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An Emerging Field of Research: Challenges in Pediatric Decision Making

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Abstract

There is growing interest in pediatric decision science, spurred by policies advocating for children's involvement in medical decision making. Challenges specific to pediatric decision research include: the dynamic nature of child participation in decisions due to the growth and development of children, the family context of all pediatric decisions, and the measurement of

preferences and outcomes that may inform decision making in the pediatric setting. The objectives of this manuscript are to describe each of these challenges, to provide decision researchers with insight into pediatric decision making, and establish a blueprint for future research that will contribute to high quality pediatric medical decision making. Much work has been done toward addressing gaps in pediatric decision science, but substantial work remains. Understanding and addressing the challenges that exist in pediatric decision making may foster medical decision-making science across the age spectrum.

Introduction

In the last decade there has been growing interest in pediatric decision science, likely spurred by policies advocating for children's involvement in medical decision making. (1, 2) In order to continue such growth, challenges specific to decision research in a pediatric context need to be understood and addressed. First, the on-going growth and development of children means that participation of the child in the decision process is dynamic. Because of this, understanding the family context and the roles of all decision stakeholders, including the patient, parent and provider, is vital to high quality pediatric medical decision making. Moreover, aspects of development and the involvement of multiple stakeholders also create challenges for measuring health state preferences. Finally, measurement of outcomes that may inform decision making requires special consideration given the rarity of many pediatric health-related events and the long time frame over which such events may occur. Understanding and addressing the challenges that exist in pediatric decision making may foster medical decisionmaking science across the age spectrum. Our objective in this manuscript is to provide decision researchers with insight into pediatric decision science and to establish a blueprint for future research that will contribute to high quality pediatric medical decision making.

Decision Participation and the Developing Child

In order to understand the challenges of pediatric decision making, the developmental context of child and adolescent medical decisions requires consideration, including biological, cognitive, psychosocial, and contextual variables. (3) From an early age, children can participate in medical decision making in developmentally appropriate ways, such as expressing an opinion or concern about the decision to be made. (4–7) Although empirical data are limited, some have hypothesized that such involvement teaches children what factors to consider when making decisions, the potential outcomes of different decisions, and the communication skills needed to participate in decision making. (8, 9) As early as age nine children can begin to make informed treatment decisions and by the time they are adolescents many have developed decision making competence: including the abilities to reason, to understand treatment options and to express reasoned preferences. (10, 11) However, psychosocial and developmental variables, such as family structure, impulse control and the ability to see long-term consequences of ones' decisions, influence decision making and continue to develop well into the mid-20s. (12) Other contextual variables, such as cultural expectations, may also influence the development and practice of decision-making skills. (13) This may be why, even if they ultimately disagree, children and

adolescents often seek their parents' input into health-related decisions and such decisions continue to be influenced by parents into young adulthood. (14–17)

Children's evolving skills and interest in decision participation present a unique set of challenges to pediatric decision making. For example, in the case of disagreement, it is generally clear that the parent's decision will prevail when the child is younger. (18) However, adolescents are more likely than younger children to believe that they should have final decision making authority. (19) Overall, collaborative decision making between parents and children can be viewed as part of normative development that precedes full decision-making autonomy. (8, 9)

The Family Context

Patients of all ages experience health and illness in the context of their lives with family. Supporting decision making in the context of families presents some specific challenges for both healthcare providers and researchers. One challenge is communication between and among multiple stakeholders, especially when each stakeholder, including patient, parent and provider, may view the options and value specific attributes differently. (20) For example, research about medication decision making for children with chronic conditions has shown that parents and adolescents may have different perspectives on the same decision. (21–24) Moreover, both may be influenced by others in their community, not traditionally considered stakeholders in medical decision making, including family, friends and school personnel. (23, 25, 26)

In addition to identifying such influential stakeholders, another challenge is engaging family members and other stakeholders in collaboration early in the decision-making process. Children, adolescents, parents, and physicians all have a range of behaviors that can facilitate or constrain collaborative decision making. (27–31) Constraining behaviors include interrupting, passive involvement of parents or children and limiting opportunities for others to speak. On the other hand, facilitating behaviors may include focusing on relationship building, information gathering, looking directly at the patient and rephrasing of questions. Exploring reactions to specific decisions, and discrepancies in how parents and children are responding, may be another way for providers to support children and parents and enhance their participation in the decision-making process. (32)

The family context can be profoundly impacted by a child's health. The effect of a child's illness on a caregiver's quality of life can be partially attributed to effects on the physical health of the caregiver. (33, 34) However, there is evidence that the illness of a family member has substantial effects on a caregiver's quality of life beyond the physical impact of caregiving and that illness also affects family members who have less of a role in caregiving. (35) Such spillover effects can be related to both the physical effects of caregiving as well as the emotional effects of having an ill family member. (36) The magnitude of these quality of life effects for caregivers and other family members has not been well-documented and the literature shows that spillover varies by condition and relationship. (37) Such effects are important outcomes to consider for pediatric decision

making. Further exploration of how these effects are influenced by the age and other traits of the patient is needed.

Pediatric Decision Research Opportunities within the Family Context

A barrier to rational decision making for parents, as well as other stakeholders, is the emotionally charged nature of many medical decisions. (38) The challenge for decision researchers is to leverage the emotions inherent in the parent-child relationship to facilitate high quality decision making. Some researchers have discussed parents' impulse to make a decision that a "good parent" would make. (39) Better understanding this and other emotional reactions to decision making will aid in the development of interventions that help parents process the emotions involved in decision making. Decision tools may need to explicitly discuss emotions, and values elicitation exercises may need to account for situations where the evidence and values are at odds, (40) as well as where there is disagreement among stakeholders. This is particularly important in the context of adolescents as there is little data indicating how parents, adolescents, and providers manage disagreements or how developing decision-making skills may facilitate successful transition to adult healthcare. (41)

Future research that builds upon what is known is essential to the growth of collaborative decision making in pediatrics. In one setting, interactive decision aids have been shown to increase physicians' success in involving parents in decision making, (42) but more such trials are needed. Observational studies have identified other potential ways to increase child involvement, including the physician gazing at the patient when asking questions (31) and parents offering fewer utterances during encounters. (29) Future studies with detailed analysis of verbal and non-verbal aspects of communication may define approaches to optimize parent and child involvement in decision making. (43)

Of course, there are times when parents are called upon to make health decisions for, rather than with, their children. In this setting, pediatric decision science offers an opportunity to examine the complexity of surrogate decisions. Surrogate decision making in adults has largely focused on making decisions for elderly relatives. (44) However, making decisions for a child may be quite different. For example, it is difficult to know "what the child would do" in contrast to an elderly relative for whom there is knowledge of past decisions and, ideally, prior discussions and legal documents to inform medical decision making.

Perhaps for this reason the prevailing framework in pediatric surrogate decision making, in many places, has been to focus on "best interests". (1, 7) This framework has its own complexities, in particular stakeholders may not all agree on which choice is in the child's best interest or how to balance the interests of multiple children. (7, 45) Other frameworks may also be considered as possible guides for pediatric decision making. For example, some suggest that a goal of decision making should be ensuring the maximal likelihood of reaching one's potential or self-fulfillment. (46, 47) Likewise, different cultures may depend upon different guiding principles for decision making. (2) While some are focused on best interests, others may be based in other traditions such as those that strive to make harmonious decisions within the context of a family. (48) More work is needed to

understand the dynamic nature of surrogate decision making across the life span, but particularly in pediatrics where prior research from adult health settings may not apply and decision frameworks may still be evolving. (26)

Measuring Outcomes of Pediatric Medical Decisions

One of the central problems for pediatric decision researchers is the paucity of high quality outcomes research to inform decisions, partially related to specific aspects of pediatric medicine. Studies of adult health care quality and outcomes have often focused on acute, life changing events such as newly recognized diabetes, stroke, myocardial infarction, or death. (49) In contrast, morbidity, mortality and chronic conditions are less common in pediatrics and adverse health events often lag health-related behaviors by many years, making such acute outcomes inadequate for measuring health or health care delivery. (50, 51) Moreover, many common pediatric health interventions, for example vaccination, are focused on preventing rare events across a population, such that measurement of effectiveness on an individual level may be insufficient. (50) In addition to the medical challenges, child health status, much like that of adults, is shaped by events outside of the medical settings, including academic performance or peer interaction in school settings. (52) For children, data on outcomes in these settings are often unavailable to providers and researchers unless provided by parents, a process that is highly variable across families and medical practices. (52)

A child's ability to provide outcomes data varies by age and developmental stage. (53) Parent proxy reporting of outcomes is an option, but parents or other caregivers may honestly disagree, complicating measurement. (53) In addition to potential disagreement among caregivers, there are challenges related to their ability to be proxy reporters for children's health outcomes. Numerous studies have revealed that parents serve as poor proxy reporters for many aspects of a child's health-related quality of life. (54, 55) Moreover, studies comparing child and parent proxy reports show weak agreement for quality of life, (56) mental health (57, 58) and health state utility measures. (59–61)

Moving Forward: A Research Agenda

In recent years progress has been made towards addressing the challenges in pediatric decision making. Research has begun to address the family context of decision making, including child and adolescent participation, but substantial work remains. Specifically, a more complete understanding of the effects and the means of increased child participation in decision making, including the role of age and developmental stage, is sorely needed. In the family context of pediatric decision making, new models of collaborative decision making that are adaptable to children of different ages and flexible enough to accommodate multiple decision stakeholders and cultural variations should be developed. Similarly, preference elicitation could be restructured as a process that includes multiple family members' input. By partnering with our colleagues who conduct work in the geriatric context, we may gain a better understanding of the skills needed for high-quality surrogate decision making across the age spectrum.

As discussed, accurate measurement of preferences related to pediatric medical decisions is made difficult by a lack of tools and by the sometimes poor agreement between parent and

child measures. We propose two possible approaches to this dilemma. First, by increasing parent and child participation in decision making, agreement may improve using existing outcomes measures. Careful research that simultaneously engages family members and measures preferences may provide insight to the relationship between engagement and preference agreement. A second possibility is that parent-child agreement, regarding outcomes and preferences, may not be the appropriate goal at all, particularly given varying cultural constructs related to decision making and family structure. (2, 47, 48, 62) New measures or methods that account for differing perspectives of the parent and child are needed.

The lack of solid outcomes data is a problem without an easy solution. Robust secondary database analyses and more rigorous controlled trials in the pediatric context are obvious long term goals. And yet, for decision researchers, the challenge is to optimize decision interventions based upon what we know now. This may mean creating tools with more “room” for parent and family participation. Examining how parents and providers can make decisions in the absence of clear medical evidence should be a research priority, given the lack of evidence that exists to guide decisions for many pediatric conditions.

More work is needed from across decision sciences to improve the understanding of pediatric medical decision. The decision science research community can support such work by understanding the inherent differences between adult and pediatric decision research, supporting the need to do research in pediatrics even when the answer is “known” in the adult setting and helping to develop decision frameworks that include or can be adapted for pediatric settings. Considering the recent rapid growth of both decision and pediatric research, we anticipate that the coming years will see a remarkable growth of pediatric decision research. In turn, such research will lead to improved family decision making, and better pediatric outcomes.

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