

Attitudes Towards Involving Children in Decision-Making Surrounding Lung Transplantation

Emily Barsky¹, Laura Berbert², Suzanne Dahlberg², and Robert Truog²

¹Children's Hospital Boston

²Boston Children's Hospital

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Abstract

Background: Medical care has shifted from a paternalistic model towards one centered around patient autonomy and shared decision-making (SDM), yet the role of the pediatric patient in decision-making is unclear. Studies suggest that many children with chronic disease are capable of participating in and even making medical decisions at a young age, and yet we do not standardly involve them. Methods: This is a single center survey study investigating physician attitudes towards involvement of children in decisions regarding lung transplantation, utilizing a hypothetical case scenario with systematic manipulation of age and maturity level. We evaluated physician belief regarding ultimate decision-making authority, attempts at reconciliation of parent-child discordance, and views towards utilizing ethics and psychiatry consultation services. Results: The majority of pediatric pulmonologists believe decision-making authority rests with the parents. The effects of age and maturity are unclear. In instances of parent-child disagreement, physician are more likely to try to convince parents to defer to the child if the child is both older and more mature. Physicians are divided on the utility of ethics and psychiatry consultations. Conclusion: Involvement of children in shared decision-making is broadly supported but poorly implemented. Despite evidence that children with chronic disease may have decisional capacity starting at a young age, the majority of physicians still grant decisional authority to parents. There are numerous barriers to involving children in decisions, including legal considerations. The role of age and maturity level in influencing these decisions appears small and warrants further investigation.

INTRODUCTION

The model for medical decision-making has fundamentally shifted over time. Dating back to the Hippocratic Oath, paternalism was deep-seated in medical care for centuries.¹ However, the rights-based movements in the 1960s led to a shift towards patient-centered care.² Autonomy became a founding principle of bioethics and dominated decision-making.³ Following these two extremes, bioethics has attempted to find a middle ground in the 21st century, by embracing the concept of shared decision-making (SDM).⁴ Herein, physicians and patients work together to optimize decision-making by utilizing the values and preferences of patients and families.⁴⁻⁶ Currently in the United States, patients are generally felt to have the ultimate autonomy to make value-based medical decisions.

Pediatric patients have a less active and more ill-defined role in decision-making. Parents or legal guardians generally make medical decisions for children under the age of 18 in the United States, while pediatric competency is determined on a case-by-case basis in Canada and Switzerland.^{7,8} Although emancipated minors and mature minor doctrines do exist, they are rare exceptions rather than the norm, and this status is rarely granted to preadolescents. While pediatric assent exists and is encouraged, it is usually not required for treatment under age 14, nor is it required for procedures or treatments deemed medically necessary. Assent and dissent carry little weight, thus attesting to the lack of standardized involvement of pediatric patients in decision-making.

However, many preadolescents and adolescents, particularly those with chronic disease, may be competent to make medical decisions. Pediatric decisional competency varies widely, and depends not only on age, but also on maturity and cognitive ability.⁹⁻¹¹ Furthermore, the presence of chronic illness results in improved medical decision-making competency. Children with chronic disease have an increased understanding over healthy peers and even some adults.^{7,12-14} Moreover, in chronic illness, medical decisions often hinge on questions of values and quality of life, rendering it even more important to involve children in these decisions.

The decision to pursue or forego pediatric lung transplantation for end-stage lung disease is one example of the complex decisions that parents make for their children. It is personal and value-laden, and varies considerably from family to family. Attitudes towards involving children in these discussions is unclear. This renders it an exemplary decision to study in the context of pediatric involvement in SDM.

In this study, we aimed to investigate physician attitudes towards involving children in decision-making surrounding lung transplantation.

MATERIALS AND METHODS

Design

This was a quantitative and qualitative cross-sectional survey conducted between January 2019 and March 2019. The study was granted exemption from the Boston Children's Hospital Institutional Review Board (IRB-P00030423).

Setting

Single-center study conducted at Boston Children's Hospital.

Participants

29 pediatric pulmonary physicians at Boston Children's Hospital in Boston, MA. Subjects were included if they were attending physicians or fellows and involved in pediatric pulmonary clinical care.

Exposures

Survey Format

Study subjects were invited to participate in an online survey. Non-responders were sent two reminder emails. The survey was anonymously conducted through Survey Monkey. No participation reward was offered.

Case scenarios and decisional factors

Baseline, hypothetical case scenarios were created, describing a female patient with cystic fibrosis (CF) and end-stage lung disease, facing the decision of whether or not to pursue long transplantation. The patient had a Forced Expiratory Volume in the first second (FEV1) of 20 percent predicted, a rapid decline in lung function, and numerous hospitalizations in the preceding year. She had respiratory insufficiency necessitating nocturnal bi-level positive airway pressure (BiPAP) and daytime supplemental oxygen. The patient was developmentally age appropriate. Her disease progression necessitated a decision regarding whether or not to proceed with lung transplantation. The physician in the scenario had been the patient's primary pulmonologist since infancy, and shared a close relationship with the patient and family.

Four case scenarios were generated by dichotomous systematic manipulation of two factors: patient age and maturity level. These decision factors were chosen given evidence that they are important in pediatric decision-making competency.⁹⁻¹¹ They were presented at two levels. The patient's age was either a pre-adolescent of 11 years old, or an adolescent of 16 years old. Maturity level was represented by whether or not the child performed the majority of her self-cares and asked thoughtful questions regarding her disease. These surrogate measures for maturity level were chosen based on CF R.I.S.E (Responsibility, Independence, Self-care, Education), a toolset widely utilized in assessing developing care independence in patients with CF.^{15,16} All content other than age and maturity was identical across the four scenarios. The four clinical scenarios were presented in randomized order. An example case scenario is as follows:

*Anna is an **11-year-old** female with end-stage cystic fibrosis, FEV1 of 20% predicted. She has had numerous hospital admissions over the last year and a rapid decline in her lung function. She is on nocturnal BiPAP and daytime supplemental oxygen. Given her disease progression, it is time to decide whether to proceed with lung transplantation. **Anna is responsible for the majority of her self cares and she asks thoughtful questions of her parents and providers regarding her disease.** She is developmentally age appropriate. You have been Anna's primary pulmonologist since infancy. You have a close relationship with her and her family. Anna and her parents have already met with the transplant team, and she is likely a candidate. They are deciding whether to proceed with listing for lung transplantation.*

Survey Question Format

Baseline data collected in the survey included respondent's age, gender, and seniority. Each case scenario was then followed by a series of six questions, unchanged across the four scenarios. Study subjects were asked to answer all questions as they would in their own clinical practice. Answer choices were dichotomized or measured on a Likert scale. Questions investigated who had the ultimate decision-making authority between the patient and the parents, how parent-child conflict might be resolved, and utilization of ethics and psychiatry consultation services (Appendix 1). Following the four case scenarios, an optional, qualitative question asked study respondents to write a few sentences describing their scenario responses.

Main Outcomes and Measures

The primary outcome was physician attitude regarding pediatric decision-making authority as influenced by patient age and maturity level. The hypothesis formulated prior to data collection was that the majority of physicians believed parents held decision-making authority surrounding transplantation, but that this would be inversely related to patient age and maturity. Secondary outcomes included physician views on attempting reconciliation of parent-child conflicts of opinions regarding the pursuit of lung transplantation, provider initiative to determine the opinion of the pediatric patient, and views towards utilizing ethics and psychiatry consultation services to reconcile conflicting opinions.

Statistical Analysis

Descriptive statistics were used to summarize all baseline demographic and outcome variables. Differences in the distribution of responses across the four scenarios was tested using Cochran's Q test. In the event that this test was significant at the two-sided 0.05 level, all pairwise comparisons ($n=6$) of the results from the 4 scenarios were made using McNemar's test while testing at a Bonferroni-adjusted $0.05/6 = 0.0083$ level.

RESULTS

Response Rate

The survey was distributed to 29 pediatric pulmonary physicians at Boston Children's Hospital. Twenty respondents (69%) completed the survey.

Baseline Demographics of Responders

The baseline characteristics of the respondents can be found in Table 1. Approximately half of the respondents were attending physicians, and approximately half were female (Table 1).

Decision-Making Authority

The majority of the physicians surveyed (65%) believed that, across the scenarios, decision-making authority regarding lung transplantation rests with the parents. A minority of physicians (5%) believed that the child had the ultimate decisional authority in all scenarios. Only 30% of physicians altered their responses based on age and maturity level. Half of these physicians felt the patient held decisional authority if she was older, independent of maturity level. There appeared to be significant differences across the four scenarios varying age and maturity level (Cochran's Q $p = 0.008$), but there was no significant difference between any of these individual subgroups with regards to the effects of either age or maturity level. Nonetheless, the data suggest a trend towards an effect of age but not maturity level in decisional authority, which was granted to the

parents of a mature and immature 11-year-old by 95% and 90% of physicians respectively, in comparison to 70% of physicians when the child was 16 years old irrespective of maturity (Figure 1).

Decision-Making Deference

If there was disagreement between the child and her parents regarding whether to proceed with lung transplantation, physicians were asked whether they would try to convince the child and/or the parents to defer to the other party. There was a difference across the four scenarios both with regards to deferring to the parent (Cochran Q's $p = 0.03$) and deferring to the child (Cochran Q's $p = 0.0002$). There was a statistically significant increased rate of trying to convince the parents to defer to the child's preferences for a mature 16-year-old versus an immature 11-year-old (80% vs. 30%; McNemar $p = 0.0016$) (Figure 2). While no other significant differences were found, there was a trend towards variation both by maturity and age in terms of attempts to convince one party to defer to the other (Figures 2 and 3).

Assessment of Patient Preferences

The majority of physicians (80-95%) felt they would ask to speak to the patient privately in order to assess the child's preferences regarding lung transplantation, with no significant difference across the four scenarios (Cochran's Q $p = 0.07$). Only a small minority of physicians (15%) altered their response based on either age or a combination of age and maturity level.

Consultation Service Utilization

In instances of parent-child disagreement, 65% of physicians felt either somewhat or very likely to obtain an ethics consultation (Figure 4). Age was only a consideration for 10% of physicians, and a combination of age and maturity was considered in 15% of patients. 58% were somewhat or very likely to obtain a psychiatric consultation to evaluate the child's decision-making capacity (Figure 4). A minority of physicians (40%) altered their responses based on age and/or maturity, with consideration of only age in 10% and a combination of age and maturity in 25% (5% did not follow a discernable pattern).

Qualitative Responses

The final survey question asked the respondent to describe his or her responses to the scenarios. Thirteen physicians (65%) completed this. There were a few common themes that emerged. First, respondent's viewpoints were often guided by legal age-related constraints. Second, there was a tension between the legal decision-making authority and a desire to grant the child decision-making capacity in certain contexts. Third, many viewed their position as one of reconciling between the various stakeholders and attempting to come to an agreement. The following excerpts from respondents illustrate these themes:

"The age of majority is 18 - regardless of "who is the major decision maker, parents or children" legally the parents have the final say until age 18." "I believe in all of the scenarios that currently the parents are the final decision makers based upon age. However, my opinion is that regardless of age, if Anna understands the components of the procedure, is able to describe the risks/benefits and is involved in her own care, that she should be eligible to make her own decisions. Although legally she is still a minor, I believe the criteria listed above would demonstrate understanding of the procedure and should allow for her to give informed consent regarding her medical decision making." "Rather, my role in shared decision making is to try to help them have the opportunity to share their thoughts and feelings, find common ground, and determine the best course of action for the patient given their goals."

These common themes highlight many of the challenges of implementing pediatric SDM.

DISCUSSION

In this single center cross-sectional survey, we found that the majority of pediatric pulmonologists believe that decision-making authority regarding pediatric lung transplantation rest with the parents rather than the child, irrespective of age and maturity level. There appeared to be a difference across the four scenarios with varying age and maturity level, but we could not fully determine the role that age and maturity played.

When the parent and child disagreed, some physician respondents would try to convince parents to defer to the child, but a minority would try to convince the child to defer to the parents. The influences of age and maturity level warrant further inquiry. The respondents were divided on the utility of ethics and psychiatry consultations.

To our knowledge, this is one of the first studies exploring subspecialty physician attitudes towards involving children with chronic lung disease in decision-making in the United States. This is an important and understudied area. The lack of significant results is likely due to the small sample size and resulting underpowering. Nonetheless, it suggests a great need for further exploration and understanding. This study suggests the presence of several significant challenges to pediatric shared decision-making.

There is national and global consensus regarding the importance of involving children in decision-making, yet implementation lags far behind. Pediatric SDM is endorsed by regulatory organizations including the American Academy of Pediatrics.^{5,17,18} Use of SDM in pediatrics is understudied.¹⁹ The limited existing evidence suggests that pediatric involvement in decision-making is beneficial to patients, through facilitation of understanding and self-confidence, increased trust and decreased fear and anxiety, and improved care.^{5,20-23} Furthermore, utilizing parents as surrogate decision-makers can be flawed, as parental decision is subject to many external influences such as impact on other family members, religious or cultural views, and emotional state, hence furthering the importance of involving children in these decisions.^{5,24} Unfortunately, despite the evidence for and support of involving children in medical decision-making, neither the nature of participation nor the practical implementation is clear.²³ SDM in pediatrics is even more complex than in adults, due to the triad of stakeholders (the physician, the patient, and the parents), variability in the child's development, and legal stipulations.^{25,26} The net result is that children are minimally involved in decisions.^{18,27-30}

This study addresses beliefs regarding pediatric SDM and barriers to it, from the perspective of one of the key stakeholders: the physician. This is an essential step in improving implementation. In this study, we identified three main barriers. First, despite the general consensus from regulatory boards to empower children to make decisions, many physicians feel conflicted and restricted by legal age-related constraints. The majority of respondents felt parents held decision-making authority because the child was under 18. Especially with younger children, physicians tended not to place significant weight on the viewpoints of children and viewed parents as the ultimate decision-makers. Second, age played some role in impacting views towards involving children in decisions, but maturity, as one important component of competency, played a very limited role. Third, physicians appeared to struggle with the process of shared decision-making, assessment of competence, and how to address conflict, yet despite this, many would not seek out assistance from ethics or psychiatry consultants.

The literature confirms these barriers. First, the legal framework renders involvement of children in decisions unclear and potentially problematic. Legally, children do not hold decisional authority under the age of 18, with the exception of emancipated minors. Furthermore, regulatory agencies reinforce the parental duties to protect children.¹⁷ Yet simultaneously, they recommend giving “due weight” to the child's preferences.¹⁷ Many legal cases have granted prevailing rights to minors, particularly in instances of treatment refusal, suggesting the decision-making cutoff of 18 years of age may be less firm than perceived.³¹⁻³³ The legal context may cause many providers to feel conflicted about encouraging pediatric patients to make decisions.

The literature also demonstrates the undue weight placed on the age of the child, and the failure to appropriately take other factors into consideration such as maturity. It is commonly assumed that ability to participate in or make decisions is age-dependent in pediatrics, and yet age is an inaccurate predictor of capacity.^{23,26} Furthermore, an age-based model fails to take into consideration many important factors such as the child's clinical situation, developmental stage, cognitive ability, maturity level, preferences, and the family situation, despite recommendations to do so.^{9,11,22,23,28,34,35}

Third, clinicians are not adequately equipped to assess competence or implement SDM. Clinicians are likely underestimating the competency of children, particularly of those with chronic disease.²⁸ Furthermore, there is a false assumption that competency is directly dependent on age rather than being a fluid concept.²⁶

Competency assessment is complex in children, and involvement of children in decisions requires adaptation to the child's varying needs and developmental level.^{25,26} Tools to assist in this are lacking.^{21,23} Without the skills and training required to perform pediatric SDM, implementation will remain limited.^{25,28}

Additional barriers to involving children in SDM reported in the literature include power concerns, concern for the child and parents' emotional states, inadequate communication skills, and insufficient time to properly involve children in decisions.^{23,25,36,37}

Children with cystic fibrosis serve as an important case study with which to assess pediatric shared decision-making and its barriers. First, their cognitive abilities are preserved, and studies have clearly shown increased competency in children with chronic disease, possibly due to their experience with illness and their interactions with parents and clinicians.^{7,12-14,38} As a result, children and adolescents with CF should have increased involvement in decisions. Second, from a physician standpoint, there is evidence that those caring for children with severe or chronic illness are more likely to involve them in decisions due to improved training in communication.^{39,40} Third, the relationships between physicians, patients, and families are often long-term, which can facilitate knowledge of the family's goals and values and thereby facilitate shared decision-making (Barry).⁶ Fourth, care decisions such as whether or not to pursue lung transplantation, are value laden and would benefit from SDM the most. However, despite this, evidence suggests that clinicians are less likely to involve children in high stakes decisions.^{23,25} Lastly, given the increasing life expectancy in CF and other chronic diseases, there is an essential emphasis on promoting patient ownership of care and preparing for the transition to adulthood.^{41,42} Yet even in this population, ripe for pediatric involvement in shared decision-making, our study found that the majority of pulmonologists would grant decisional authority to the parents, even in the instance of an adolescent with signs of maturity and care ownership.

Interventions aimed at improving pediatric involvement in SDM are understudied.²⁵ In fact, within the CF population, a 2019 Cochrane review attempting to evaluate interventions for promoting SDM in children with CF yielded zero randomized control trials.²¹ Decisional aids, which help to inform patients about their options and align decisions with values, have been quite effective in adult SDM but similar studies in pediatrics are lacking.^{6,34,43} The dearth of research in this area is staggering, and points to the desperate need for continued investigation of both the barriers to implementing pediatric SDM, and interventions to assist in the implementation.

Limitations

This study has several limitations. First, the hypothetical case used may not accurately reflect physician attitudes and action in clinical practice. Second, survey questions are open to respondent interpretation, and the limited qualitative data limits interpretation. Third, the study format risks selection bias based on survey completion, although the response rate of 69% is acceptable. Fourth, the sample size of physicians was small and restricted to a single center. This resulting in the inability to detect many significant effects, despite suggestion of several trends, significantly limiting the findings and the generalizability. Fifth, the study was very limited in scope. It evaluated only one chronic disease, and only one clinical scenario within this. As a result, the broader implications outside of CF and chronic illness in general, are not entirely clear. Lastly, this study only evaluated physician beliefs towards pediatric shared decision-making, and did not address the views of pediatric patients or their parents. Nonetheless, it is an important first step in identifying physician barriers towards pediatric shared decision-making, and it may be applicable to many other populations.

Future directions

There is a great need for further research in this area. This research ought to be expanded with a larger sample size to further clarify the effects of age and maturity level and to evaluate for replicability across care centers, disease states, and pediatric specialties. Physician preparedness to assess competency and implementation of shared decision-making also warrants investigation, and may shed additional light on this topic. Furthermore, assessing clinician attitudes towards pediatric involvement in decision-making in chronic disease is only one component in identifying barriers to pediatric SDM and increasing implementation.

Further investigation of the attitudes of the children and their parents is also warranted. Lastly, there is a need to investigate potential interventions, such as decisional aids, in helping to promote the implementation of SDM in pediatrics.

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