Parents’ Expectations from Pediatric Care

by

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Abstract

**Objective:** The purpose of this literature review is to describe published reports about parents’ expectations and satisfaction in relation to pediatric care.

**Methods:** MeSH search terms were employed to find studies conducted in the US between 2005 - 2011. PubMed and Research Scholar were the resources used.

**Results:** Four of the nine articles investigated well-child care and two of the nine articles investigated provider’s communication in inpatient pediatric care. Each publication reports about a unique feature of pediatric care. Parents favor electronic medical record systems (EMS), physician professionalism, and want providers to offer explanations about events which they perceived to be medical errors in their child’s care. Parents want reassurance and to discuss their priorities in well-child visits. Parents perceive group well-child positively. They prefer taking their child to a regular clinician to develop a patient-provider relationship and to receive anticipatory guidance. Parents find greater satisfaction when allowed to be present during emergency procedures. Also, age-appropriate immunization of young children is associated with high parental satisfaction with early pediatric care. Besides nurses’ and physicians’ behavior, communication with physicians and waiting times are important considerations for parents during inpatient pediatric care.

**Conclusion:** Understanding parents’ expectations and satisfaction with pediatric care is essential for developing effective pediatric programs, specific interventions, and training curricula. Understanding family expectations is central to the provision of patient-centered care.
Parents’ Expectations from Pediatric Care

Introduction

The purpose of this literature review is to describe parents’ reported expectations and satisfaction in relation to pediatric health care. The goal of pediatric care is improvement of children’s health. The responsibility of their health and well being does not rest solely on the health care providers. There is an increasing awareness of the important role of parents in promoting the health and well-being of their children. Since most of the patients in pediatric care are young and communication is mainly between the provider and the parents, parents are responsible for evaluating many aspects of the quality of care. (1) In order to improve pediatric care, the first step is to understand the gaps between the expectations of parents and the services provided. In identifying these barriers to pediatric care, parents are, increasingly, a vital part of the pediatric care team and in a unique position to report on the care their children receive. Parents’ perceptions and experiences of barriers to care may differ from those of health care providers in important ways. These differences indicate, among other things, the sometimes enormous social and cultural gaps that separate parents and health care providers. The providers are acculturated to the world of health care, while parents may experience the medical world as foreign and opaque, a new and different culture. Understanding parents’ perceptions is the key to developing programs and interventions to minimize barriers and is crucial to the provision of patient-centered care. (2)

In pediatrics, family-centered care (FCC) has emerged on the basis of the realization that family is the key resource of strength and sustenance of the child and that the family’s and child’s perspectives and information are necessary in clinical decision-making. (3) According to
the American Academy of Pediatrics (AAP), FCC increases patient and family satisfaction and improves pediatric outcomes. For example, some children seem to recover faster and are discharged earlier when mothers are involved in their post-tonsillectomy care than children whose mothers do not participate in their care. Moreover, family presence (FP) during healthcare procedures reduces the anxiety for the child and the parents. FP does not prolong the procedure when parents are given the opportunity to be at the bedside. (3) However, the perspectives of patients and families have often been missing from health care, leading to patient dissatisfaction. For example, well-child care that provides developmental and preventive services for children ages newborn through 21 years (4) is currently an inefficient service, not aligned with the expectations and needs of many families. It follows the one-size-fits-all approach, which subjects many families to unnecessary visits, while other families remain deprived of essential services due to constraints of time or resources. (5) The experience of care perceived by the patient and family is an increasingly important consideration in assessing health care quality. FCC is about bringing the family’s perspectives straight into health planning, delivery, and assessment of health care, to improve healthcare quality and safety. Studies show that partnerships between providers, patients and families improve the quality of care and increase provider and patient satisfaction. (6) One such study on associations of FCC with health care outcomes for children with special health care needs was seen to be associated with less delayed health care and fewer unmet medical service needs. (7)

Patient- and family-centered care (PFCC) acknowledges the important and constant role of the family in providing medical care and encourages mutually beneficial collaborations between the patient, family and health care professionals. (8) The practice of PFCC promotes
the health and well-being of children and families and is guided by the principles of dignity/respect, information sharing, participation, and collaboration. (6) It honors patient and family perspectives and choices including their cultures, strengths, values, and knowledge and considers them key-decision makers in the patient’s healthcare. The ultimate goal of PFCC is to create the standard of practice that will lead to high quality services, best outcomes, and patient satisfaction. (8)

The AAP introduced the concept of medical home which reinforces that the medical care of children should be accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. The pediatrician and the family share mutual responsibility. (9) A new model for 21st century of medical practice, the patient-centered medical home is an approach to providing comprehensive primary care for children, youth, and adults in a healthcare setting that facilitates partnerships between physicians, patients, and patient’s families. Patients actively take part in clinical decision-making and feedback is required to make sure patients’ expectations are being met. Moreover, at the practice level, patients and families participate in quality improvement activities. (10) Family involvement is the critical ingredient of the medical home model as families are the real consumers of their child’s healthcare. Parents expect timely and technically expert care, up-to-date medical information, care that meets all the needs of their children, and a communication approach that respects their culture, language, and religious beliefs. However, results from the National Survey of Children with Special Healthcare Needs, conducted in 2005-2006, shows that 23% of parents did not get family support services and 33% of parents did not receive family-centered care. (9)
Literature Search and Retrieval Process

PubMed and Research Scholar were used to search on the following MeSH terms: 

*parental satisfaction, parental perspective, parental expectation, perception of care, pediatrics, pediatrician, evaluation, outcome, well-child care, patient, family, parent, parental, primary care, emergency care, acute care, physician-patient communication, family-centered care, and medical home.* These terms were sometimes combined as needed to produce desired results.

Each article identifies a unique aspect of parents’ expectations from pediatric care. There were nine studies that met the search criteria and all were reviewed. All studies were conducted in the US between 2005 - 2011.
Critical Review of the literature

Synthesis and Summary Evidence

Parents’ have expectations about many aspects of pediatric care including preventive care, acute inpatient care, ambulatory and emergency care. Four of the nine studies discuss what parents need and want from preventive care or well-child care (WCC). (14-16,18) The primary reasons for parents’ attending WCC are to seek reassurance and an opportunity to discuss their priorities. They want feedback to be sure that the growth and development of their child is normal and feel encouraged when acknowledged by the pediatrician for having done a good job as a parent, which reconfirms their parenting skills. (15) Participating mothers in a group well-child care program called Well Babies perceive these group sessions positively and as an effective way to tackle important issues in children’s health care. The benefits of receiving support from other women, developmental comparisons, learning from others experiences, more parental involvement in care, and more time spent in the visit reflect high parental satisfaction. (14)

Seeing a regular clinician for preventive care is associated with improved parent-rated quality of health care for young children. For example, as Inkelas et al. report, the measures of interpersonal quality ratings were significantly higher for children with a regular clinician compared with those without one (69 vs. 65, P = 0.01). Similarly, anticipatory guidance content scores were significantly higher for children who had a regular clinician than with those who did not (82 vs. 80, P = 0.03). (16) After controlling for factors that independently influence self-reports of experiences with care, only interpersonal care quality is higher for children with a regular clinician. In a community health center setting, parents of African American and Hispanic children reported that they experienced higher interpersonal quality and content of care
with a regular clinician. (16) In a prospective cohort study, the majority of mothers in 24 pediatric practices across the US expressed satisfaction with pediatric health care. The positive effect was due to the association between satisfaction with early pediatric care utilization and all immunization measures received. Only 4% of the mothers expressed dissatisfaction with pediatric health care. The negative effect was due to a reduced utilization of well-child care which limited the timeliness of age-appropriate immunizations. Their children were significantly less likely to have obtained the age-appropriate 2-month well-child visit and had significantly fewer total age-appropriate visits by 24 months of age. (18)

Two of the nine studies highlight parents’ need for good communication between pediatric health care providers and parents during inpatient care. (12,19) Characteristics of physicians, including attributes and behavior, are important factors in determining parents’ perceptions of the level of professionalism of pediatric health care providers. Families most frequently identify 5 characteristics of physician professionalism that affect the parents’ satisfaction: caring/concern, good communication, knowledge, skill, and honesty/attitude. (12) The study by Ammentorp et al. found gaps between parents’ priorities and satisfaction. Parents’ whose children have been admitted for acute care were least satisfied with the waiting time related to admission and to fulfillment of the child's needs, and medical information/communication by physicians about care and treatment. Parents’ were most satisfied with the behavior of nurses and gave physicians' performance during acute pediatric care the highest priority score. (19) Additionally, parents perceive a variety of events to be medical errors such as behavior of nurses and gave physicians' performance during acute pediatric care the highest priority score. (19) Additionally, parents perceive a variety of events to be medical errors such as
as behavior of nurses and gave physicians' performance during acute pediatric care the highest priority score. (19) Additionally, parents perceive a variety of events to be medical errors such as prescribing an incorrect medication or radiographs missing a fracture. When an error occurs parents want providers to offer an explanation of what has happened, acknowledge the impact of the event, apologize and accept the responsibility. These responses will help to avoid additional physical harm to the child, emotional distress to the parent and damage to the parent-provider relationship in all aspects of pediatric care. (13)

Mangurten et al. report the effectiveness of family presence during pediatric emergency care. Parents experience was positive when offered the option to be present at the bedside during resuscitation and invasive procedures as it helped their child and eased their fears. Parents were satisfied that everything possible was done and would prefer to be present in the future. Even in the event of death, parents’ believed their presence helped the grieving process. (17) Lastly, parents prefer more of their pediatric physicians to use an electronic medical record (EMR) as they report improved quality of doctor care, more up-to-date information, and better understanding of medical tests with EMR usage in the ambulatory practice than paper charts.(11)

Six of the nine studies on the subject of parents’ expectations from pediatric health care were hospital-based. (11,12,14,17-19) In two of the studies parents were recruited from the general public (e.g. local schools, health centers, and day care). (13,15) Further, only one study was population-based and obtained its large sample of 2068 participants from the National Survey of Early Childhood Health (NSECH). (16) The Schempf et al. study had a large sample size of 4896 families. (18) A rare finding observed in the EMR implementation study by Rosen et al. was the missing sample size. All other studies, however, had a small sample
size ranging from 11 to 300. While the study design of two of nine studies was cross-sectional, (16,19) only one was a prospective cohort study (18) and another was a descriptive study (17). All others were qualitative studies.

Overall, only two studies deserve special mention as they both have stronger evidence compared to other studies. These studies are “Does having a regular primary care clinician improve quality of preventive care for young children” by Inkelas et al. (16) and “Parental satisfaction with early pediatric care and immunization of young children” by Schempf et al. (18) Although, the study design in the report by Inkelas et al. is cross-sectional where the nature of cause-effect relationship is uncertain, its large sample size of 2068 young children is from a national parent survey of early childhood health. Besides, it has strong measures of healthcare quality and employs bivariate and multivariate analyses adjusting for factors such as race/ethnicity and health insurance and the study yields statistically significant results. The study design in the report by Schempf et al. is well-designed prospective cohort with 4896 participants from pediatric practices in the US. The measures of age-appropriate well-child care utilization are strong. A global measure is used to directly assess parental satisfaction with their child’s health care as well. The study includes bivariate and multivariate statistical analyses adjusting for socio-demographic characteristics and yields statistically significant results. I have confidence in these two studies.

Gaps in the literature

The studies have several limitations and only a few strengths. Parents’ satisfaction was directly measured with early pediatric care/immunization, acute inpatient pediatric care, and EMR usage in 3 of the nine studies. (11,18,19) In most of the studies parents’ satisfaction was
not assessed directly, but satisfaction level was perceived by the authors based on their priorities and experiences with pediatric care. (12-17)

Although, Well Babies program is quite new, authors associated retention of pediatric patients in the practice at one year with parental satisfaction. As the program grows, the perspectives of incoming participants about group visits may change. Moreover, the program is a continuation of the current group prenatal care at a teaching hospital whose participants already had a successful experience with group visits. (14) In another study, participants addressing core issues about well-child care were self-selected and may represent parents more involved in health care. Their experiences with and views about well-child visits cannot be generalized to all US families. (15) Also, the EMR study without a known sample size and conducted in an academic pediatric rheumatology practice at a tertiary care children’s hospital has limited relevance to the general pediatric practice. (11)

In a study evaluating family presence during emergency procedures only those parents who accepted the family presence option were selected as suitable candidates and hence generalizability of the family responses is limited. Moreover, as parents were interviewed 3 months following the FP event, there is a possibility of a recall bias due to their retrospective recollections. (17) Additionally, the sample in the study exploring parents’ perceptions of medical errors was not from a medical setting but was chosen from the general public, hence neither medical information could be verified nor its quality be assessed to infer that medical error has indeed occurred. (13) Further, in citing professionalism expectations, patient families’ lack of literacy may impact and limit the understanding of words about physician professionalism as listed by the resident-physicians and may bias the results. (12)
The basis for causal inference was limited in these observational studies. Using parent rating of having a regular provider in a cross-sectional survey without any explicit definition of the duration of parent-provider relationship, a causal relationship between having a regular clinician and quality of care cannot be acknowledged. (16) In a prospective cohort study, by Schempf et al. a causal relationship between satisfaction and immunization could not be established inspite of controlling for sociodemographic and maternal health care-utilization variables. (18)

**Conclusions**

In most of these studies satisfaction is only implied and not measured. Because only 3 studies have examined the association between fulfillment of expectations and satisfaction and have directly assessed satisfaction, more research is needed. (11,18,19). Based on theory, future studies should be well-designed prospective cohort studies that yield evidence from sufficiently large probability samples, involve estimation of odds ratios, relative ratios, and other healthcare quality measures and control for potential confounders (e.g. parents’ literacy, race/ethnicity) in data analysis to confirm an association between parents’ expectations and satisfaction and use the results to promote generalizability. Understanding parents’ expectations and satisfaction with pediatric care is essential for developing effective pediatric programs, specific interventions, and training curricula, thereby improving the quality of pediatric care.

We have learned some important lessons from the review. Besides the new role for group well-child visits in addressing essential issues in pediatric primary care, there is a continued role for individual well-child visits. Moreover, young children who have a regular clinician for preventive care show modest gains in quality of care. Further, there are important problems in
the quality of pediatric care with regard to parents’ understanding of medical information, waiting times, and communication between physicians and parents, which are some major areas for improvement.

We have still to learn more and go a long way. Although, FCC is essential to patient health, satisfaction, and health care quality, research is hindered by a lack of true validated measures and outcome measures. The measures that evaluate family impressions of care do not connect any precise actions with overall health and outcomes. Aligned with a vision of effective health care delivery, FCC embraces information sharing, partnering, respect, and negotiation between health care providers and families, yet there are no studies that include all of these principles. (20) An implication of parents having a positive experience with pediatric care is that they may be more likely to seek care for their child in the future, which could decrease unmet health care needs.
References


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# Appendix: Articles reviewed for parents’ expectations from pediatric care, 2005 - 2011

<table>
<thead>
<tr>
<th>Citation/Purpose</th>
<th>Sample Size/Setting</th>
<th>Study Design</th>
<th>Major Findings</th>
<th>Limitations/Strengths*</th>
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</thead>
<tbody>
<tr>
<td>Rosen et al. (2011). J. Med Internet Res, 13</td>
<td>N= parents of all children with rheumatology disorders for routine follow-up, convenience sample</td>
<td>Quality improvement Study (Program evaluation Study)</td>
<td>Families reported increased satisfaction with the EMR compared with the paper chart</td>
<td>Limited application to the general pediatric physician workforce as the study is conducted in an academic pediatric rheumatology practice</td>
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<tr>
<td><strong>To evaluate the effect of implementation of an electronic medical record (EMR) system on parent satisfaction in an academic pediatric rheumatology practice</strong></td>
<td>Academic pediatric rheumatology practice in Children’s Hospital of Pittsburgh</td>
<td></td>
<td>Parent-rated quality of care provided by the doctor was statistically higher using the EMR (P &lt; .001), more up-to-date information (P = .03), and better understanding of medical tests (P = .05)</td>
<td><em>Parents’ satisfaction with EMR usage was assessed</em></td>
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<td>Parent survey consisted of 12 statements, used a 5-point Likert scale and administered 1 month prior to EMR and 3 months post-EMR implementation</td>
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<td>Parents reported they would prefer other child’s physicians to use an EMR (P = .01) to benefit from more time and better communication with the doctor</td>
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<td>Regis et al. (2011). Pediatrics, 127</td>
<td>N = 40 families, 58 residents</td>
<td>Qualitative and Quantitative Study</td>
<td>Families identified 5 most important characteristics of physician professionalism: caring/concern, good communication, knowledge, skill, and honesty/attitude From a comprehensive list of words describing attributes</td>
<td>The literacy level of the survey may have restricted family understanding of words about professionalism listed by the residents</td>
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<td><strong>To examine family and medical residents’ perspectives about the attributes and behaviors of physician professionalism</strong></td>
<td>North Carolina Children’s Hospital</td>
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<td>Conducted medical resident focus groups and anonymous semi-structured interviews of patient families</td>
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<td>Parents were provided with a comprehensive list of words written by the residents describing professionalism</td>
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<tr>
<td>Interviewer used a written guide to collect family perspectives on the attributes/behaviors of physician professionalism</td>
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<td>Interviews lasted for 5 to 20 minutes</td>
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<td>Mazor et al. (2010). Journal of Patient Safety, 6</td>
<td>N = 35 parents of diverse ethnic groups</td>
<td>In-depth Qualitative Study</td>
<td>Parents perceive events such as prescribing an incorrect medication or radiographs missing a fracture as</td>
<td>The sample was not from a medical setting but was chosen from the general public, hence neither</td>
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<td>Parents’ ages ranged from 21 to 59 years; children’s ages ranged from newborn to 17</td>
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<tr>
<td>Study</td>
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<tr>
<td>To identify parents’ perceptions of events, which they thought to be medical errors in their child’s care</td>
<td>Parents recruited from the general public, data collected by detailed qualitative 1/2 to 1 hour interviews</td>
<td>medical errors</td>
<td>Parents expect providers to offer explanation of what has happened, acknowledge the impact of the event, apologize and accept the responsibility. Medical information could be verified and its quality be assessed to infer that a medical error has occurred.</td>
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<tr>
<td>Page et al. (2010). Fam Med, 42</td>
<td>N=11 pregnant women in 3rd trimester at the UNC’s Family Medicine Center and an affiliated birth-center</td>
<td>Descriptive Study</td>
<td>Five themes were associated with group well-child visits: support from other women, developmental comparisons, learning from others experiences, more parental involvement in care, and more time spent in the visit. Retention in the pediatric practice beyond WellBabies program reflected high parental satisfaction. Well Babies program is a new program that is an extension of group prenatal care at UNC.</td>
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<td>Radecki et al. (2009). Pediatrics, 124</td>
<td>N=131 parents, grouped according to their children’s ages (0-2, 3-5, and 6-12 years)</td>
<td>Semi-structured Qualitative Study</td>
<td>Primary reasons for parents’ attending well-child care visits were reassurance and an opportunity to discuss their priorities. Parents wanted confirmation that their child’s growth and development were normal and also affirmation of their parenting skills. Parents valued an ongoing relationship with the same clinician. Qualitative data provided details needed to understand parents’ perspectives about well-child care. Unlike quantitative surveys, focus groups allowed an in-depth description. Participants self-selected and may be more involved in healthcare. Their experiences with and views on well-child visits cannot be generalized to all US families.</td>
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<tr>
<td>Inkelas et al. (2008). Med Care, 46</td>
<td>N = 2068 young children, 4 to 35 months</td>
<td>Cross-sectional study</td>
<td>Healthcare quality measures of interpersonal quality ratings and anticipatory guidance content scores were significantly higher for children with a regular clinician than for those without (interpersonal quality = 69 vs 65, P = 0.01 and anticipatory guidance = 82 vs 80, P = 0.03). Parent’s rating of having a regular provider can be misleading as the study lacks a definition of the duration of the parent-provider relationship. Cross-sectional survey cannot establish a causal relationship between having a regular clinician and parental satisfaction.</td>
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<td>Study</td>
<td>Sample Description</td>
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<td>Mangurten et al. (2006) Journal of Emergency Medicine, 32</td>
<td>N = 66 parents who chose to be at the bedside while their child, at least 18 years of age, was undergoing a resuscitation intervention or invasive procedure</td>
<td>Descriptive Study</td>
<td>Patient care was uninterrupted in 100% of FP cases. All families reported that in a similar situation they would be at the bedside again</td>
<td>Only parents who accepted the family presence option were selected as suitable candidates in the study. Generalizability of the families’ responses is limited. Possibility of recall bias due to parents’ recollections after 3 months</td>
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<tr>
<td>Schempf et al. (2007). Arch Pediatr Adolesc Med, 161</td>
<td>N = 4896 families enrolled at 24 pediatric practices across the US</td>
<td>Prospective cohort Study</td>
<td>Parental satisfaction with pediatric healthcare was high. Majority (two-thirds) of mothers rated their infant’s healthcare as excellent, while 27% as good and 4% reported as fair/poor. There was association between satisfaction with healthcare and all immunization measures examined</td>
<td>The temporal sequence between parental satisfaction and immunization could not be established. *Parents’ satisfaction with early pediatric health care/ immunization was assessed</td>
</tr>
<tr>
<td>Ammentorp et al. (2005). Arch Pediatr Adolesc Med, 159</td>
<td>N = 300 parents of children admitted for acute care in pediatric ward of a regional hospital in Denmark</td>
<td>Cross-sectional Study</td>
<td>Received response rate of 84% for section 1 questionnaires about priorities and response rate of 67% for the section 2 questionnaires about satisfaction level</td>
<td>*Parents’ satisfaction with inpatient pediatric care was assessed</td>
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pediatric care in order to determine the ability of physicians and nurses to provide care and treatment that fulfills parents' needs

Dimensions of service quality were selected for a self-administered questionnaire.

Parents were asked about priorities after admission and were asked to report their level of satisfaction with the care they had received after discharge.

A 5-point Likert scale items listed under 6 main categories: access to care and treatment, information and communication related to care and treatment, information about practical conditions, physicians' behavior, nurses' behavior, and access to service.

Patients least satisfied with the waiting time related to admission as well as to fulfillment of the child's needs, and information given about care and treatment.

Parents most satisfied with the behavior of nurses although they gave physicians' performance the highest priority score.