chronic illness need contact with different specialists throughout childhood. As a result, parents in this study had experience from many specialties within pediatric care.

Semi-structured interviews were conducted with these parents of chronically ill children. The interviews were performed by one of the two researchers. Each interview lasted between 60-90 minutes and was tape-recorded. Memos and field notes were made during and directly after every interview. All interviews were typed verbatim.

For Study 4, a questionnaire that examined hospital staff’s perceptions of parental involvement was developed by the researchers. Subject areas and items were the results of focus group discussions. Three focus groups were performed, one group with experienced registered nurses (n=7), one group with recent nursing graduates (n=6) and one group with
The questionnaire consisted of 26 questions concerning perceptions of parents in pediatric hospital care. Background questions concern hospital staff's age, sex, years of working experience, length of employment at the current workplace, and approximate work time spent in direct contact with parents. The questionnaire was piloted in three units in another pediatric hospital, one that was not part of the main study.

A total of 338 questionnaires were distributed to physicians, nurses, and assistant nurses during a two week period. Three inpatient units took part in the study — oncology, neurology, and surgery — at three different children’s hospitals. Hospital staff on these units were asked to participate because one hypothesis of this study was that staff perceptions could differ according to the patient clientele being treated at the unit. The questionnaire was distributed in the hospital, together with a prepaid return envelope. Hospital staff members that were off work during this time, e.g. for vacation or parental leave, did not receive the questionnaire. This study was conducted in the fall of 2003. Questionnaire responses were anonymous and no reminders were sent out.

Data analysis

The parent questionnaire in Study 1 consists of eight indices. Each index, which is comprised of a number of questionnaire items, was tested by means of confirmatory factor analysis using oblique rotation. Internal reliability of each index was measured using Cronbach’s alpha. Index values were calculated for each individual respondent by totaling the score on the component index items. The resulting sum was then converted to a percentage of the maximal achievable index score. Each index had a maximum value of 100%, which is optimal, and a minimum value of 0%. All indices are presented as a percentage. The gap between actual scores and the top score of 100% was termed the improvement potential. Descriptive statistics were used to calculate mean values for all respondents for each respective index.

Independence of indices was evaluated by correlation analysis. Correlation analysis was also used to examine correlations of items within indices, in order to ensure that correlations of items to other indices were lower than correlations of items within indices.

One-way analysis of variance (ANOVA) was used to examine possible differences in index values in different groups of parents, for example differences between parents of inpatients and parents of outpatients, or if parents’ anxiety influenced their ratings. ANOVA with post hoc test using Tukey was used when comparing more than two groups.

Multiple regression analysis was used to test the predictive validity of the questionnaire. The overall quality grade was the dependent variable. Each of the eight indices was entered as an independent variable in the regression model, in a effort to determine possible predictors of a positive global quality grade from parents. The hospital department, the child’s age, and the severity of illness (as judged by the parents) were included as independent variables in order to control for the possible effects of these factors.

In Study 2 confirmatory factor analysis was again used to further examine the reliability of the questionnaire indices. Internal consistency of the indices was tested by Cronbach’s Alpha. ANOVA was used to compare mean index scores for respondents and non-respondents to the
main questionnaire, and to compare mean index scores for parents who responded both to the main questionnaire and to the follow-up questionnaire three weeks later. All ANOVA analyses were controlled for patient (child) age and sex.

The Levene statistic was used to test for homogeneity of variance in the groups being studied, due to discrepancy in sample sizes of the groups being compared. The Brown-Forsythe statistic was used as a measure of significance when equality of group variances could not be assumed. Statistical significance for all analyses was set at $p<0.5$.

Chi square and Fisher’s exact tests were used to compare respondents with non-respondents with regard to dichotomous background variables.

In Study 3, a qualitative approach was chosen, using the constant comparative method for analyzing the data (Polit and Hungler 1991). After each interview, the researcher carefully read the material several times to get a deeper understanding of what each individual parent had said. All interviews were transcribed by the same researcher and all interviews were analyzed independently by two researchers. The material was coded as concepts, and themes were identified and named. This process began with the first interview, and all data in the following interviews was compared with codes found in the first interview. Coding and categorizing involves constant comparison, a method used to find similarities and differences in incoming data (Strauss and Corbin 1990). The codes were sorted into subgroups of codes that seemed to belong together, and in the final process the subgroups emerged into themes.

In Study 4, exploratory factor analysis was performed in order to study whether correlation between questionnaire items would allow for the creation of one or more indices. An index is comprised of a number of questionnaire items that are statistically interrelated. Confirmatory factor analysis was then conducted, using principal components analysis for factor extraction. Cronbach’s Alpha was calculated as a measure of internal reliability for each index.

Chi-square analysis was used to study possible differences between respondents for discrete variables, such as age, profession and length of work experience. Chi-square analysis was also used to examine whether questionnaire respondents differed from non-respondents with regard to certain background factors. Analysis of Variance (ANOVA) with post hoc tests using Tukey was employed to compare mean index values between units and between hospitals.
**Ethical considerations**

The Pyramid Questionnaire includes few background questions, in order to ensure anonymity of the respondent. Anonymity is emphasized in an effort to encourage response and minimize the effects of social desirability on parent response. However, this makes it difficult to categorize different groups of parents to compare the characteristics of different questionnaire respondents, as well as to compare respondents with non-respondents. The questionnaires were distributed to parents by hospital staff, upon arrival at the unit. Boxes for completed questionnaires were available at every unit. The hospital staff were never able to see the completed questionnaires. Parents were also given the option of completing the questionnaire at home and sending it directly to the research institute by prepaid mail. This procedure also aimed at minimizing social desirability.

In Study 2, when examining non-respondents, the follow-up questionnaires were sent home to parents. While this is a possible source of confounding, the mail-out/mail-back method was considered the most practical and cost-efficient. To employ other methods, such as personal or telephone interviews, would introduce new sources of possible bias as well as intrusion on personal integrity.

In Study 3, the interviewer was not directly involved in providing care. The parents who took part in the interviews were informed both in written form and verbally that their participation was voluntary and that they could chose to stop whenever they wanted.

In Study 4, the respondents to the questionnaire were anonymous. The questionnaires were distributed in the hospital and came with a prepaid envelope.

Studies 2 and 3 were approved by the local Ethical Committee at The Karolinska Hospital. Study 4 was approved by the regional Ethical Committees of the participating hospitals.
RESULTS

Study 1

In Study 1, a total of 912 questionnaires were distributed to parents in the hospital. The response rate was 68%, with a total of 624 questionnaires returned. The response rate for the individual departments ranged from 43% to 89%. Forty-one per cent of the responding parents had children who were hospitalized as inpatients during the time of the survey, and 59% had been outpatients. This demonstrates that the questionnaire could be used in both in-patient and out-patient settings.

Results showed that the questionnaire demonstrated satisfactory validity and reliability. Reliability estimates were greater than 0.70 in all but one index and consistent over time. Inter-index correlations were generally lower than 0.60, indicating index independence. Parents in this study were most satisfied with Staff attitudes, Care processes, and Medical treatment. However, parents in this study gave significantly lower ratings for Accessibility and Staff work environment, compared with the other two children’s departments in the pilot study one year earlier.

Significant predictors for a positive overall quality grade from parents were Care processes and Medical treatment. In the pilot study performed one year earlier, Information about illness and Accessibility were significant predictors for a positive overall quality grade. A greater percentage of parents at Astrid Lindgren Children’s Hospital, 24%, considered their children to be severely ill, compared with 14% of parents at the regional hospitals one year earlier.

Study 2

In Study 2, a follow-up questionnaire was sent home to 140 randomly selected parents who had visited the hospital during the two weeks when the main questionnaire was distributed. The response rate for the follow-up questionnaire was 50% with 70 questionnaires returned. Of these, 30 parents (43%) had also answered the main questionnaire in the hospital, 32 parents (46 %) had not received the main questionnaire in the hospital, and 7 parents (10%) had seen the questionnaire in the hospital but had chosen not to answer it. The group of parents who did not receive the main questionnaire in the hospital did not show any significant differences in quality ratings compared to the group of parents who answered both in the hospital and also the follow-up questionnaire three weeks later. The small group of active non-respondents, n=7, rated Information about illness and the overall quality grade significantly lower than those parents who had responded to the main questionnaire.

Study 3

Fourteen parents were interviewed about their perceptions of and experience with involvement in pediatric hospital care. Four themes emerged from the interviews. These included Support, Professionalism, Work environment, and Responsibility. In the support theme, parents pointed out the need for support and being heard by hospital staff. Professionalism is described as when hospital staff expect that the parents will participate in the care of the child, but it is never discussed with them. Parents also described situations where the child had to undergo an unpleasant procedure and there was no discussion with the child and the parent of how the procedure was going to be performed. During the procedure hospital staff took for granted that parents should participate, but didn’t always tell them how or to what extent. Work environment concerns work routines, and hospital staff are in a hurry and sometimes understaffed. Parents of chronically ill children experience that the responsibility for the planning and co-ordination of the child’s treatment, including contacts
with the different caregivers and the school, falls on them as parents. They also feel that they have to be up-to-date in their knowledge of the latest research concerning their child’s illness and sometimes suggest new treatment methods to the child’s physician.

**Study 4**

A questionnaire that measures hospital staff’s perceptions of parental involvement in pediatric care was developed by the researchers. A total of 338 questionnaires were distributed to hospital staff, including physicians, registered nurses, and assistant nurses, working in oncology, surgery, and neurology units in three university hospitals. The response rate was 61%, with 207 questionnaires returned. Two indices could be developed out of the questionnaire items, Work routines and Work strain. Higher scores on both these indices indicate positive ratings, compared to staff who lacked good routines, i.e. good work routines and less work strain.

Main results from the study showed that hospital staff at oncology units rated the two indices of Work routines and Work strain significantly higher than did both surgical and neurological units. Oncology units seem to have better routines for involving parents in the child’s care and experience less strain from parental demands, as compared to the other units. Hospital staff that experienced that they had good routines for parental involvement also felt they had ample time to talk to parents.

There were no statistically significant differences for index ratings between professional groups with regard to years of experience, work time at the present workplace, or amount of time spent with parents in one’s daily work.
DISCUSSION

Primary findings
The results of Study 1 demonstrated an instrument with satisfactory validity and reliability for measuring quality of care from the parents’ perspective. Previous studies have demonstrated that the instrument can be used in benchmarking with other hospitals and units, and also to compare results over time within the same unit (Arnetz and Arnetz 1996). The response rate was 68%, which should be considered acceptable for an anonymous questionnaire study with no reminders. Parents of both inpatients and outpatients responded to the questionnaire, 41% and 59% respectively. These results demonstrated the applicability of the instrument in both inpatient and outpatient settings.

The two indices Care process and Medical treatment were predictors for a positive overall rating; one explanation of this might be that 24% of the responding parents considered their children to be severely ill compared with 14% of parents at the regional hospitals. In the study one year earlier at the two regional hospitals, Information about illness and Accessibility were significant predictors for a positive overall rating. This indicates that predictors for a positive overall rating may vary with the hospital’s patient clientele, or with the expectations the family has for treatment.

However, the response rate of 68% raised questions concerning possible non-response bias. Some earlier studies have shown that non-response to a survey can affect the results when non-responders differ systematically from responders and found evidence that non-responders are likely to be less satisfied with medical care, while results from other studies found no non-response bias (Barkley and Furse 1996).

In Study 2 a follow-up questionnaire was used to investigate whether there actually were differences in quality ratings between responders and non-responders. The small group of active non-responders (n= 7) rated the Information about illness index and the overall grade significantly lower. These results can not be generalized because of the small number of individuals, at the same time, the results can not be overlooked, as the fact remain that we still know very little about non-respondents to parent questionnaires.

The second aim of the study was to examine if quality ratings differ when parents are asked, both in the hospital and then three weeks after the visit, to rate certain aspects of hospital care. There were no significant differences in quality ratings, which could support the opinion that time, short enough, is not that important when evaluating quality of care. The follow-up questionnaire was sent out three weeks after the visit at the hospital, a rather short time that could minimize the risk for recall bias.

The second study pinpointed a number of difficulties that need to be considered when conducting investigations of non-response. The main questionnaire was distributed to parents in the hospital, while the follow-up questionnaire was mailed home to parents. Other methods could be used, such as personal or telephone interviews, but this would introduce new sources of possible bias. It is also important to examine whether it is possible to increase the number of background questions while still maintaining the parents’ anonymity, in order to get more knowledge on characteristics of non-respondents.

Study 3 aimed at gaining a deeper understanding of parental involvement in pediatric care in order to clarify the parental role and develop guidelines for parental involvement.
Previous studies have demonstrated that there is a widespread agreement that parental involvement is an essential element of quality of care for children in the hospital (Evans 1992, Callery 1997).

Fourteen parents were interviewed by the same researcher. All these parents had children with chronic illnesses. A number of studies compare expectations of parents of chronically ill children with expectations of parents who visit the hospital with their child for a minor illness (Gibson 1995). Children with a chronic illness require treatment throughout childhood and growing up, and thus comprise an important group on which to focus. If you manage to establish a trust of medical care and health professionals from the start, the chronic illness will hopefully affect the patient less in adult years. In particular, children’s and parents’ views concerning information and involvement may play an important role in adherence to treatment.

Four themes emerged from the interviews; these include Support, Professionalism, Work environment, and Responsibility. Underlying all these themes is a need for a more clear and open communication between parents and hospital staff. Research indicates that the most important indicator of quality of care for parents was to be included in decisions about their child’s care (Cygan et al. 2002). Parents called for communication improvements and a guide or an outline providing a clear understanding of what to expect when and from whom, according to Sobo et al. (2002). Hallström and Runeson (2001) demonstrated similar findings, where clear communication and mutual agreements are prerequisites for satisfying parental and children’s needs in hospital.

In our study parents expressed the need for an open communication, which is similar to the findings mentioned in the studies above. However, parental role ambiguity seems to be due to a paradox; on the one hand there is a need for emotional support, and on the other hand a sensitivity to the staff’s own situation, including a fear of upsetting a good working relationship between family and staff.

Parents who are regularly or often in the hospital with their child are quite sensitive to hospital staff’s work situations. They are well aware that is sometimes stressful and that there can be a shortage of staff. At the same time, they noticed that things sometimes could be done in a more efficient way. A more structured way of working may facilitate a clearer communication with parents. A more structured way of working could include oral and written information about the unit’s routines for their most common examinations and treatments. The most important element, though, is that staff have a common goal for their work and a culture which enables them to have time to discuss policies and clarify parental role in the care of the child. In the end it is the child’s wellbeing that must be in focus, and one way to support the child through the hospitalization is by supporting the parent.

In Study 4 hospital staff’s perceptions of parental involvement were examined. The main results demonstrated that units (in this study oncology units) with good routines for making parents involved in their child’s care also experienced less strain due to parental demands than did units with unclear routines, where hospital staff experienced more strain from parents’ demands. There were no significant differences between the different professions in attitudes towards parental involvement. There were no significant difference in attitudes related to the length of working experience; this supports results by Johnson and Lindschau (1996), where years of employment did not affect attitudes towards parental involvement.
One possible reason for differences between units could be due to the situations of the patients being treated. The severity of the underlying disease results in a more open and mature attitude among both staff and parents. In this study, hospital staff on oncology units differed significantly from the other units in their routines for parental involvement, and experienced less strain from parents’ demands. This is in line with results of a study by Daneman et al. (2002), where hospital staff on specialty units like cardiology and oncology were significantly more accepting of parental participation. It seems logical that good routines in general facilitate daily working life for hospital staff, and that good routines for making parents involved in their child’s care facilitate collaboration with families.

Methodological issues in questionnaire studies

Three of the four studies in this thesis use data from questionnaire studies and some of the methodological challenges concerning questionnaires must be reviewed.

Anonymity

All of the questionnaires used in the three studies were anonymous, with no possibility of identifying any individual. Anonymity was used in part for ethical reasons, but also in an effort to encourage response. However, this makes it difficult to categorize different groups of parents to compare the characteristics of different questionnaire respondents, as well as to compare respondents with non-respondents. Previous studies concerning parental participation had shown that parental experiences are more influenced by individual factors such as gender, anxiety and preference for control than by social factors such as education, occupation, and civil status (Casey 1995, Kristensson-Hallström 1999).

In a study published recently by Seid et al. (2003), parents’ perceptions of primary health care quality were examined. Results from this study showed that parents reported varied ratings according to race/ethnicity. Language ability emerges here as an important factor in primary care experiences. However, this study was performed in the United States and these results may not be generally applicable to countries with other health care systems. There was, however, a connection between children who had public health insurance and those with private insurance, and this difference persisted even after accounting for race/ethnicity and language.

Distribution

In the first study questionnaires were distributed to parents by hospital staff upon arrival to the units. Ehnfors and Smedby (1993) used a similar method for the same purpose, to get a high response rate by involving hospital staff in distributing the questionnaire. However, it is very important that the person who gives out the questionnaire finds the study interesting and important. For most hospital staff, it is important to gain knowledge about parents’ views — what they think is good and what needs improving.

The distribution of questionnaires in the hospital was done on a structured schedule, based upon the number of patients and time of arrival at the unit. The number of questionnaires distributed to each unit was calculated to be in proportion to the number of patients’ visits to the unit in a two-week period. The number of patient’s visits varies from day to day, which
resulted in every unit making its own schedule for distributing the questionnaire. No exclusion criteria were made. This means that we do not know how many parents with a language other than Swedish answered the questionnaire. What we do know is that parents who speak another language and are unable to speak Swedish usually have an interpreter accompanying them.

Several researchers have discussed the pros and cons of distributing a questionnaire in the hospital or sending it home after the patient’s discharge. Ehnfors and Smedby (1993) found both positive and negative effects on questionnaire results depending on time and place for answering the questionnaire. Some patients’ ratings given during the hospital stay tended to be more critical while others were more positive, especially in situations where patients felt they were in a situation of dependency. Also, if some time had passed before the questionnaire was answered, fewer negative answers could be expected.

Response rate and non-respondents

Other factors that can influence the validity of questionnaire results are the response rate and the number of non-respondents. The response rate is of importance to the validity of the results. For epidemiological studies a response rate of 80% has been proposed as an absolute minimum, whereas for patient satisfaction studies a much lower response rate has been accepted (Barkley and Furse 1996, Sitzia and Wood 1998). However, a study with a low response rate may still provide generalizable results, if it can be shown that respondents and non-respondents do not differ in regard to key outcome variables (Thomsen 2000).

Non-response to a survey can affect the validity of the results when non-respondents differ systematically from respondents. Deming pointed out that increasing sample size might decrease the variance of response, but had no effect on the bias of non-response (Deming 1980). Some researchers have found evidence that non-respondents are likely to be less satisfied with medical care, while others found no non-response bias (Barkley and Furse 1996).

To our knowledge no previous studies have examined the effects of non-response in questionnaires geared to patients’ relatives. However, the limitation of the present study should be considered. The response rate on the follow-up questionnaire was not more then 50%. The response rate on the main questionnaire, 63%, while not optimal, was substantially higher. This might be explained by the fact that parents felt the questionnaire more relevant to answer while still in the hospital, than they felt it was three weeks after leaving the hospital. Previous studies of non-response in patient surveys have reported similar response rates. Lasek et al. (1997) achieved a response rate of 54%, while the study by Holt et al. (1997) had a response rate of 49%. Neither of these studies found indication of bias due to non-response. Hansson and Höglund (1995) reported higher response rate from a sample of psychiatric inpatients that answered a questionnaire before leaving the hospital, compared to another sample that responded at home.

In our study of non-respondents there were no statistically significant differences in quality ratings when comparing parents who answered the questionnaire in the hospital to those who answered three weeks later. Even though it is a relatively small sample, these results could contribute to the opinion that time does not have that much impact on parents’ ratings.
The group of active non-respondents (n=7) were the only group that did differ in regard to two of the three outcome variables of interest. However, the small sample of active non-respondents in our study makes it difficult to generalize these results. Further studies of non-response are necessary in order to gain a better understanding of ways in which respondents and non-respondents differ in their views of quality of care.

**Reliability and validity**

Internal consistency of indices were estimated by means of Cronbach’s alpha. Seven of the eight indices used in the first study had Cronbach’s alpha of 0.76 or higher. One index, Information about routines had Cronbach’s alpha of 0.62. Two indices, Information about illness and Participation, were also used in the follow-up questionnaire. Results from this study demonstrated Cronbach’s alpha between 0.84 and 0.76 respectively for the indices. In the questionnaire used in the fourth study where hospital staff’s perceptions were investigated, two indices were developed, Work routines and Work strain. These two indices had Cronbach’s alpha between 0.81 and 0.77, respectively. According to Bowling (2002), there is no agreement about the minimum acceptable level for internal consistency reliability. However, Cronbach’s alpha exceeding 0.70 is commonly accepted as a satisfactory measure of the reliability of the questionnaire.

Construct validity for the parent questionnaire was examined by using correlation analysis for independence of indices as well as correlation of all items to all indices. Correlation analysis also revealed a higher correlation between parents’ ratings of the overall quality grade and various work environment variables, compared with variables concerning waiting times. These findings offer further evidence of the validity of the parent questionnaire. Predictors of quality of care can be used to evaluate the instrument’s responsiveness to change over time. Responsiveness is a measure of the association between the change in the observed score and the change in the true value in the construct (Bowling 2002). The parent questionnaire was used two times at Astrid Lindgren Children’s Hospital with two years in between. Results from the second measurement demonstrated improvement in one or two the indices for some units, for example one unit had rather low ratings on Information about illness the first time and at the second measurement ratings were higher. Management on this unit had chosen to work strategic with this index.

**Methodological issues in qualitative studies**

In this thesis both quantitative and qualitative methods have been used. The third study, which is a qualitative study, aims at gaining deeper knowledge about parental involvement. Fourteen parents were interviewed in this study. The parents recruited first were active in the Parents’ Council at the hospital. The other parents were recruited with a technique called snowball sampling, i.e. initial respondents are asked to suggest others they know in the target group who could be invited to take part (Bowling, 2002 p. 380). The disadvantage with this technique is that is limited to members of a specific network. But for this purpose this network of parents of chronically ill children had the knowledge and experience of the interest.
A common problem for qualitative methods is the question of sampling size. Sampling sizes are necessarily small because of the complexity of the data to analyze, which is time-consuming. The data aim to provide rich insights in order to understand specific phenomena rather than statistical information. Bowling (2002, p. 380) gives “the rule of the thumb” of sampling size. This is that when the same stories, themes, issues, and topics are emerging from the study subjects, then a sufficient sample size has been reached. In our study, after eight interviews, similar stories, and issues came up. By the fourteenth interview no new data emerged that contributed significantly to the information already related.
CONCLUSIONS AND FURTHER STUDIES

Conclusions from these four studies are as follows:

-- The parent questionnaire demonstrated satisfactory reliability and validity; the instrument can be used in both inpatient and outpatient settings.
-- The parent questionnaire can be used for comparing results between different units, and also to compare results over time within the same unit.
-- When conducting questionnaire studies, there is a need to be observant of the issue of non-respondents and its impact on the results.
-- Qualitative studies can add a body of deeper knowledge of certain aspects to existing quantitative data.
-- A clear association was found between work routines and hospital staff’s perceptions of parental involvement. Hospital staff who experienced good routines for parental involvement, also experience less strain from parents’ demands compared to staff on other units. Future studies are needed on determinants of hospital staff’s attitudes towards parental involvement.
-- Routines for parental involvement need to be established in order to achieve a true communication with parents.

Hospitals today are required to document and report measures and results. One aspect of pediatric hospital care is the quality of care from the viewpoint of the parents of the children being cared for. For hospital management a questionnaire can be used as a tool in the work with continuing quality improvement. It is important to be able to trust questionnaire results, which is why instruments for measuring should be valid and reliable. When response rates are low, studies of non-response are important.

As a complement to quantitative data from questionnaire surveys it is important to add qualitative data from interviews or focus groups with patients or relatives. The qualitative data gives hospital management a deeper understanding of certain issues, and it can also be used to develop new questions in questionnaires.

This thesis contributes knowledge concerning different methods for measuring parents’ views of quality of pediatric care to aid hospital management’s ongoing quality improvement. It also increases awareness of the limitations of different methods, of knowing what to measure and how to do it, as well as pointing out the weaknesses of different methods. Further studies needs to focus on comparing results from patient and parents surveys with medical outcome, to se whether there are connections or not.

Quality improvement is an ongoing process in which both hospital staff and management should be involved, striving for the best possible quality in care delivery. Further studies needs to be performed where hospital staff’s perceptions of parental involvement are investigated in a larger setting. Hospital staff who can promote and exemplify the best of participatory and empowering practice for parents and families must also be empowered. Health care facilities need management philosophies that support participation and empowerment for staff and for the population served by the hospital (Darbyshire 1995).

Hopefully, this thesis will also contribute to awareness about hospital staff’s work environment and its importance in delivering high quality of care. Staff work routines and
guidelines for parental involvement is one aspect of developing a true and accurate communication with families. It would be of value in futures studies to further assess the optimal integration of parental involvement both from a patient and work environment perspective.
SAMMANFATTNING (in Swedish)

Avhandlingen bygger på fyra delarbeten, varav de första två är publicerade, det tredje accepterat och det fjärde i manus. Syftet med avhandlingen är att få kunskap om och att utveckla mätmetoder för hur föräldrar upplever sin roll i barnsjukvården och deras syn på vårdkvaliteten.


Två frågeställningar uppkom efter första studien, dels om icke-svarande skiljer sig från svarande och dels fanns ett behov att få mer kunskap om begreppet delaktighet och vad det innebär för föräldrarna.

I den andra studien genomfördes därför en bortfallsanalys, där syftet var att undersöka om de föräldrar som aktivt väljer att inte svara på enkäten skiljer sig i sina uppfattningar om vården från de föräldrar som svarar, och dels undersöka om föräldrars bedömning av vårdkvalitet förändras över tid. Föräldraenkäten, identisk med den som användes i första studien, delades ut på sjukhuset under en två veckors period. Vid detta tillfälle delades 1094 enkäter ut. Tre veckor senare skickades en uppföljningsenkät hem till 140 slumpvis utvalda föräldrar. Uppföljningsenkäten, en kortare versionen av den ursprungliga enkäten bestod av 17 frågor, förutom bakgrundsfrågor om de svarande föräldrarna var två av mätområden från den ursprungliga enkäten med, Information om sjukdomen och Delaktighet. Dessutom ombärs föräldrarna att ge ett övergripande betyg på en VAS skala från 1-10. Sextio personer svarade på uppföljningsenkäten, vilket gav en svarsfrekvens på 50%. Resultatet visade att de som aktivt valt att inte svara på enkäten på sjukhuset, skilde sig i sin uppfattning om vården jämfört med de som svarat. De som aktivt valt att inte svara var dock liten, 7st, vilket gör att det inte går att generalisera resultatet. Föräldrar som svarat på både enkäten på sjukhuset och på uppföljningsenkäten tre veckor efteråt, hade inte förändrat sin uppfattning om vården. Trots att studien endast omfattar få aktiva icke-svarare indikerar ändå resultatet att det är viktigt att vara observant på de som inte svarar och att ibland undersöka den gruppen närmare.

I det tredje arbetet intervjuades fjorton föräldrar till kroniskt sjuka barn om sina upplevelser och erfarenheter av delaktighet i barnsjukvården. Intervjuerna spelades in på band och skrevs ut ordagrant. När intervjuerna analyserats framkom fyra teman som väsentliga för delaktighet:


Slutsatserna och den kliniska tillämpningen av avhandlingsarbetet är flera;
- ett testat och validerat instrument för att mäta vårdkvalitet i barnsjukvård ur föräldrarnas perspektiv har utarbetats,
- instrumentet har visat sig fungera i en klinisk situation,
- instrumentet kan användas för att göra jämförelser på vårdkvalitet mellan olika enheter och inom varje enhet över tid,
- instrumentet har kunnat visa på förbättringsområden,
- att vara observant på de som inte svarar på enkäter och regelbundet undersöka om de skiljer sig från de som svarar,
- åtminstone fyra områden har visat sig väsentliga för föräldrarnas delaktighet i vården,
- visat på skillnader mellan olika specialiteter vad gäller rutiner för föräldrarnas delaktighet i vården,
- att personalens arbetsmiljö är en väsentlig del av vårdkvalitet sett från föräldrarnas perspektiv.
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REFERENCES


A doctoral dissertation from the Faculty of Medicine, Uppsala University, is usually a summary of a number of papers. A few copies of the complete dissertation are kept at major Swedish research libraries, while the summary alone is distributed internationally through the series *Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine*. (Prior to July 1985, the series was published under the title “Abstracts of Uppsala Dissertations from the Faculty of Medicine”.)