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

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Abstract

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.

Keywords

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

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 disease[1] and the development of new treatments with new tradeoffs, there is a growing need to

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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 (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 Pediatrics[10] 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 decisions[12] 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 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 treatments[20] 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 child[19] 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 disease[42–44] 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 physician[39] 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 child[32] or feeling they failed as a parent if a feeding tube is needed[2] 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 child[30] to the surgeons' experience[50] 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] develop-mentally 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 making[63] 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 decisionmaking 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 decisionmaking 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 quality[3] 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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Table 1

Included Articles (Listed Chronologically by Year)

Authors	Location	Method	Participants	Focus
Abel-Boone and others[28]	United States	Qualitative ethnography	30 health care providers, 27 parents	• 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	• 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)	• Types of decisions; decision-making process; satisfaction with decision making
Higgins and Kayser- Jones[39][a]	United States	Qualitative ethnography	24 parents	• Processes and influencing factors in decision making about cardiac transplantation
Wharton and others[57]	United States	Survey	76 parents	• Parent attitudes about interactions with their child's health care providers when making "critical life" decisions
Götz and others[16]	Austria	Survey	106 parents	• Preferences and needs for information about lung transplantation in cystic fibrosis
Hinds and others[48][b]	United States	Mixed methods (survey and interviews)	39 parents, 16 physicians, 3 nurses, 2 chaplains	• Define which treatment decisions are most difficult for parents of children with cancer; factors that influence parent and provider

Authors	Location	Method	Participants	Focus
				decision making
Singh and others[54]	United States	Conjoint analysis	159 parents	• 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	• Treatment of upper respiratory infection
Gwyn and Elwyn[73c]	United Kingdom	Discourse analysis	1 outpatient encounter	• Treatment of upper respiratory infection
Pyke-Grimm and others[34d]	Canada	Mixed methods (survey and interviews)	58 parents	• Decision-making role preferences, information needs, and the relationship between them in pediatric oncology
Kluwin and Stewart[24]	United States	Qualitative interviews	35 parents	• 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	• 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	• Appropriateness of decision conflict scale for substitute decision making
Higgins[40a]	United States	Qualitative ethnography	24 parents	• 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	• End-of-life treatment–related decision-making processes of parents, providers, and patients in

Authors	Location	Method	Participants	Focus
				pediatric oncology
Little and others[21]	United Kingdom	Randomized controlled trial	315 children	• 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	• Parent perceptions of and experiences with decision making about treatment withdrawal for neonates
Tait[33]	United States	Survey	308 parents	• 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	• Decision-making processes in asthma treatment
Gagnon and Recklitis[15]	United States	Survey	118 parents	• Decision-making preferences in pediatric oncology; association of preferences with parents' involvement in their own health care and use of complementary therapies
Guerriere and others[2][e]	Canada	Qualitative interviews	50 mothers	• Uncertainty in decisions about gastrostomy tube insertion; information and supports used in decision making
Holm and others[68]	United States	Focus groups	45 parents	• Parent perceptions of their participation in the medical care

Authors	Location	Method	Participants	Focus
				of their child with cancer
Li and others[42]	United States	Survey	83 parents	• Influences on parent decision making about communication modality for their deaf child
Miller and Drotar[65]	United States	Survey	82 mother-adolescent dyads	• 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	• 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	• Parent and child participation in inpatient nursing and medical decisions
Mello and others[80]	United States	Nonrandomized controlled trial	127 parents	• 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	• Parent medication-related roles in cystic fibrosis treatment; information use and decision-making involvement
Daniel and others[45]	United Kingdom	Qualitative interviews	9 mothers	• Decision-making process about elective leg-lengthening surgery

Authors	Location	Method	Participants	Focus
Merenstein and others[18]	United States	Survey (randomized scenarios)	466 parents	• 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	• 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	• Experiences of treating ADHD with stimulants; influences on treatment decisions
Hansen and Hansen[46]	Canada	Qualitative interviews	10 parents	• Treatment decisions in ADHD; experiences with ADHD medication
Pyke-Grimm and others[41][d]	Canada	Mixed methods (survey and interviews)	58 parents	• Factors that influence parents' roles in oncology treatment decision-making role
Spiro and others[23]	United States	Randomized controlled trial	238 children	• 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	• 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)	101 outpatient encounters	• Deliberation in visits for acute concerns, including degree of parent and child involvement
Hankins and others[64]	United States	Survey	7 children, 30 parents	• Treatment preferences and

Authors	Location	Method	Participants	Focus
				decision-making factors among children with sickle cell anemia and their parents
Lan and others[55]	Taiwan	Qualitative interviews (phenomenology)	9 mothers	• Understand process of making decisions about surgery for child with congenital heart disease
Leslie and others[52]	United States	Qualitative interviews	28 parents/caregivers	• Diagnosis and treatment trajectories in ADHD; role of medication use in trajectory
Tarini and others[19]	United States	Survey	130 parents	• 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	• Communication preferences in pediatric cancer; preferred participation role in medical decision making
Knopf and others[63]	United States	Survey	82 adolescents, 62 parents	• Decision-making preferences of adolescents with chronic disease and their parents' preferences for them
Okubo and others[25]	Japan	Qualitative interviews	26 parents	• Decision-making processes and perceived risks and benefits of cochlear implantation
Brinkman and others[44]	United States	Focus groups	52 parents	• Treatment decision making in ADHD
McKenna and others[37]	United Kingdom	Survey	66 parents	• Information needs and involvement in decision making related to the care of children with cancer

Authors	Location	Method	Participants	Focus
Michelson and others[30]	United States	Mixed methods (qualitative and quantitative analysis of interviews)	70 parents	• 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	• Parent and child perspectives on collaborative decision making in chronic disease
Mühlbacher and others[20]	Germany	Discrete choice experiment	219 patients and parents	• Treatment preferences in ADHD
Feudtner and others[27]	United States	Prospective cohort	43 parents	• 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	• Shared decision-making patterns in asthma and ADHD
Hsieh and others[51]	United States	Survey	64 parents	• 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	• Decision-making processes for cochlear implantation; information sources used in decision making
Fiks and others[53]	United States	Qualitative interviews	60 parents, 30 pediatricians	• 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.