

What Is Known about Parents' Treatment Decisions? A Narrative Review of Pediatric Decision Making

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Background. With the increasing complexity of decisions in pediatric medicine, there is a growing need to understand the pediatric decision-making process. **Objective.** To conduct a narrative review of the current research on parent decision making about pediatric treatments and identify areas in need of further investigation. **Methods.** Articles presenting original research on parent decision making were identified from MEDLINE (1966–6/2011), using the terms “decision making,” “parent,” and “child.” We included papers focused on treatment decisions but excluded those focused on information disclosure to children, vaccination, and research participation decisions. **Results.** We found 55 papers describing 52 distinct studies, the majority being descriptive, qualitative studies of the decision-making process, with very limited assessment of decision outcomes. Although parents' preferences for degree of participation in pediatric decision making vary, most are interested in sharing the decision with the provider. In addition to the provider, parents

are influenced in their decision making by changes in their child's health status, other community members, prior knowledge, and personal factors, such as emotions and faith. Parents struggle to balance these influences as well as to know when to include their child in decision making. **Conclusions.** Current research demonstrates a diversity of influences on parent decision making and parent decision preferences; however, little is known about decision outcomes or interventions to improve outcomes. Further investigation, using prospective methods, is needed in order to understand how to support parents through the difficult treatment decisions. **Key words:** randomized trial methodology; risk factor evaluation; population-based studies; scale development/validation; patient decision making; provider decision making; risk communication or risk perception; health state preferences, utilities, and valuations; judgment and decision psychology; informed consent; education; pediatrics. (*Med Decis Making* 2012;32:246–258)

When deciding about treatment in both acute and chronic pediatric disease settings, patients, parents, and clinicians face challenging

decisions due to tradeoffs between disease effects, treatment effectiveness, and side effects. With increasing rates of pediatric chronic disease¹ and the development of new treatments with new tradeoffs, there is a growing need to understand the decision-making process in pediatrics. This understanding is key to the development of methods for minimizing negative decision outcomes, such as worry, stress, decisional regret, and poor quality decision making,² and for promoting high-quality decisions, which are informed, in line with families' values, and result in minimal regret.³

Decision-making interactions between providers and patients—or, as in pediatrics, between providers, patients, and parents—are often considered to occur along a continuum. At one end of this continuum, the patient and/or parent is fully responsible for the decision (autonomous decision making), and at the other, the physician has full responsibility

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(paternalistic decision making). Between these 2 extremes are various increments of shared responsibility in decision making.⁴ Shared decision making, in which the physician and family work together to select an evidence-based option, in line with a family's values and preferences,⁵ is often viewed as the ideal.⁶ This is particularly true in the case of preference-sensitive decisions, those with multiple medically reasonable options that have differing pros and cons. However, parents may not want shared decision making in all cases. Understanding the role parents prefer to have in decisions about their child's medical care is key to supporting decision making in a family-centered care environment.⁷

Moreover, concepts and evidence from the adult-care setting cannot always be adapted to the child-parent-physician triad.^{6,8} Even the simplest pediatric decisions may be more complicated than similar decisions in adult medicine. For instance, issues arise around identifying the relevant stakeholders and the degree to which each should participate in decision making. Given that an adult's role in decision making, for instance, choosing for self versus choosing for others, influences treatment preferences,⁹ it may be inappropriate to apply directly the findings from research among adult patients making their own decisions to decisions in pediatrics. At the same time, proxy decision making in pediatrics differs from that in the adult setting, largely because of children's increasing developmental capacities over time, changing biology and greater potential for long-term risks, and benefits from medical care. In adult proxy decisions, the patient's past decisions and behavior can serve as a reference to guide future decisions, even in the absence of an explicit conversation about health care wishes. In contrast, because child preferences and decision-making capacity are limited by the child's stage of development, parents must reference their own preferences and goals for the child when making pediatric treatment decisions.

Improving shared decision making in pediatrics can only be accomplished when there is an understanding of how parents make, and wish to make, medical decisions for their children. The growing emphasis on shared decision making, by groups such as the American Academy of Pediatrics¹⁰ and the Institute of Medicine,¹¹ provides the impetus for this review of the research focused on decision making in the pediatric setting. Through this review, we sought to understand the current research on parent decision making about pediatric treatments and identify areas in need of further investigation.

METHODS

Search Strategy

We used structured methods to find and select reviewed studies. We searched MEDLINE (1966–6/2011), combining the terms “decision making,” “parent,” and “child,” each mapped to the appropriate medical subject heading of the United States National Library of Medicine. We limited our search to English-language studies. Additionally, we hand-searched bibliographies of included articles and consulted colleagues for relevant papers.

Study Selection

We screened titles and abstracts for original research articles with a primary focus on pediatric treatment decision making. As such, we excluded papers focused on screening tests, health-seeking behaviors, food choices, information disclosure to children, ethics, and home safety. Additionally, we excluded 2 topics in which the legal or political context are substantially different from other pediatric decisions and for which reviews exist, namely, vaccination decisions¹² and research participation decisions.¹³ Of note, the screening resulted in all papers published prior to 1989 being excluded.

We found 55 relevant articles describing 52 distinct studies. Study design and methods, number of participants, study location, and results were extracted from each article by a single author (EAL) (Table 1). Because of the variety of clinical settings, small sample sizes, and large number of descriptive studies, we did not conduct a systematic review or qualitative meta-analysis. Instead, we chose to showcase the breadth of the literature in pediatric decision making. We have organized the results to highlight the major themes encountered in this literature. These themes were decided upon through review of the literature and discussion among the authors of this article. While all reviewed articles are found in Table 1, not all fit into the major themes. Similarly, some articles merited inclusion in more than one theme.

RESULTS

Overview of the Research

The parent decision-making research primarily consists of small qualitative or mixed-methods

Table 1 Included Articles (Listed Chronologically by Year)

Authors	Location	Method	Participants	Focus
Abel-Boone and others ²⁶	United States	Qualitative ethnography	30 health care providers, 27 parents	<ul style="list-style-type: none"> Provider and parent perceptions about communication around end-of-life decisions in the neonatal intensive care unit; parents' involvement and experience with end-of-life treatment decisions
Bradbury and others ⁵⁰	United Kingdom	Mixed methods (survey and qualitative interviews)	34 families	<ul style="list-style-type: none"> Decision-making processes and influencing factors in pediatric reconstructive hand surgery
Angst and Deatrick ³⁶	United States	Qualitative interviews	20 children with cystic fibrosis and their parents, 8 children with scoliosis and their parent(s)	<ul style="list-style-type: none"> Types of decisions; decision-making process; satisfaction with decision making
Higgins and Kayser-Jones ^{39a}	United States	Qualitative ethnography	24 parents	<ul style="list-style-type: none"> Processes and influencing factors in decision making about cardiac transplantation
Wharton and others ⁵⁷	United States	Survey	76 parents	<ul style="list-style-type: none"> Parent attitudes about interactions with their child's health care providers when making "critical life" decisions
Götz and others ¹⁶	Austria	Survey	106 parents	<ul style="list-style-type: none"> Preferences and needs for information about lung transplantation in cystic fibrosis
Hinds and others ^{48b}	United States	Mixed methods (survey and interviews)	39 parents, 16 physicians, 3 nurses, 2 chaplains	<ul style="list-style-type: none"> Define which treatment decisions are most difficult for parents of children with cancer; factors that influence parent and provider decision making
Singh and others ⁵⁴	United States	Conjoint analysis	159 parents	<ul style="list-style-type: none"> Attributes of growth hormone therapy that contribute to parent decision making; differences in parent preferences for treatment attributes
Elwyn and others ^{73c}	United Kingdom	Discourse analysis	2 outpatient encounters	<ul style="list-style-type: none"> Treatment of upper respiratory infection
Gwyn and Elwyn ^{79c}	United Kingdom	Discourse analysis	1 outpatient encounter	<ul style="list-style-type: none"> Treatment of upper respiratory infection
Pyke-Grimm and others ^{34d}	Canada	Mixed methods (survey and interviews)	58 parents	<ul style="list-style-type: none"> Decision-making role preferences, information needs, and the relationship between them in pediatric oncology

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Table 1 (continued)

Authors	Location	Method	Participants	Focus
Kluwin and Stewart ²⁴	United States	Qualitative interviews	35 parents	<ul style="list-style-type: none"> Information sources and influencing factors in decisions about cochlear implantation
Steinberg and others ²⁶	United States	Mixed methods (interview, survey, and preference study)	20 families	<ul style="list-style-type: none"> Parent values and outcome preferences in decisions about cochlear implantation
Guerriere and Llewellyn-Thomas ^{69e}	Canada	Mixed methods (decision conflict scale and mapping of qualitative data)	49 mothers	<ul style="list-style-type: none"> Appropriateness of decision conflict scale for substitute decision making
Higgins ^{40a}	United States	Qualitative ethnography	24 parents	<ul style="list-style-type: none"> Decision-making styles related to decisions about cardiac transplantation
Hinds and others ^{29b}	Studies 1 and 2: United States Study 3: United States, Hong Kong, Australia	3 studies in one paper: 1) mixed methods, 2) qualitative interviews, 3) qualitative interviews	1) 39 parents, 16 physicians, 3 nurses, 2 chaplains; 2) 52 parents, 10 adolescents, 22 physicians; 3) 43 parents	<ul style="list-style-type: none"> End-of-life treatment-related decision-making processes of parents, providers, and patients in pediatric oncology
Little and others ²¹	United Kingdom	Randomized controlled trial	315 children	<ul style="list-style-type: none"> To compare immediate with delayed prescriptions of antibiotics for acute otitis media; to evaluate symptom resolution, school absence, and antipyretic use in the 2 groups
McHaffie and others ³¹	United Kingdom	Interviews with quantitative analysis	108 parents	<ul style="list-style-type: none"> Parent perceptions of and experiences with decision making about treatment withdrawal for neonates
Tait ³³	United States	Survey	308 parents	<ul style="list-style-type: none"> Decision-making participation preferences in their child's anesthetic care; associations between participation in decisions and satisfaction with care
Meng and McConnell ⁴³	United States	Focus groups	28 children and their parents	<ul style="list-style-type: none"> Decision-making processes in asthma treatment
Gagnon and Recklitis ¹⁵	United States	Survey	118 parents	<ul style="list-style-type: none"> Decision-making preferences in pediatric oncology; association of preferences with parents' involvement in their own health care
Guerriere and others ^{2e}	Canada	Qualitative interviews	50 mothers	<ul style="list-style-type: none"> Uncertainty in decisions about gastrostomy tube insertion; information and supports used in decision making

(continued)

Table 1 (continued)

Authors	Location	Method	Participants	Focus
Holm and others ⁶⁸	United States	Focus groups	45 parents	<ul style="list-style-type: none"> Parent perceptions of their participation in the medical care of their child with cancer
Li and others ⁴²	United States	Survey	83 parents	<ul style="list-style-type: none"> Influences on parent decision making about communication modality for their deaf child
Miller and Drotar ⁶⁵	United States	Survey	82 mother-adolescent dyads	<ul style="list-style-type: none"> Relationship between mother and adolescent perceptions of diabetes-related decision-making autonomy, diabetes-related conflict, and treatment adherence
Siegel and others ²²	United States	Uncontrolled trial	194 children	<ul style="list-style-type: none"> Determine acceptability of a safety-net antibiotic prescription among parents of children with acute otitis media; assess whether antibiotic usage could be decreased through the use of such a prescription
Hallstrom and Elander ⁶⁷	Sweden	Observational (direct observation and qualitative analysis)	24 hospitalized children and their parents	<ul style="list-style-type: none"> Parent and child participation in inpatient nursing and medical decisions
Mello and others ⁶⁰	United States	Nonrandomized controlled trial	127 parents	<ul style="list-style-type: none"> Intervention to improve decision making and satisfaction among families of children in the pediatric intensive care unit
Slatter and others ⁴⁹	United Kingdom	Qualitative interviews	17 parents	<ul style="list-style-type: none"> Parent medication-related roles in cystic fibrosis treatment; information use and decision-making involvement
Daniel and others ⁴⁵	United Kingdom	Qualitative interviews	9 mothers	<ul style="list-style-type: none"> Decision-making process about elective leg-lengthening surgery
Merenstein and others ¹⁸	United States	Survey (randomized scenarios)	466 parents	<ul style="list-style-type: none"> Preferred decision-making style for treatment of otitis media; satisfaction with different decision-making styles
Sharman and others ³²	United States	Qualitative interviews	14 parents	<ul style="list-style-type: none"> Identification of factors important to parents making end-of-life decisions for children in a pediatric intensive care unit
Charach and others ⁴⁷	Canada	Focus groups	17 parents	<ul style="list-style-type: none"> Experiences of treating ADHD with stimulants; influences on treatment decisions

(continued)

Table 1 (continued)

Authors	Location	Method	Participants	Focus
Hansen and Hansen ⁴⁶	Canada	Qualitative interviews	10 parents	<ul style="list-style-type: none"> Treatment decisions in ADHD; experiences with ADHD medication
Pyke-Grimm and others ^{41d}	Canada	Mixed methods (survey and interviews) Randomized controlled trial	58 parents	<ul style="list-style-type: none"> Factors that influence parents' roles in oncology treatment decision-making role
Spiro and others ²³	United States	Randomized controlled trial	238 children	<ul style="list-style-type: none"> Determine effect of "wait-and-see prescription" on rates of antibiotic use and adverse effects in acute otitis media
Young and others ⁶²	United Kingdom	Qualitative interviews and focus groups	11 children, 12 parents, 10 physiotherapy practitioners	<ul style="list-style-type: none"> Child, parent, and practitioner perspectives of shared decision making in community-based physiotherapy for children with cerebral palsy
Cox and others ³⁸	United States	Observational (videotaped encounters and quantitative analysis) Survey	101 outpatient encounters	<ul style="list-style-type: none"> Deliberation in visits for acute concerns, including degree of parent and child involvement
Hankins and others ⁶⁴	United States	Survey	7 children, 30 parents	<ul style="list-style-type: none"> Treatment preferences and decision-making factors among children with sickle cell anemia and their parents
Lan and others ⁵⁵	Taiwan	Qualitative interviews (phenomenology)	9 mothers	<ul style="list-style-type: none"> Understand process of making decisions about surgery for child with congenital heart disease
Leslie and others ⁵²	United States	Qualitative interviews	28 parents/caregivers	<ul style="list-style-type: none"> Diagnosis and treatment trajectories in ADHD; role of medication use in trajectory
Tarini and others ¹⁹	United States	Survey	130 parents	<ul style="list-style-type: none"> Parent self-efficacy; perceived participation in inpatient medical decision making
Zwaanswijk and others ³⁵	The Netherlands	Online focus groups	7 children, 11 parents, 18 survivors of pediatric cancer	<ul style="list-style-type: none"> Communication preferences in pediatric cancer; preferred participation role in medical decision making
Knopf and others ⁶³	United States	Survey	82 adolescents, 62 parents	<ul style="list-style-type: none"> Decision-making preferences of adolescents with chronic disease and their parents' preferences for them
Okubo and others ²⁵	Japan	Qualitative interviews	26 parents	<ul style="list-style-type: none"> Decision-making processes and perceived risks and benefits of cochlear implantation
Brinkman and others ⁴⁴	United States	Focus groups	52 parents	<ul style="list-style-type: none"> Treatment decision making in ADHD

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Table 1 (continued)

Authors	Location	Method	Participants	Focus
McKenna and others ³⁷	United Kingdom	Survey	66 parents	<ul style="list-style-type: none"> Information needs and involvement in decision making related to the care of children with cancer
Michelson and others ³⁰	United States	Mixed methods (qualitative and quantitative analysis of interviews)	70 parents	<ul style="list-style-type: none"> Parent decision making about withdrawal of care for children in the pediatric intensive care unit; factors influencing hypothetical decisions to withdraw care
Miller ⁶¹	United States	Qualitative interviews and focus groups	18 children, 16 parents	<ul style="list-style-type: none"> Parent and child perspectives on collaborative decision making in chronic disease
Mühlbacher and others ²⁰	Germany	Discrete choice experiment	219 patients and parents	<ul style="list-style-type: none"> Treatment preferences in ADHD
Feudtner and others ²⁷	United States	Prospective cohort	43 parents	<ul style="list-style-type: none"> Pediatric palliative care decision making; association of parent affect and emotional patterns with end-of-life decisions
Fiks and others ¹⁴	United States	Secondary analysis of Medical Expenditure Panel Survey	1397 children with ADHD, 2738 children with asthma 64 parents	<ul style="list-style-type: none"> Shared decision-making patterns in asthma and ADHD
Hsieh and others ⁵¹	United States	Survey	64 parents	<ul style="list-style-type: none"> Factors contributing to parent decision making about vesicoureteral reflux treatment
Hyde and others ¹⁷	Australia	Mixed methods (survey and interviews)	247 parents surveyed, 27 parents interviewed	<ul style="list-style-type: none"> Decision-making processes for cochlear implantation; information sources used in decision making
Fiks and others ⁵³	United States	Qualitative interviews	60 parents, 30 pediatricians	<ul style="list-style-type: none"> Parent and physician understanding of shared decision making in ADHD treatment

a, b, d, e. Both articles use the same study sample.

c. One case is discussed in both articles.

Table 2 Methods Used in Included Studies

Method	N
Qualitative	21
Mixed methods ^a	8
Survey with <100 participants	7
Survey with >100 participants	5
Trial	4
Quantitative analysis of videotaped observations	1
Quantitative analysis of interviews	1
Prospective cohort study	1
Secondary analysis of national database	1
Discourse analysis	1
Discrete choice experiment	1
Conjoint analysis	1

a. Included both a qualitative and a quantitative component.

studies (Table 2). In fact, the reviewed papers had a mean of 85 and a median of 54 subjects (excluding Fiks and others,¹⁴ a secondary analysis of the Medical Expenditure Panel Survey). However, as the field has gained a foothold among pediatric researchers, the variety of methods and sample sizes has increased. In recent years, several larger surveys (sample size >100) related to parent preferences or involvement in decision making have been conducted.¹⁵⁻¹⁹ Additionally, a few larger experimental studies, including a discrete choice experiment in which participants choose between theoretical treatments²⁰ and trials of “wait-and-see” antibiotics as a choice for otitis media treatment,²¹⁻²³ have been completed. The majority of studies focused on decision processes with very limited research into decision interventions or outcomes.

The publications reviewed for this article represent a heterogeneous clinical mixture, addressing primarily preference-sensitive decisions. Many of the reviewed studies represent niches, for example, decisions about cochlear implants^{17,24-26} or end-of-life care,²⁷⁻³² whose lessons may be hard to carry over to other areas of pediatrics. However, there are themes (parents’ role in decision making, influences on parent decision making, parents’ perspectives on the physician’s role, and parent/child decision-making interactions) that run across clinical domains and serve as the framework for this review.

Parents’ Role in Decision Making

The reviewed studies offered insight into parents’ roles in decision making through observation as well

as direct inquiry. Overall, our review found that most parents prefer an active role in decision making. For example, when presented with scenarios about treating otitis media, parents reported higher satisfaction with a proposed shared decision-making approach compared with a paternalistic approach.¹⁸ Similarly, surveys and qualitative interviews in both anesthesia and oncology have shown that most parents want an active role in decision making,³³ and parents are more interested in collaborative decision making than either an autonomous or a paternalistic approach.^{15,34,35} One mixed-methods study found that decision-making preferences are stable over time.³⁴ However, stability may be situation dependent, as other research has found parents’ preferred roles vary according to the child’s diagnosis, the specific decision, and the parents’ knowledge base.^{36,37}

Research in outpatient settings shows inconsistent decision-making roles for parents. In one study, observation of outpatient visits for acute concerns showed that most parents were passively involved in creating treatment plans. However, it is not clear from the study whether this was the parents’ preferred role.³⁸ In contrast, the “wait-and-see” prescription for treatment of otitis media, in which parents are asked to fill a prescription only if their child does not improve in 48 hours, is a well-studied and accepted intervention to increase parent involvement in decision making.²¹⁻²³ Finally, a secondary analysis of the Medical Expenditure Panel Survey (a large-scale national survey focused on the health care system, including health care use and accessibility) found that nearly two thirds of households where a child has asthma or attention-deficit/hyperactivity disorder (ADHD) report high levels of shared decision making with their pediatric provider. This suggests that parents and providers are engaging one another in decision making about the child’s chronic condition.¹⁴

Unlike the variation seen in outpatient settings, studies from inpatient settings found parents were consistently interested in participating in decision making. One survey found that most parents felt they participated in medical decision making for their hospitalized child, although the method or degree of participation was not assessed.¹⁹ Another group of researchers found that parents have a range of approaches to decision making and that the information needs may differ according to an individual’s decision-making approach. For instance, parents who use a more logic-based process want more detailed information and information from

more sources than do other parents.^{39,40} Just as parents want to be involved in other treatment decisions, they also want to be involved in end-of-life decisions and feel they are the key decision maker in this setting.³⁰

Influences on Parents' Decision Making

As in the adult medicine setting, decision making in pediatrics does not occur in isolation. Rather, parents' decision making is influenced, often in inconsistent ways, by a diversity of factors. For example, prior health care experiences have variable influences on parents' decision making. In outpatient acute care visits, Cox and others found that parents who were more active in decision making had fewer visits in the prior year.³⁸ This contrasts with the inpatient setting where participation in decision making was associated with prior hospitalization of the child¹⁹ and with oncology where parents tended to be more involved in treatment decisions that occurred over longer time frames.⁴¹ Additionally, experience with similar situations, such as with another family member, may influence parent decision making, particularly in the setting of end-of-life decisions.³² In both inpatient and outpatient settings, the influence of prior experience may reflect parents' growing understanding of the disease⁴²⁻⁴⁴ and proposed treatments, particularly as a child's condition changes and the need for treatment becomes more or less clear.^{2,36,44-47}

Provider recommendations are another common influence on parents' decision making.^{17,29,41,42,48-51} For instance, in end-of-life decisions, although some parents did not strongly consider physician-estimated prognosis,³⁰ many reported information from providers was the biggest influence on decision making.²⁹ Similarly, in a recent survey of parents making decisions about treatment for children with vesicoureteral reflux, more than 90% considered the urologist's opinion to be very or extremely important.⁵¹

Of course, physicians are not the only people who may influence parents' decision making. Depending on the clinical setting, family,³⁹ school staff,⁴³ other parents, or community members with disease-specific experience may influence decision making.^{17,24,25,50,52,53} Perhaps the most important person who influences parents' decision making is the child. Both the child's own preferences, for example, in elective surgery or attempts to discontinue chronic medications, and the parents' goals for their child are key.^{17,26,32,36,41,44,54}

In many cases, familial and emotional factors may have a more significant role than recommendations from the physician³⁹ or other individuals. In fact, multiple studies, in a variety of clinical settings, have suggested that parents' decision making is influenced by emotions^{2,27,32,44,55} as well as by their beliefs and values.^{29,30,39,44,48,56} For instance, parents' feelings of guilt at wanting more time with their child³² or feeling they failed as a parent if a feeding tube is needed² may influence their decision-making process. Similarly, parents' decision making may be influenced by their faith,^{29,30} by personal beliefs such as the importance of "not giving up,"³⁹ or by the social acceptability of a proposed treatment.⁴⁴

Parents' Perspectives on the Physician's Role

Given the centrality of the parent-physician relationship in pediatric decision making, it is worth considering parents' perspective on the physician's role in decision making. As noted previously, many parents prefer some version of shared decision making,¹⁸ and they see the physician as a partner in decision making.⁵³ From the parental perspective, a key role for physicians (and other health care providers) is providing parents with the information needed to make a preference-sensitive decision.^{29-32,53,57} Such information may range from the prognosis for their child³⁰ to the surgeons' experience⁵⁰ to detailed, accurate treatment information.^{36,49} In some cases, particularly when a decision does not seem preference sensitive, parents perceive the physicians' role to be to determine the necessary care, with their own role being to follow the recommendation.³⁶ Parents appreciate the information provided by physicians and the opportunity to partner with them in defining treatment goals for their child.⁴² They also recognize the limits of individual physician's knowledge and find that in some cases their own decision making is hindered by physicians' inadequate disease-specific knowledge.⁴⁹ Thus, there is a conflict between parents' needs and desires for information from providers and the providers' abilities or preferences related to offering information.

Parent and Child Decision-Making Interactions

Although children may not be considered legally competent to make medical decisions,⁸ developmentally appropriate decision-making roles for children exist.^{8,57-59} Understanding how parents and

children interact in making medical decisions is an aspect of decision making that is unique to pediatrics. This is partially because, although young children may have limited decision-making abilities, many adolescents have achieved independence in other areas of their life and start seeking autonomy in treatment decisions.⁶⁰

Qualitative and observational research shows that parents may need assistance in determining when and how to include children in decisions.^{16,36} In chronic disease, qualitative research suggests that parents and children may engage each other in treatment decisions^{17,61} or may assume specific decision roles. For instance, the child may determine the timing of home treatments, whereas the parent may prioritize the treatment relative to other family needs.⁶² Another approach to including children is asking for their opinion or for information that helps with parental decision making.⁶¹ Although collaboration occurs less frequently with rapid decisions,⁶¹ younger children, and sicker children,^{50,61} parents often involve their child in end-of-life decisions.³² Perhaps not surprisingly, although they often wanted to engage their child in the decision-making process, some parents report filtering the information provided to their child or trying to influence their child's decision.^{45,61}

When surveyed separately about decision making⁶³ and treatment preferences,⁶⁴ parents and children often disagreed with each other. Parents and adolescents both tended to prefer a passive decision-making role for the adolescent. However, only one third of parent-child dyads agreed with one another regarding the preferred role for the adolescent.⁶³ Among adolescents with diabetes, discrepancies in perceptions of the child's decision-making autonomy were associated with greater diabetes-related conflict between the parent and child but were unrelated to adherence.⁶⁵ In addition to disagreeing about the decision-making role, one study showed that parents and children may disagree about which treatment is preferred or about key influences on the decision.⁶⁴

DISCUSSION

Review of the literature on parents' decision making highlights overarching themes with both clinical and research implications. Consistent with literature pertaining to adult decision making,⁶⁶ parents' preferences for involvement in treatment decision making vary based on the clinical

decision^{30,36,37,39,40,54,67} and other factors, including their relationship with the health care provider,^{16,17,33,45,50,55,68} opinions of others in their social network,^{17,24,25,39,43,50,52} and emotions.^{2,16,32,39} Given the importance of the relationship with the provider and the complexity of many treatment decisions, it is not surprising that even parents who report preferring autonomous decision making strongly consider professional opinions when making treatment decisions for their child.^{17,29-32,37,42,49,50,57} Of course, across clinical scenarios, the source, amount, and type of information parents want when making decisions vary from person to person, even when faced with similar decisions.^{2,16,28,31,32,36,49,69}

Importantly, this review highlights the differences between the medical decision process in pediatrics and the process in adults deciding for themselves or in adult proxy decision making. For instance, in addition to the parent-patient-physician triad, there are often other individuals participating in or influencing the process, such as school staff or members of community advocacy groups.^{24,25,44,53} Moreover, given a child's increasing decision-making capabilities, parents struggle to know when and how to include their child in treatment decisions.^{16,36,45,61} This contrasts with adult health care proxy decision making in which patients have diminishing decision-making capacity but may have had prior conversations or established living wills that outlined their treatment desires and gave them a clear role in decision making.^{70,71}

The current research limits our ability to determine the best course of action to address some of the intricacies of pediatric decision making but suggests areas for future research. Given that many parents were happy with their level of involvement, even if it was not their stated role preference,³⁷ providers may not realize when they are not meeting families' needs. Therefore, research addressing the best way to give providers the skills to elicit parents' decision-making preferences is needed.^{72,73} Similarly, although there is a growing body of literature about parents' decision support needs, including a recent systematic review,⁷⁴ there is little evidence of how and when to best meet these needs nor research focused on where parents get information to support their decisions. For instance, most of the reviewed literature was written in the "Internet age," yet none of the articles addressed the role of the Internet, which is likely an important source of information for families and an area for future research. There is also a persistent need to

understand the role of children, particularly adolescents, in pediatric decision making, as both children and parents appear open to a role for children but may be unclear about how to involve them.^{36,57,63,67} Finally, actively engaging others who assist parents in decision making, such as relatives or teachers, will require a system in which families are encouraged to identify and include such individuals in the decision process.

The lack of large studies further limits clinicians' and policy makers' abilities to know how to apply the current knowledge. As such, there is a significant need for further research in the field of pediatric decision making. For instance, although studies suggest that decisions in pediatric chronic disease may be more of a process than a discrete event,^{44,45,75} we are unaware of any longitudinal studies. Understanding the steps and sequence of decision making may help determine where researchers and clinicians can intervene to improve the process and support parents' decision making. There is also a noticeable lack of studies addressing decision outcomes and interventions aimed at improving them.⁷⁶ Only in otitis media, where it has been shown to decrease antibiotic use, has the outcome of active parent involvement in decision making been well studied.^{21,23} As part of understanding the entire decision process, there must be evaluation of the direct outcomes of decision making, such as decision quality³ and regret,⁷⁷ as well as less direct results including health care costs, psychosocial well-being, and medical outcomes.^{20,47}

Using a narrative approach to this review, rather than conducting a systematic review, allowed us to consider the breadth of the existing literature but does have limitations. First, only one author extracted data; therefore, there is a chance of individual bias influencing the results. Also, all studies were given equal consideration rather than evaluating the quality of the evidence related to pediatric decision making. This choice was made because of the nature of the existing literature but does influence the overall generalizability of our results. Additionally, although they were broad, our search terms may have missed some relevant literature. We attempted to minimize this risk by also reviewing articles' bibliographies. Of interest, although we searched back to 1966, the earliest included article was from 1989. Many of the excluded papers were editorials or focused on physicians' decision making. We believe this indicates that research trends

reflect the clinical trends in which decision-making paradigms moved from a paternalistic model to a shared decision-making model.^{5,78}

Effecting clinical change in pediatric decision making will require providers who can assess and adapt to parents' needs and preferences.^{72,73} Assessing parents' needs, preferences, and decision-making skills may serve as a logical stepping stone to developing decision-support tools and encouraging family participation in decision making.^{2,19} Moreover, given that providing parents with information without other decision support is insufficient to fully supporting decision making,⁷⁴ it is crucial that both research and clinical work in decision making advance rapidly to meet the challenges parents face in deciding about treatments for their children.

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REFERENCES

1. Van Cleave J, Gortmaker SL, Perrin JM. Dynamics of obesity and chronic health conditions among children and youth. *JAMA*. 2010;303(7):623–30.
2. Guerriere DN, McKeever P, Llewellyn-Thomas H, Berall G. Mothers' decisions about gastrostomy tube insertion in children: factors contributing to uncertainty. *Dev Med Child Neurol*. 2003;45(7):470–6.
3. Elwyn G, Miron-Shatz T. Deliberation before determination: the definition and evaluation of good decision making. *Health Expect*. 2010;13(2):139–47.
4. Kon AA. The shared decision-making continuum. *JAMA*. 2010;304(8):903–4.
5. Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Soc Sci Med*. 1999;49(5):651–61.
6. Fiks AG, Jimenez ME. The promise of shared decision-making in paediatrics. *Acta Paediatr*. 2010;99(10):1464–6.
7. Franck LS, Callery P. Re-thinking family-centred care across the continuum of children's healthcare. *Child Care Health Dev*. 2004;30(3):265–77.
8. Gabe J, Olumide G, Bury M. 'It takes three to tango': a framework for understanding patient partnership in paediatric clinics. *Soc Sci Med*. 2004;59(5):1071–9.
9. Zikmund-Fisher BJ, Sarr B, Fagerlin A, Ubel PA. A matter of perspective: choosing for others differs from choosing for yourself in making treatment decisions. *J Gen Intern Med*. 2006;21(6):618–22.

10. AAP. Family-centered care and the pediatrician's role. *Pediatrics*. 2003;112(3 Pt 1):691-7.
11. Institute of Medicine. 100 initial priority topics for comparative effectiveness research. Available from: <http://www.iom.edu/~media/Files/Report%20Files/2009/ComparativeEffectivenessResearchPriorities/Stand%20Alone%20List%20of%20100%20CER%20Priorities%20-%20for%20web.pdf>
12. Sturm LA, Mays RM, Zimet GD. Parental beliefs and decision making about child and adolescent immunization: from polio to sexually transmitted infections. *J Dev Behav Pediatr*. 2005;26(6):441-52.
13. Barfield RC, Church C. Informed consent in pediatric clinical trials. *Curr Opin Pediatr*. 2005;17(1):20-4.
14. Fiks AG, Localio AR, Alessandrini EA, Asch DA, Guevara JP. Shared decision-making in pediatrics: a national perspective. *Pediatrics*. 2010;126(2):306-14.
15. Gagnon EM, Recklitis CJ. Parents' decision-making preferences in pediatric oncology: the relationship to health care involvement and complementary therapy use. *Psychooncology*. 2003;12(5):442-52.
16. Gotz I, Labenbacher I, Eichler I, Wojnarowski C, Gotz M. Health-independent lung transplantation information of parents of children with cystic fibrosis. *Transplantation*. 1997;64(5):742-7.
17. Hyde M, Punch R, Komesaroff L. Coming to a decision about cochlear implantation: parents making choices for their deaf children. *J Deaf Stud Deaf Educ*. 2010;15(2):162-78.
18. Merenstein D, Diener-West M, Krist A, Pinneger M, Cooper LA. An assessment of the shared-decision model in parents of children with acute otitis media. *Pediatrics*. 2005;116(6):1267-75.
19. Tarini BA, Christakis DA, Lozano P. Toward family-centered inpatient medical care: the role of parents as participants in medical decisions. *J Pediatr*. 2007;151(6):690-5.
20. Muhlbacher AC, Rudolph I, Lincke HJ, Nubling M. Preferences for treatment of attention-deficit/hyperactivity disorder (ADHD): a discrete choice experiment. *BMC Health Serv Res*. 2009;9:149.
21. Little P, Gould C, Williamson I, Moore M, Warner G, Dunleavy J. Pragmatic randomised controlled trial of two prescribing strategies for childhood acute otitis media. *BMJ*. 2001;322(7282):336-42.
22. Siegel RM, Kiely M, Bien JP, et al. Treatment of otitis media with observation and a safety-net antibiotic prescription. *Pediatrics*. 2003;112(3 Pt 1):527-31.
23. Spiro DM, Tay KY, Arnold DH, Dziura JD, Baker MD, Shapiro ED. Wait-and-see prescription for the treatment of acute otitis media: a randomized controlled trial. *JAMA*. 2006;296(10):1235-41.
24. Kluwin TN, Stewart DA. Cochlear implants for younger children: a preliminary description of the parental decision process and outcomes. *Am Ann Deaf*. 2000;145(1):26-32.
25. Okubo S, Takahashi M, Kai I. How Japanese parents of deaf children arrive at decisions regarding pediatric cochlear implantation surgery: a qualitative study. *Soc Sci Med*. 2008;66(12):2436-47.
26. Steinberg A, Brainsky A, Bain L, Montoya L, Indenbaum M, Potsic W. Parental values in the decision about cochlear implantation. *Int J Pediatr Otorhinolaryngol*. 2000;55(2):99-107.
27. Feudtner C, Carroll KW, Hexem KR, Silberman J, Kang TI, Kazak AE. Parental hopeful patterns of thinking, emotions, and pediatric palliative care decision making: a prospective cohort study. *Arch Pediatr Adolesc Med*. 2010;164(9):831-9.
28. Abel-Boone H, Dokecki PR, Smith MS. Parent and health care provider communication and decision making in the intensive care nursery. *Child Health Care*. 1989;18(3):133-41.
29. Hinds PS, Oakes L, Furman W, et al. End-of-life decision making by adolescents, parents, and healthcare providers in pediatric oncology: research to evidence-based practice guidelines. *Cancer Nurs*. 2001;24(2):122-34, quiz 135-6.
30. Michelson KN, Koogler T, Sullivan C, Ortega Mdel P, Hall E, Frader J. Parental views on withdrawing life-sustaining therapies in critically ill children. *Arch Pediatr Adolesc Med*. 2009;163(11):986-92.
31. McHaffie HE, Lyon AJ, Hume R. Deciding on treatment limitation for neonates: the parents' perspective. *Eur J Pediatr*. 2001;160(6):339-44.
32. Sharman M, Meert KL, Sarnaik AP. What influences parents' decisions to limit or withdraw life support? *Pediatr Crit Care Med*. 2005;6(5):513-8.
33. Tait AR, Voepel-Lewis T, Munro HM, Malviya S. Parents' preferences for participation in decisions made regarding their child's anaesthetic care. *Paediatr Anaesth*. 2001;11(3):283-90.
34. Pyke-Grimm KA, Degner L, Small A, Mueller B. Preferences for participation in treatment decision making and information needs of parents of children with cancer: a pilot study. *J Pediatr Oncol Nurs*. 1999;16(1):13-24.
35. Zwaanswijk M, Tates K, van Dulmen S, Hoogerbrugge PM, Kamps WA, Bensing JM. Young patients', parents', and survivors' communication preferences in paediatric oncology: results of online focus groups. *BMC Pediatr*. 2007;7:35.
36. Angst DB, Deatrck JA. Involvement in health care decisions: parents and children with chronic illness. *J Fam Nurs*. 1996;2(2):174-94.
37. McKenna K, Collier J, Hewitt M, Blake H. Parental involvement in paediatric cancer treatment decisions. *Eur J Cancer Care (Engl)*. 2010;19(5):621-30.
38. Cox ED, Smith MA, Brown RL. Evaluating deliberation in pediatric primary care. *Pediatrics*. 2007;120(1):e68-77.
39. Higgins SS, Kayser-Jones J. Factors influencing parent decision making about pediatric cardiac transplantation. *J Pediatr Nurs*. 1996;11(3):152-60.
40. Higgins SS. Parental role in decision making about pediatric cardiac transplantation: familial and ethical considerations. *J Pediatr Nurs*. 2001;16(5):332-7.
41. Pyke-Grimm KA, Stewart JL, Kelly KP, Degner LF. Parents of children with cancer: factors influencing their treatment decision making roles. *J Pediatr Nurs*. 2006;21(5):350-61.
42. Li Y, Bain L, Steinberg AG. Parental decision making and the choice of communication modality for the child who is deaf. *Arch Pediatr Adolesc Med*. 2003;157(2):162-8.
43. Meng A, McConnell S. Decision-making in children with asthma and their parents. *J Am Acad Nurse Pract*. 2002;14(8):363-71.

44. Brinkman WB, Sherman SN, Zmitrovich AR, et al. Parental angst making and revisiting decisions about treatment of attention-deficit/hyperactivity disorder. *Pediatrics*. 2009;124(2):580–9.
45. Daniel E, Kent G, Binney V, Pagdin J. Trying to do my best as a mother: decision-making in families of children undergoing elective surgical treatment for short stature. *Br J Health Psychol*. 2005;10(Pt 1):101–14.
46. Hansen DL, Hansen EH. Caught in a balancing act: parents' dilemmas regarding their ADHD child's treatment with stimulant medication. *Qual Health Res*. 2006;16(9):1267–85.
47. Charach A, Skyba A, Cook L, Antle BJ. Using stimulant medication for children with ADHD: what do parents say? A brief report. *J Can Acad Child Adolesc Psychiatry*. 2006;15(2):75–83.
48. Hinds PS, Oakes L, Furman W, et al. Decision making by parents and healthcare professionals when considering continued care for pediatric patients with cancer. *Oncol Nurs Forum*. 1997;24(9):1523–8.
49. Slatter A, Francis SA, Smith F, Bush A. Supporting parents in managing drugs for children with cystic fibrosis. *Br J Nurs*. 2004;13(19):1135–9.
50. Bradbury ET, Kay SP, Tighe C, Hewison J. Decision-making by parents and children in paediatric hand surgery. *Br J Plast Surg*. 1994;47(5):324–30.
51. Hsieh MH, Madden-Fuentes RJ, Bayne A, et al. Cross-sectional evaluation of parental decision making factors for vesicoureteral reflux management in children. *J Urol*. 2010;184(4 Suppl):1589–93.
52. Leslie LK, Plemmons D, Monn AR, Palinkas LA. Investigating ADHD treatment trajectories: listening to families' stories about medication use. *J Dev Behav Pediatr*. 2007;28(3):179–88.
53. Fiks AG, Hughes CC, Gafen A, Guevara JP, Barg FK. Contrasting parents' and pediatricians' perspectives on shared decision-making in ADHD. *Pediatrics*. 2011;127(1):e188–96.
54. Singh J, Cuttler L, Shin M, Silvers JB, Neuhauser D. Medical decision-making and the patient: understanding preference patterns for growth hormone therapy using conjoint analysis. *Med Care*. 1998;36(8 Suppl):AS31–45.
55. Lan SF, Mu PF, Hsieh KS. Maternal experiences making a decision about heart surgery for their young children with congenital heart disease. *J Clin Nurs*. 2007;16(12):2323–30.
56. Li Y, Bain L, Steinberg AG. Parental decision-making in considering cochlear implant technology for a deaf child. *Int J Pediatr Otorhinolaryngol*. 2004;68(8):1027–38.
57. Wharton RH, Levine KR, Buka S, Emanuel L. Advance care planning for children with special health care needs: a survey of parental attitudes. *Pediatrics*. 1996;97(5):682–7.
58. AAP. Informed consent, parental permission, and assent in pediatric practice. Committee on Bioethics, American Academy of Pediatrics. *Pediatrics*. 1995;95(2):314–7.
59. Hallstrom I, Elander G. Decision making in paediatric care: an overview with reference to nursing care. *Nurs Ethics*. 2005;12(3):223–38.
60. La Greca AM, Prinstein MJ. Peer group. In: Silverman WK, Ollendick TH, eds. *Developmental Issues in Clinical Treatment of Children*. Needham Heights, MA: Allyn & Bacon; 1999. p 171–98.
61. Miller VA. Parent-child collaborative decision making for the management of chronic illness: a qualitative analysis. *Fam Syst Health*. 2009;27(3):249–66.
62. Young B, Moffett JK, Jackson D, McNulty A. Decision-making in community-based paediatric physiotherapy: a qualitative study of children, parents and practitioners. *Health Soc Care Community*. 2006;14(2):116–24.
63. Knopf JM, Hornung RW, Slap GB, DeVellis RF, Britto MT. Views of treatment decision making from adolescents with chronic illnesses and their parents: a pilot study. *Health Expect*. 2008;11(4):343–54.
64. Hankins J, Hinds P, Day S, et al. Therapy preference and decision-making among patients with severe sickle cell anemia and their families. *Pediatr Blood Cancer*. 2007;48(7):705–10.
65. Miller VA, Drotar D. Discrepancies between mother and adolescent perceptions of diabetes-related decision-making autonomy and their relationship to diabetes-related conflict and adherence to treatment. *J Pediatr Psychol*. 2003;28(4):265–74.
66. Lown BA, Clark WD, Hanson JL. Mutual influence in shared decision making: a collaborative study of patients and physicians. *Health Expect*. 2009;12(2):160–74.
67. Hallstrom I, Elander G. Decision-making during hospitalization: parents' and children's involvement. *J Clin Nurs*. 2004;13(3):367–75.
68. Holm KE, Patterson JM, Gurney JG. Parental involvement and family-centered care in the diagnostic and treatment phases of childhood cancer: results from a qualitative study. *J Pediatr Oncol Nurs*. 2003;20(6):301–13.
69. Guerriere D, Llewellyn-Thomas H. Substitute decision-making: measuring individually mediated sources of uncertainty. *Patient Educ Couns*. 2001;42(2):133–43.
70. Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med*. 2010;362(13):1211–8.
71. Vig EK, Starks H, Taylor JS, Hopley EK, Fryer-Edwards K. Surviving surrogate decision-making: what helps and hampers the experience of making medical decisions for others. *J Gen Intern Med*. 2007;22(9):1274–9.
72. Edwards A, Elwyn G. Inside the black box of shared decision making: distinguishing between the process of involvement and who makes the decision. *Health Expect*. 2006;9(4):307–20.
73. Elwyn G, Gwyn R, Edwards A, Grol R. Is 'shared decision-making' feasible in consultations for upper respiratory tract infections? Assessing the influence of antibiotic expectations using discourse analysis. *Health Expect*. 1999;2(2):105–17.
74. Jackson C, Cheater FM, Reid I. A systematic review of decision support needs of parents making child health decisions. *Health Expect*. 2008;11(3):232–51.
75. Whitney SN, Ethier AM, Fruge E, Berg S, McCullough LB, Hockenberry M. Decision making in pediatric oncology: who should take the lead? The decisional priority in pediatric oncology model. *J Clin Oncol*. 2006;24(1):160–5.
76. Stewart JL, Pyke-Grimm KA, Kelly KP. Parental treatment decision making in pediatric oncology. *Semin Oncol Nurs*. 2005;21(2):89–97, discussion 98–106.
77. Brehaut JC, O'Connor AM, Wood TJ, et al. Validation of a decision regret scale. *Med Decis Making*. 2003;23(4):281–92.
78. Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *JAMA*. 1992;267(16):2221–6.