

Ethics of Pediatric and Young Adult Medical Decision-Making: Case-Based Discussions Exploring Consent, Capacity, and Surrogate Decision-Making

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Abstract

Introduction: Most medical decisions in pediatrics involve surrogate decision-makers. Because of this, pediatricians are even more likely to encounter ethical conflicts and dilemmas surrounding medical decision-making. Pediatricians continue to report a lack of preparedness to manage situations when conflicts and dilemmas arise, suggesting a gap in education. In response to this gap, we developed a module on the ethics of medical decision-making focused on pediatrics. **Methods:** The Ethics of Pediatric and Young Adult Medical Decision-Making module included three case-based, small-group sessions on decision-making capacity and advance directives, parental decision-making, and informed consent and adolescent assent. Session materials were developed based on expert opinion and previously published content. Sessions were developed for pediatric residents; however, medical students rotating on pediatrics also participated in most sessions. Trainees completed pre- and postsession assessments of comfort and understanding. **Results:** An average of 19 learners completed each session. Understanding of ethical principles increased after each session. Seventy-nine percent of trainees reported increased understanding of ethical principles related to decision-making capacity, and 88% reported increased understanding of standards of surrogate decision-making. Following the session on obtaining consent and assent, 71% of trainees reported comfort obtaining consent compared to 57% reporting comfort obtaining assent. **Discussion:** This module successfully increased trainee comfort with many ethical issues related to pediatric medical decision-making. Areas where trainee comfort was still low postsession—specifically, obtaining consent or assent—are content areas where actual practice of these psychomotor skills is likely necessary.

Keywords

Pediatrics, Medical Ethics, Ethics, Bioethics, Medical Decision-Making, Ethical Principles, Principle-Based Ethics, Capacity, Surrogate Decision-Making, Informed Consent, Assent

Educational Objectives

By the completion of this module, the learners will be able to:

1. Describe the necessary components of decision-making capacity.
2. Report increased understanding of the ethical principles of parental decision-making.
3. Report increased comfort obtaining informed consent and adolescent assent.
4. Describe an initial approach to managing ethical conflicts and dilemmas surrounding medical decision-making.

Citation:

deSante-Bertkau J, Herbst LA. Ethics of pediatric and young adult medical decision-making: case-based discussions exploring consent, capacity, and surrogate decision-making. *MedEdPORTAL*. 2021;17:11094. https://doi.org/10.15766/mep_2374-8265.11094

Introduction

Surrogate decision-makers are advocates for patients who are unable to make decisions for themselves or who lack decision-making capacity. In most situations, this includes patients under the age of 18 as well as some young adults with developmental disabilities or neurologic impairment. Because of this, pediatricians are often confronted with ethical conflicts or dilemmas related to assessing a patient's capacity, involving a child in medical decision-making, and evaluating a parent's surrogate decision-making.

Since 1987, ethical decision-making has been part of the American Board of Pediatrics (ABP) Certifying Exam.¹ Physicians face ethical challenges, and the Accreditation Council for Graduate Medical Education (ACGME) recognizes that trainees should demonstrate adherence to ethical principles as a component of professionalism.² In 1997, the ACGME began requiring a structured

curriculum in medical ethics for all pediatric residency programs.³

Despite these requirements, surveys of pediatric residency program directors have revealed significant variability in how ethics and professionalism are taught in pediatric residency programs.^{3,4} Some of the most recent data include a 2009 survey of pediatric program directors in which 80% of respondents reported using lectures to teach ethics and 72% used seminars based on real cases. However, only 29% of respondents reported being knowledgeable about the topics covered in their ethics curricula.³ A 2013 survey of pediatric program directors demonstrated that many respondents were unaware of resources for teaching ethics and professionalism.⁴ Additionally, curricula are geared to small-group discussions with individual facilitators, placing a higher burden of work on faculty. Given the dependence on faculty support, it is not unexpected that many recent residency graduates report gaps in their ethics education in training.^{5,6}

In 2017, the General Pediatrics Content Outline for the in-training examination specifically called out the ethics of medical decision-making as a content area for testing.⁷ This domain includes critical concepts such as capacity, informed consent, adolescent assent and dissent, parental permission, and standards of surrogate decision-making for pediatric patients. These ethical concepts and frameworks are encountered by pediatricians in their daily practice. Unfortunately, this aspect of medical ethics has also been identified as an educational need, and despite how common these issues are, they can become a topic of moral distress when clinicians feel unprepared to handle them. Educators and learners in multiple medical specialties have identified ethics of medical decision-making as an area where further education is desired.⁸⁻¹⁰ One survey of young pediatricians reported that 93% of respondents encountered ethical issues related to consent for and with minors after training.⁵ A survey of recent pediatric residency graduates reported levels of confidence or extreme confidence as low as 33% when addressing issues of adolescent dissent.¹¹ This reported discomfort is supported by data indicating a knowledge gap. A survey of recent pediatric residency graduates found that only half of respondents could correctly answer questions on assent and parental permission.⁶ A test of ethics knowledge in neonatology given to medical learners and clinicians of varying levels of training revealed that informed parental permission and surrogate decision-making were one of the lowest scoring areas, with multiple questions receiving less than 40% correct responses.¹²

While there are ongoing efforts to increase ethics training, including the ethics of medical decision-making, in pediatrics, there remains a lack of published curricula to bridge this gap. In 2011, the American Academy of Pediatrics (AAP) published a case-based bioethics teaching guide for pediatric residents.¹³ The curriculum includes sections on Informed Consent and Assent in Pediatrics, Minors as Decision-Makers, and Pediatrician-Parent-Patient Relationship: Obligations of Veracity, Fidelity, and Confidentiality.¹³ However, the utilization and efficacy of this curriculum are largely unstudied, and it does not provide a rigorous framework for implementation. Additionally, other published curricula on pediatric ethics concentrate primarily on the integration of the ethical principles of beneficence, nonmaleficence, autonomy, and justice into pediatric practice^{14,15} but do not directly focus on medical decision-making. Current published curricula on the ethics of medical decision-making and capacity center on older adults as opposed to young adults with cognitive impairment.^{16,17} The same holds true for content focused on performing informed consent, and therefore, the concept of pediatric assent is not addressed.^{18,19} In addition, several of these published curricula utilize standardized patient encounters,^{15,18,19} which can be too time intensive or costly to integrate into some residency programs.

The Ethics of Pediatric and Young Adult Medical Decision-Making module is part of a longitudinal, interactive Palliative Medicine and Medical Ethics curriculum embedded within our institution's broader 18-month pediatric residency morning-report curriculum that provides at least two opportunities for residents to receive the content during the course of their residency. This module is an introduction to the broad topic of ethics of medical decision-making in specific pediatric clinical scenarios. The module, as well as the broader curriculum, addresses both the gaps in training and comfort reported by pediatricians and pediatric trainees and the dearth of published curricula and ethics resources. The module has been successfully implemented during a traditional morning-report structure. Modules dedicated to the ethics of medical decision-making in the pediatric population are an important contribution given how frequently such issues are encountered in clinical practice.

Methods

Curriculum Design and Implementation

The Ethics of Pediatric and Young Adult Medical Decision-Making module was built up utilizing Kern's six-step approach to curriculum development.²⁰ Members of the residency leadership were engaged in the concept design and provided us with nine morning-report sessions, with one occurring every other

month, throughout the residency curriculum to offer a specialized curriculum regarding palliative care and medical ethics. Each morning-report session was 45 minutes in length and utilized a small-group, case-based format that had been successfully employed for other content areas within the residency curriculum. We utilized the AAP Bioethics Residency Curriculum¹³ and expert opinion to develop each individual session.

All pediatric residents who were on day shifts for inpatient rotations, as well as those on inpatient-based electives, were expected to attend morning report each day. Additionally, medical students completing their third-year inpatient pediatric clerkship or acting internship in pediatrics were expected to attend. While attendance was mandatory, the residency program understood that acute patient care needs might inhibit the ability of residents to attend each morning-report session.

Module Content and Organization

The module included three sessions: Decision-Making Capacity and Advance Directives (Appendices A-C), Parental Decision-Making (Appendices D-F), and Informed Consent and Adolescent Assent (Appendices G-I). Our sessions were presented to all medical students and residents currently on pediatric rotations and followed the same general format. To prepare for each session, the room was arranged in tables divided by learners' current rotation to provide an environment where trainees of varying levels were mixed into groups of six to 10. An attending physician with certification as a health care ethics consultant provided the content and facilitated all sessions. The instructor directions (Appendices B, E, and H) supplemented the PowerPoint content so that attending physicians without dedicated ethics training could provide the material. Surveys were distributed at each seat prior to the start of each session; a presession survey was completed prior to the start of each session, and a postsession survey was completed at the end of each session (Appendices C, F, and I). Each session included two breakout portions where the senior resident(s) at each table led small-group discussion for 5-10 minutes. Following each session, the facilitator guided large-group discussion and provided feedback or clarification on ethical concepts for an additional 3-5 minutes. Sessions could be completed in any order or individually based on the needs of the trainees.

The first session was constructed to teach learners how to assess decision-making capacity and how advanced directives can be utilized in the clinical setting. The instructor used the PowerPoint slides (Appendix A) to deliver a 45-minute interactive didactic (facilitator notes in Appendix B). The session reviewed a case where decision-making capacity was unclear and provided the

trainees with guidance on how to determine capacity as well as resources to help if capacity was unclear. Additionally, the session focused on the benefit of completing advance directives. This session may be less applicable for care settings that do not include any patients age 18 or older.

The second session reviewed ethical standards for parental decision-making in medical scenarios. The instructor used the PowerPoint slides (Appendix D) to deliver a 45-minute interactive didactic (facilitator notes in Appendix E). The session focused on surrogate decision-making and the best interest standard. It depicted cases where the decisions of a parent were questioned and provided an ethical framework for exploring whether or not a decision was ethically acceptable. The session offered trainees tips and guidance on how to approach conversations regarding controversial medical decision-making with parents.

The third session taught the concepts of informed consent and assent, focusing on the variety of standards for adequate informed consent and the process of including a child's assent in medical decision-making. The instructor used the PowerPoint slides (Appendix G) to deliver a 45-minute interactive didactic (facilitator notes in Appendix H). This session explored two cases; the first outlined the elements necessary to provide informed consent, and the second described the approach for obtaining adolescent assent. The case on assent additionally explored some of the ethical challenges arising if parents object to their child's involvement in decision-making surrounding the child's care.

Assessment Tools

Given the lack of standard assessment tools in medical ethics education, we evaluated the success of our curriculum based on learner-reported understanding and comfort pre- and postsession. The session assessments (Appendices C, F, and I) were developed by the session leader based on the session content and specific learning objectives. Assessment questions asked the learner to evaluate their level of understanding and comfort on a 5-point Likert scale (1 = *strongly disagree*, 5 = *strongly agree*). Because these sessions focused on incorporating the ethical principles of medical decision-making into clinical practice, our assessment tool measured understanding and comfort utilizing these skills as opposed to knowledge acquisition of definitions or concepts.

Data Analysis

Institutional review board approval for this educational intervention was obtained from Cincinnati Children's Hospital Medical Center on April 30, 2017 (ID: 2016-5681). While

attendance at the morning-report sessions was mandatory, completion of the assessments was voluntary. Written informed consent was waived by the institutional review board, and consent was implied by completion of the assessments. All assessments were anonymous.

Responses from the pre- and postsession Likert-scale questions evaluating learning objectives for the morning-report case-based small-group discussions were dichotomized as learners who agreed that the session met the objective (*strongly agree* and *agree*) and others (*strongly disagree*, *disagree*, and *neutral*). Responses were analyzed using chi-square analysis. Subgroup analysis based on the level of learner training was also performed.

Results

On average, 19 learners completed assessments for each session, although numbers and level of training of the learners varied. The average number of residents who attended each session was 11, of whom eight were interns. Medical students accounted for an average of seven learners per session attending and participating in the Decision-Making Capacity and Advance Directives and Parental Decision-Making sessions. Incomplete assessments were not included in data analysis. In addition to analyzing all learners, we performed subgroup analysis of medical students and residents for those who reported their level of training to better understand which learners gained the most benefit from these sessions.

Comfort with and understanding of the sessions' learning objectives increased across all three sessions and both learner subgroups. There was greater reported comfort with understanding ethical principles (two-thirds of all learners) compared with comfort in applying the principles to patient interactions (half of all learners.) For example, following the Decision-Making Capacity and Advance Directives session, 79% of learners reported comfort with understanding the elements

of decision-making capacity, but only 50% reported comfort discussing advance care planning with adult patients. Parental Decision-Making had mixed results as well. Only one session, Informed Consent and Adolescent Assent, did not demonstrate either statistical improvement or more than 80% agreement in Likert-scale posttest questions. Compared to residents, medical students expressed equivalent comfort with the ethical principles of medical decision-making, with the exception of a decreased number reporting comfort with the elements of decision-making capacity compared with residents. There was a statistically significant increase in the percentage of medical students who felt comfortable with the elements of decision-making capacity, however (Table).

Discussion

This module is an important addition to previously published pediatric ethics curricula¹³ because it addresses clinical scenarios commonly encountered in pediatric practice. The pretest responses prior to our sessions supported previously published data about gaps in medical ethics education.^{3,5,6,11,21,22} The format, which combines formal didactic presentations and small-group case discussions, allows trainees to explore ethical considerations in a way that may be more accessible for some learning environments than curricula utilizing standardized patients, which themselves do not have robust data on efficacy.²³ As a whole, our Palliative Care and Medical Ethics curriculum is a valuable addition to graduate medical education given the ACGME, ABP, and AAP requirements for formal education in palliative care and in ethics.^{2,3,24}

Presession, approximately half of all learners, and in some cases less than 25%, reported comfort with or understanding of the pertinent ethical principles, supporting our claim of a knowledge gap regarding the ethics of medical decision-making. Questions assessing cognitive understanding of principles demonstrated that 79%-88% of learners reported postsession understanding

Table. Percentage of Learners Who Either Agreed or Strongly Agreed Pre- and Postsession

Session and Question	Residents				Medical Students				All Learners			
	No.	% Agree		p	No.	% Agree		p	No.	% Agree		p
		Pre	Post			Pre	Post			Pre	Post	
Decision-Making Capacity and Advance Directives	11				11				28			
I am comfortable that I understand the elements of decision-making capacity.		54	82	.17		18	64	.03		43	79	<.05
I am comfortable discussing advance care planning with adult patients.		36	64	.20		18	46	.17		29	50	.10
Parental Decision-Making	9				3				16			
I understand the different standards for surrogate decision-making.		11	78	<.05		0	100	<.05		19	88	<.05
I am comfortable applying the criteria for medical neglect to a clinical decision.		11	56	.05		0	67	.08		6	62	<.05
Informed Consent and Adolescent Assent	14				0							
I am comfortable obtaining informed consent from an adult patient or from a parent of a pediatric patient.		57	71	.43								
I am comfortable obtaining assent from an adolescent patient.		57	57	1.00								

of ethical principles, suggesting that our module was able to provide an ethical framework for navigating medical decision-making conflicts and dilemmas. Unfortunately, only 44%-67% of learners felt comfortable counseling or making recommendations in these clinical scenarios after the sessions, suggesting a further educational need for practicing these skills. Additionally, while the curriculum led to self-reported improvement in comfort in many topics, all sessions had one-third to one-half of residents who did not report comfort with all of the Likert-scale posttest questions, suggesting further educational interventions are necessary to solidify learning in these areas. Finally, while one session, Informed Consent and Adolescent Assent, failed to show either statistical improvement or more than 80% agreement in Likert-scale posttest questions, this was an anomaly in our Palliative Care and Medical Ethics curriculum. The assessment tool for this session asked learners to assess their comfort obtaining consent and assent. We hypothesize increasing comfort in these areas was limited due to the need to practice these skills to increase comfort, as data from other medical subspecialties indicate that discomfort with obtaining informed consent is common among trainees.²⁵

Overall improvement in medical student comfort and knowledge also indicates that our curriculum could be successfully implemented with other learners of various levels of training. With the exception of comfort discussing advance care planning with adult patients, medical students reported increased comfort with and understanding of our learning objectives.

Implementation Lessons Learned

As previously stated, a primary challenge we faced following initial curriculum development and implementation was the breadth of content that could be included when educating on palliative care and medical ethics.²⁶ We tailored the structure of our sessions to fit into the morning-report curriculum, which allowed for better attendance than embedding sessions into individual rotations.

Although learner participation can be difficult in small-group sessions, we did not find it to be a problem during these sessions. Discussions were lively and often had to be stopped to allow for time for large-group report-out. We found that encouraging groups to be a mix of different levels of learners sparked more discussions compared to groups that represented a single level of training. In particular, senior trainees could provide content knowledge regarding some of the discussion questions and, more importantly, often validated the cases as being representative of their own clinical experience to date. The use of experienced senior residents and, when present, hospital

medicine attendings was critical to the success of the small-group discussions since we did not have enough experts in palliative care and ethics to lead all the discussions.

Finally, a common barrier to implementing a medical ethics curriculum is lack of faculty experience.³ Our sessions were led by a pediatrician with a master's degree in medical ethics and certification as a health care ethics consultant. The ethics content for each session is available in the attached PowerPoints (Appendices A, D, and G), making it possible for a medical educator with experience and adequate preparation to facilitate the sessions.

Limitations and Future Directions

The primary limitation to our study is our sample size. Morning-report conference attendance was limited due to rotation schedules and clinical responsibilities. So, despite having more than 200 residents in all our programs and 12 or more medical students rotating most of the time, attendance at morning-report conferences was significantly lower. Of note, our Informed Consent and Adolescent Assent session occurred around winter break, when no medical students were rotating. The timing of this session is likely why there was particularly low attendance. Additionally, Parental Decision-Making was given during February, when low attendance may have been related to high winter patient census. Overall low morning-report attendance was addressed by the pediatric residency program as a whole by repeating the entire curriculum every 18 months, giving every resident at least two opportunities to attend each session.

Dissemination of our curriculum to other residency programs will depend on each program's curricular structure and availability of faculty. In order to adapt to other curricular structures, the module could be completed as individual sessions occurring in three 30- to 60-minute sessions or as an entire module in a single half-day session. While a content expert is helpful to fill in any gaps identified during the large-group sharing, small-group discussions have been successfully led by senior residents, which also increases the accessibility of this module to all types of residency programs. Finally, we recognize that the legal environment varies by location of practice. Most of our cases are based on real patients at our institution. While we believe that the clinical scenarios are pervasive among our audience, some case discussions could vary depending on local legal statutes regarding advance directives and do-not-resuscitate forms.

Because of the lack of standard assessment tools in medical ethics education, we were not able to evaluate our modules with a validated assessment tool. Additionally, we were only

able to assess learner comfort and understanding immediately surrounding the session and were unable to evaluate for a possible decline in comfort and understanding over time. As discussed above, we were also unable to evaluate how residents and medical students implemented the ethical frameworks and principles discussed in these modules during their clinical practice.

We also experienced limitations in the data collected from our assessment tools. We had several learners not indicate their level of training, excluding them from subgroup analysis. For our Informed Consent and Adolescent Assent session, we had a small sample size, as only 14 learners attended. Although we did not receive significant qualitative feedback on our assessment tools, we received verbal feedback from the residency program and chief residents that the residents valued our sessions and appreciated the opportunities for discussion.

Our Ethics of Pediatric and Young Adult Medical Decision-Making module demonstrated increased understanding of and comfort with the ethical frameworks of medical decision-making in pediatrics. Future ethics curricula would ideally provide learners with opportunities to practice navigating these clinical scenarios in simulated situations. Simulation or role-play would allow learners to operationalize the knowledge they acquire in the small-group sessions, particularly in sessions where comfort with a skill is still low postsession. This would allow for assessment that focuses not only on comfort or understanding but also on objective performance measures of these skills. For medical ethics education as a whole, there is a need for validated assessment tools to evaluate learner content knowledge and track that knowledge over time.

Conclusions

The Ethics of Pediatric and Young Adult Medical Decision-Making module achieved improvement in self-reported comfort with and understanding of the ethical frameworks related to pediatric decision-making. This module helps to fill a knowledge gap in residency education that has been identified in the literature.^{3-6,8-12} It can also help fulfill the ethics requirements of the ACGME, ABP, and AAP. While our module demonstrates increases in self-reported comfort and understanding, future curricula should focus on evaluating how residents utilize this knowledge in clinical practice.

Appendices

- A. Decision-Making Capacity Didactic.pptx
- B. Decision-Making Capacity Instructor Directions.docx

- C. Decision-Making Capacity Evaluation.docx
- D. Parental Decision-Making Didactic.pptx
- E. Parental Decision-Making Instructor Directions.docx
- F. Parental Decision-Making Evaluation.docx
- G. Informed Consent Didactic.pptx
- H. Informed Consent Instructor Directions.docx
- I. Informed Consent Evaluation.docx

All appendices are peer reviewed as integral parts of the Original Publication.

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Acknowledgments

Thanks to Dr. Armand Antommara for assistance with the content development and acting as a facilitator for sessions. Thanks to Dr. Jennifer O'Toole for her guidance regarding development of the assessment tools and to Dr. Lilliam Ambroggio for her guidance on statistical analysis.

Disclosures

None to report.

Funding/Support

None to report.

Ethical Approval

The Cincinnati Children's Hospital Medical Center Institutional Review Board approved this study.

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Received: June 17, 2020

Accepted: November 2, 2020

Published: February 11, 2021