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Shared Decision-Making with Parents of Acutely Ill Children: A Narrative Review

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Abstract

Background—Shared decision-making (SDM) has mostly been used with adults and parents in the primary care setting, and there is limited knowledge on the use of SDM with parents of acutely ill children.

Objective—To review the literature on SDM with parents in the management of acutely ill children.

Data Sources—We searched MEDLINE, SCOPUS, PsycINFO, the Cochrane Library, and ClinicalTrials.gov for English language studies published from the time of database inception to February, 2017.

Study Eligibility Criteria—Use of SDM with parents for children age 18 years with an acute medical problem.

Results—We identified 2 ongoing clinical trials and 10 published studies meeting inclusion criteria: 2 using hypothetical SDM scenarios, 1 mixed-methods study, and 7 intervention studies.

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Only 1 study compared an SDM intervention to usual care in a randomized controlled trial. The limited literature demonstrates that parents of acutely ill children have differing preferences for testing and/or treatment, and that they generally want the opportunity to express those preferences through an SDM process. Use of SDM often results in acutely ill children undergoing fewer and/or less intensive testing or treatment, though the effect on outcomes is unclear.

Conclusions and Implications—Parents welcome participation in SDM for management decisions with their acutely ill child. Further investigation is needed to determine how best to implement SDM with parents of acutely ill children and to assess the impact of SDM on outcomes.

Keywords

decision making; child; child, preschool; infant; infant, newborn; adolescent; emergency service; hospital; acute disease

Introduction

Shared decision-making (SDM) is used to engage patients in medical decisions by incorporating their preferences and what is most important to them (i.e. their values) in making complex decisions involving two or more rational options. In SDM, the provider uses the available evidence to present and discuss the potential benefits and harms of testing or treatment options, and the patient's preferences are then elicited to inform a joint decision.¹ The American Academy of Pediatrics has endorsed SDM for pediatric patients and their families,² including in acute care environments such as the emergency department (ED).³ However, the vast majority of research that assesses the impact of SDM on outcomes has been conducted in adult patients;⁴ there are few studies of SDM in children.⁵ In both adults and children, SDM has been mainly evaluated in the primary care setting.^{4,5}

Infants, children, and adolescents who present with an acute illness or injury (e.g. rapid in onset, of short duration, and in need of urgent medical care) are a population in which SDM may have particular benefit. For these “acutely ill children,” testing is often invasive and painful, and the risks of treatment (e.g. antibiotics for a child 2 years old with acute otitis media) may outweigh the benefits if the probability of an adverse outcome is low. However, there are several potential barriers to the use of SDM with parents of acutely ill children. In the acute care setting, decisions are often made under significant time pressure and clinicians have expressed concern about the feasibility of using SDM when urgent decision-making is required.⁶ Additionally, providers may have difficulty explaining management options when there is conflicting evidence or imprecise estimates of risk.⁷ Although both providers and parents have been found to be familiar with the concept of SDM, they also report insufficient knowledge on how to implement SDM in practice.⁶ Finally, stress and fatigue in the setting of an acute illness may impair the ability of parents to fully participate in the decision-making process. To best inform current practice, education, and research, we reviewed the literature on SDM with parents in the management of acutely ill children.

Our Findings

We searched MEDLINE, SCOPUS, PsycINFO, the Cochrane Library, and [ClinicalTrials.gov](https://www.clinicaltrials.gov) using combinations of the terms “ decision making,” “shared decision making,” “decision aid,” “infant,” “child,” “children,” “adolescent,” “acute disease,” and “emergency department.” We limited our search strategy to studies published in the English language but did not limit by year of publication. For inclusion in this narrative review, studies needed to meet the following criteria: 1) inclusion of children age 18 years, and 2) use of SDM with parents for children presenting with an acute medical problem. We found 10 published articles that met these criteria, and categorized them as studies that reported on hypothetical scenarios, mixed-methods studies, or interventions. We also identified 2 ongoing randomized controlled trials.

Hypothetical Scenarios

Two studies have evaluated SDM using hypothetical scenarios. A 2005 study randomized 466 parents in a waiting room of a family practice clinic to read 1 of 3 clinical vignettes that described either a paternalistic approach (i.e. recommended by the physician) to prescribing antibiotics for a child with acute otitis media or 1 of 2 SDM approaches that included a safety net antibiotic prescription. The parents in all 3 groups then completed a survey to assess their satisfaction with the process as well as their likelihood of opting for antibiotics. Parents in the SDM groups were more satisfied with the hypothetical visit and a lower proportion responded that they would opt for immediate use of antibiotics for acute otitis media compared with parents in the paternalistic approach group.⁸

A second study published in 2015 surveyed 350 adults in an ED waiting room, and reported that the vast majority would prefer to be counseled before a head computed tomography (CT) was ordered for their “hypothetical” child in the ED. Additionally, their preference for CT varied based on the pretest probability of finding an abnormality.⁹ These 2 studies demonstrate that parents welcome involvement in SDM in different populations of acutely ill children and that they may prefer less intensive testing or treatment after participating in SDM.

Mixed-Methods

A mixed methods study in 2013 assessed SDM by audiotaping interactions between a healthcare professional (doctor or nurse) and parents of children hospitalized because of a possible ventricular shunt malfunction, and subsequently surveying both parents and providers one week after hospital discharge.¹⁰ Of the 19 parents and 14 healthcare professionals who participated, the majority agreed that most elements of SDM occurred in reaching a diagnosis and establishing a treatment plan, though healthcare professionals perceived SDM to occur more often than did parents. The majority of participants were satisfied with the extent of parents’ involvement in decision-making; however, healthcare professionals identified time constraints as a barrier to effective communication and parents felt that healthcare professionals did not always listen to them during the decision-making process.¹⁰

Interventions

Seven studies evaluated an intervention to facilitate SDM with parents of acutely ill children. Six of these studies employed an information sheet or decision aid. Decision aids describe testing or treatment options and present the risks and benefits of alternative approaches. They may also help patients or parents consider and express their values, elicit their preferences for participation in decision-making, and choose the preferred option.¹¹ The International Patient Decision Aids Standards (IPDAS) Collaboration has developed 12 quality criteria for the development and use of decision aids.¹² The purpose of these criteria is to establish an evidence-based framework for the content, development, assessment, and implementation of decision aids, to ensure their quality and effectiveness in practice.¹² These criteria emphasize that decision aids should 1) be developed using stakeholder input, 2) use plain language to share information about the pros and cons related to available options, 3) provide a platform in which patients (or parents) are able to express their values, 4) facilitate deliberation about the options given each decision maker's values, and 5) ensure that patients participate in the decision-making process at the level they desire.¹² Studies in adults have compared the use of decision aids with "usual care" in various diseases and have demonstrated their positive impact on outcomes.^{4,13}

Of the 7 studies that included an intervention, only 1 was a randomized trial that compared the intervention to a "usual care" group (Table 1). Two studies published by the same author in 1997 used information sheets to facilitate SDM. In the first study, parents of well-appearing children age 3 to 36 months with fever $\geq 39^{\circ}$ C were given an information sheet that described the likelihood that the fever was caused by a virus, the risks of serious bacterial infections, and how to test for and how to treat these infections. Following review of this information sheet, the treating physician made a management recommendation and the parents expressed their preferences for testing as well as treatment (oral vs. parenteral vs. no antibiotics). The majority of parents chose to avoid testing and agreed to receive oral rather than parenteral antibiotics for treatment (primarily for otitis media), though 10 parents chose parenteral antibiotics. Most parents expressed satisfaction with their level of participation in the decision. While the sample was small, there were no adverse outcomes reported.¹⁴ In the second study, parents of children with actual or hypothetical lacerations were given an information sheet that described options for management of lacerations and elicited parents' preferences for local anesthesia (topical vs. infiltrated) and procedural sedation (yes vs. no). The majority of parents chose infiltrated local anesthesia and no procedural sedation, and nearly all preferred to be included in the decision-making process.¹⁵ Both of these studies demonstrated that most parents prefer less intensive testing and treatment when given the option during a SDM process. However, parents were not asked what aspects of the presented options were most valuable to them in making a decision, and a comparison group was not included.

Two subsequent studies published in 2009 and 2013 used educational materials to describe 1) the process, risks, and benefits of oral vs. intravenous rehydration for children with vomiting and/or diarrhea,¹⁶ and 2) the risks and benefits of head CT vs. observation for children who presented after head trauma.¹⁷ Parents in both studies then completed a survey that included their preferences as well as the reasons for their choice, and a management

decision was made jointly by the parent and the physician. These studies expanded on the prior investigations in that the authors assessed parents' values. However, the association between parents' preferences and treatment received was not reported and there were no comparison groups.^{16,17}

The only multicenter clinical trial that has evaluated the effect of a decision aid on both clinical and decisional outcome measures in acutely ill children is the 2012 DECISION+2 trial.¹⁸ This trial included a decision aid that met many of the IPDAS criteria, including modification of the SDM intervention after a pilot trial.^{19,20} In this cluster randomized trial of 9 family practice "teaching units," clinicians were randomized to usual care or to participate in a 2-hour online tutorial followed by a 2-hour interactive workshop that included videos, exercises, and decision aids aimed to help clinicians communicate the risks of a bacterial respiratory infection as well as the harms and benefits of antibiotics. Decision aids were also available in all of the family practice "teaching units" randomized to the intervention group. A smaller proportion of children received antibiotics and a higher proportion of parents reported that they played an active role in the decision-making process in the intervention group than in the control group. There was no difference in clinical outcomes between the 2 groups at 2 weeks.¹⁸

In a 2015 study, treating physicians assigned parents of children hospitalized for community-acquired pneumonia to a "shared decision" or "unshared decision" group based on the time of admission (day or evening, respectively). Fourteen of 18 parents in the shared decision group chose oral antibiotics for treatment, and 13 of these 14 parents reported "needle punctures hurt" as the reason for this choice. However, over half of parents in the "unshared decision" group should have been assigned to the "shared decision" group based on time of admission, which may have reflected physician reluctance to engage in SDM.²¹

The most recent SDM intervention study in acutely ill children was the 2016 "Patient Choice" trial, in which parents of children with acute uncomplicated appendicitis were counseled on the treatment options and then chose between operative and non-operative management.²² Three-quarters of children whose parents chose non-operative management did not undergo surgical intervention within 1 year, and they had fewer disability days and lower healthcare costs than did the children that underwent surgery. There was neither use of a decision aid nor a description of the SDM process between the parents and surgeons, so it is not clear how SDM occurred.²²

Two large ED-based, clinician-level randomized controlled trials, "Head CT Choice"²³ and "Acute Otitis Media Choice"²⁴ are currently in-progress. "Head CT Choice" is a multicenter trial that compares use of a rigorously developed decision aid with usual care for children with minor head trauma who have 1 or 2 risk factors for clinically-important traumatic brain injury. Outcomes to be assessed include knowledge, satisfaction, and engagement of parents, as well as rates of CT and clinically-important traumatic brain injury.²³ "Acute Otitis Media Choice" compares a decision aid to usual care for the decision to use immediate antibiotics vs. a watch and wait prescription for children with acute otitis media.²⁴

Summary of the Literature

In review of the published English language studies that we identified with our search strategy, there are limited data available to guide SDM in acutely ill children, and only 1 investigation has evaluated the impact of a decision aid on outcomes compared to usual care. Given the limitations of these investigations, it is difficult to evaluate the benefits of SDM in acutely ill children as well as the most effective method to implement SDM with parents in this population. However, published data demonstrate that parents' preferences for testing and/or treatment of acutely ill children vary, and that many want the opportunity to express those preferences through an SDM process. Additionally, use of SDM and/or a decision aid generally results in acutely ill children undergoing fewer and/or less intensive testing or treatment, though the effect on clinical outcomes is unclear.

It is important to put these findings in context with the literature on SDM with parents of non-acutely ill children as well as with adults in the acute care setting. Similar to our narrative review, a 2015 systematic review of SDM in pediatrics found significant heterogeneity of interventions to facilitate SDM and that less than half of SDM interventions for parents and children had been formally studied in randomized controlled trials. The limited outcome data available demonstrated that SDM increased parents' knowledge and reduced decisional conflict, and that it might improve satisfaction.⁵ While the literature is also limited, for adults in the acute care setting SDM is associated with improvements in patients' knowledge, satisfaction, and engagement in decision-making, and with a reduction in healthcare resource utilization without an increase in adverse events.^{13,25}

Future Directions

Large multicenter investigations such as DECISION+2 are necessary to have sufficient power to assess the impact of SDM on outcomes in acutely ill children. Additionally, as with the DECISION+2 decision aid, future investigations should evaluate decision aids developed using the IPDAS criteria. While there is also a role for studies of SDM that do not involve use of a decision aid, these investigations should similarly include an SDM process that is rigorously planned and described so that it can be reproduced.

There are several additional areas for researchers, clinicians, and educators to address. First, none of the studies included in this review assessed parents' preferences based on their level of health literacy. As parents of low health literacy are less likely to feel a partnership with physicians in decision-making,²⁶ it is critical that approaches to SDM for acutely ill children meet the needs of diverse parents who are less prepared and empowered to participate in SDM. Additionally, all of the studies in this review used SDM with parents. Though children have expressed a preference to be involved in decision-making in other settings,^{27,28} there is limited knowledge of SDM with older children and adolescents,^{5,29} including those who are acutely ill. The feasibility and acceptability of involving children in the SDM process should therefore be evaluated.

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Table 1
 Summary of studies that evaluated a shared decision-making intervention with parents of acutely ill children

Study	Population	Age of Children	Participants	Study Design	Intervention	Comparison Group (Yes/No)	Outcome Measures
Yamamoto, 1997 ¹⁴	Children with fever at risk for occult serious bacterial infections	3 mos–3 yrs	37	Observational	Information sheet Tests and Treatment selection (preferences) sheet	No, all parents received the intervention	Parents' preferences for tests and for treatment Testing/treatment performed Return visit to the ED
Yamamoto, 1997 ¹⁵	Children with actual and hypothetical lacerations	6 days–7 yrs	45 with actual lacerations, 94 with hypothetical lacerations	Observational	Information and preferences sheet	No, all parents received the intervention	Parents' preferences for method of local anesthesia and for procedural sedation Interventions performed on children with actual lacerations
Karpas, 2009 ¹⁶	Children with vomiting and/or diarrhea	6 mos–5 yrs	260	Observational	Educational materials Preferences/Values survey	No, all parents received the intervention	Parents' preference for IV vs. PO rehydration Reasons for expressed preference
Légaré, 2012 ¹⁸	Adults and children with acute respiratory infection	Mean: 4.9 yrs. ^a	99 children	Parallel cluster randomized trial	DECISION+2: 2-hour online tutorial, 2-hour interactive workshop, decision aids	Yes, DECISION+2 compared to Usual Care	Primary: Proportion of parents that decided to use antibiotics immediately after consultation Secondary: Decisional conflict Perception that SDM occurred Decisional quality Adherence to the decision Repeat consultation Decisional regret Quality of life Intention to engage in SDM in future consultations
Karpas, 2013 ¹⁷	Children with head trauma	2 yrs	134	Observational	Educational materials Preferences/Values survey	No, all parents received the intervention	Parents' preference for head CT vs. observation Reasons for expressed preference
Rosati, 2015 ²¹	Children hospitalized with community-acquired pneumonia	3 mos–5 yrs	95	Observational	Leaflet on community-acquired pneumonia followed by parents being assigned to a "shared decision" group (i.e. parents made the decision on route of antibiotic administration) or "unshared decision" group (i.e. physician made the decision)	Yes, shared decision group compared to unshared decision group	Satisfaction Route of antibiotic administration (shared decision group) Reason for choice of antibiotic route (shared decision group)
Minneci, 2016 ²²	Children with acute uncomplicated appendicitis	7–17 yrs	102	Observational	Counseling on the treatment options followed by allowing parents to choose between	Yes, Non-operative compared to operative management (i.e. appendectomy within 12 hours of admission)	Primary: Success of non-operative management defined as no appendectomy at 1-year

Study	Population	Age of Children	Participants	Study Design	Intervention	Comparison Group (Yes/No)	Outcome Measures
					non-operative and operative management ^b		Secondary: Proportion that developed complicated appendicitis Disability days Healthcare costs

^a Study included adults and children. Mean age of children (age range not provided)

^b No decision aid used

^c Primary outcome only for children whose parents chose non-operative management

Abbreviations: ED, emergency department; IV, intravenous; PO, per os; SDM, shared decision-making; CT, computed tomography