Taking account of children’s preferences in treatment decisions

PEDiatric ASENT
Disclosures

The presenters have no financial conflicts of interest to disclose.
Overview

• Pediatric assent is a process of involving children who lack the capacity for decision-making in decision making about their care.

• Capacity for decision-making (DMC) generally involves (Grisso and Appelbaum 1998):
  • The ability to express a choice
  • The ability to understand information relevant to treatment decision making
  • The ability to appreciate the significance of that information for one’s own situation, especially concerning one’s illness and the probable consequences of one’s treatment options; and
  • The ability to reason with the relevant information so as to engage in a logical process of weighing treatment options
Overview

• Part of the difficulty in defining specifically what it is that “pediatric assent” names is that in practice, much depends on the developmental sophistication of the child, such that no univocal conception is sufficient.

• Conceptions of pediatric assent range from something approximating acquiescence to non-legally binding informed consent.

• Most robust conception of assent requires the overlay of a developmental arc, which betrays the complexity of navigating assent in pediatric practice.
Overview

• Older children often have DMC, and some studies have suggested their decision-making is similar to adults, while other studies have suggested that there are key differences, particularly under certain conditions.

• “Age was a good predictor of competence on the MacCAT-CR (area under the receiver operating characteristics curve, 0.90). In children younger than 9.6 years, competence was unlikely (sensitivity, 90%); in those older than 11.2 years, competence was probable (specificity, 90%). The optimal cut off age was 10.4 years (sensitivity, 81%; specificity, 84%).” (Hein et al. 2014)
AAP 1995 first embraces “pediatric assent” as an ongoing process that entails at least the following elements:

• Helping the patient achieve a developmentally appropriate awareness of the nature of his or her condition.
• Telling the patient what he or she can expect with tests and treatment(s).
• Making a clinical assessment of the patient’s understanding of the situation and the factors influencing how he or she is responding (including whether there is inappropriate pressure to accept testing or therapy).
• Soliciting an expression of the patient’s willingness to accept the proposed care. (AAP Committee on Bioethics 1995, 315–16)
Overview

• AAP 2016 elaborates value of child participation in health care

  • “[D]issent by the pediatric patient should carry considerable weight when the proposed intervention is not essential and/or can be deferred without substantial risk” (AAP Committee on Bioethics 2016, 4; Katz, Webb, and AAP Committee on Bioethics 2016, e8).

  • One circumstance in which children “will have to” receive a treatment is when a failure to provide that treatment would cause “serious risk of significant harm” (AAP Committee on Bioethics 2016, 5; Katz, Webb, and AAP Committee on Bioethics 2016, e13).
Deficient Accounts of the Value of Pediatric Assent: Instrumental Reasons

1. Best interests (pathway to compliance, information for diagnosis)

2. Developing future autonomy

These reasons are unstable because they will not tell in favor of pediatric assent whenever involving children in decision making would not encourage compliance, disclose relevant information, or foster future autonomy.
Deficient Accounts of the Value of Pediatric Assent: Non-Instrumental Reasons

• 1. Cultivating trust (might also be instrumental)

• 2. Respect for persons (respect for emerging autonomy)
Deficient Accounts of the Value of Pediatric Assent: Non-Instrumental Reasons

• But in grounding of non-instrumental reasons, particularly with regard to respect for persons, the AAP resorts to notions of Kantian autonomy:

  • [Kant's categorical] imperative notes that we are obliged to act out of fundamental respect for other persons by virtue of their personal autonomy. This imperative forms the moral basis to respect others and ourselves as moral equals and provides moral support for the concept of informed consent. Although many, if not most, patients in pediatric practice lack the agency required to be truly autonomous agents, this framework remains important in providing the background for continued respect of their moral potential (Katz, Webb, and AAP Committee on Bioethics 2016, e2, emphasis added).
Deficient Accounts of the Value of Pediatric Assent: Non Instrumental Reasons

• Derrington and Paquette have recently observed that this sleight of hand is common in pediatric ethics, according to which providers are inveighed to respect child patients as persons, in the absence of “other aspects of the typical language around respect for persons, such as autonomy or self-determination,” but, somewhat paradoxically, in a context in which those Kantian ideals are presumed to be the basis of respect for persons (2018, 26, italics original).

• Other problems with future autonomy arguments.
We have argued that the expressed preferences of DMC-lacking patients have inherent moral value, grounded in considerations of liberty and respect for persons (Wasserman and Navin 2018).

Liberty - is normatively basic and intrusions on it require justification.

Respect for persons –
  • We take for granted that even people who lack decision-making capacity can be persons.
Capacity for Preferences as Grounding the Moral Value of Pediatric Assent

• Preferences always have non-zero moral value

• There are always defeasible moral reasons to grant preferences

• Where a preference is defeated by weightier claims about, a (justified) moral harm has been committed

• ...This is significant practical implications for policy and practice.
When Soliciting Assent is Required

All three AAP documents state that children’s preferences should not be solicited whenever a particular treatment options is inevitable:

- [N)o one should solicit a patient’s views without intending to weigh them seriously. In situations in which the patient will have to receive medical care despite his or her objection, the patient should be told that fact and should not be deceived (AAP Committee on Bioethics 1995, 315–16).

- [O]ne should not solicit a child’s assent if the treatment or intervention is required to satisfy goals of care agreed on by the physician and parent or surrogate (AAP Committee on Bioethics 2016, 2; Katz, Webb, and AAP Committee on Bioethics 2016, e8).

- [A]ssent should only be solicited if some element of refusal will be respected (Katz, Webb, and AAP Committee on Bioethics 2016, e9).
When Soliciting Assent is Required

• Not clear that soliciting assent can be divested from other parts of the clinical interaction (e.g. explaining a procedure to the child).

• Assent could be solicited even when dissent will not be honored in such a way that the child does not feel deceived.

• Results from a logical error: AAP implicitly embraces the contradictory conclusion that child patients’ preferences have no moral weight (they ought not to be solicited) whenever children’s preferences have less moral weight than other considerations (i.e. when the treatment decision is a foregone conclusion).
Bartholome and Apologizing to Children

Bartholome (the author of the 1st draft of the AAP’s 1995 statement) claimed that treating a child over their objection always involves a moral wrong.

• When treating over objection is, on balance, the most ethical thing to do, the pediatrician should *apologize* to the child for the moral harm that they have done.

• Our arguments support this more nuanced and complex understanding of the moral terrain of pediatric ethics.
The human disposition toward an *affect heuristic* (Zajonc 1980) suggests that we tend to think good outcomes have few or no downsides (Kahneman 2011, 140).

It is a consequence of the arguments we make in this paper that pediatric practice may frequently involve clinicians in unavoidable, and ultimately justified, ethical violations.

It takes a kind of moral bravery to do this work since, as we have argued elsewhere (Wasserman and Navin 2018), treating patients over their objections always involves moral violations, even when coercive treatment is ultimately ethically justified.
Based on...

Wasserman, Jason Adam; Mark Christopher Navin; Christian John Vercler. Forthcoming. “Pediatric Assent and Treating Children over Objection.” Manuscript accepted at *Pediatrics*.


References (cont)

Team Based Learning

Team Based Learning (TBL) is a well-defined instructional strategy used by many US medical schools.

**Medical School Objectives:**

- learning and retention of information
- understanding of material
- student engagement
- professional life skills

OUWB promotes the use of TBL in the curriculum.

Team Based Learning

TBL Structure - 3 Phases:

1) Pre-Class Preparation
2) Readiness Assurance
   a) Individual Readiness Assurance Test (iRAT)
   b) Team Readiness Assurance Test (tRAT)
3) Application Exercises
Team Based Learning

Application Exercises Phase

Adheres to the “4 Ss” rule of TBL:

1) **Same** problem
2) **Significant** problem
3) **Specific** choice
4) **Simultaneous** report

Team Based Learning (TBL) has been successfully used in GME as well.

Albany Medical College - Internal Medicine Program

- Implemented weekly TBL to replace traditional conference lectures
- Medical Knowledge Self-Assessment Program drove the content
- Pre-Class Preparation included readings from standard texts and journals (e-mailed as PDFs one week prior to TBL)
- TBL questions based on content, modifying existing board-style questions
- 90 minute TBL sessions (ample time to cover 5 iRAT/tRAT and 5 Application Exercises)

Team Based Learning

“How often do you complete the TBL readings ahead of time?”

[Bar graph showing frequency distribution of residents' reading completion rates.]

## Resident Perceptions of TBL

<table>
<thead>
<tr>
<th>Survey Question</th>
<th>Strongly Disagree, No. (%)</th>
<th>Disagree, No. (%)</th>
<th>Neutral, No. (%)</th>
<th>Agree, No. (%)</th>
<th>Strongly Agree, No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preassigned readings are manageable</td>
<td>0 (0)</td>
<td>7 (11)</td>
<td>7 (11)</td>
<td>25 (39)</td>
<td>25 (39)</td>
</tr>
<tr>
<td>Improves understanding of challenging clinical concepts</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>2 (3)</td>
<td>23 (36)</td>
<td>38 (59)</td>
</tr>
<tr>
<td>Group problem-solving effective way to learn patient care</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>2 (3)</td>
<td>13 (20)</td>
<td>49 (77)</td>
</tr>
<tr>
<td>Team activities solidify knowledge from readings</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>3 (5)</td>
<td>12 (19)</td>
<td>49 (77)</td>
</tr>
<tr>
<td>TBL helps me be more confident caring for patients</td>
<td>0 (0)</td>
<td>1 (2)</td>
<td>8 (13)</td>
<td>25 (39)</td>
<td>30 (47)</td>
</tr>
<tr>
<td>I learn better from TBL than lectures</td>
<td>1 (2)</td>
<td>4 (6)</td>
<td>10 (16)</td>
<td>12 (19)</td>
<td>37 (58)</td>
</tr>
</tbody>
</table>

\(^a\) N = 89 (64 responders).

# Team Based Learning

**Faculty Perceptions of TBL**

<table>
<thead>
<tr>
<th>Survey Question</th>
<th>Strongly Disagree, No. (%)</th>
<th>Disagree, No. (%)</th>
<th>Neutral, No. (%)</th>
<th>Agree, No. (%)</th>
<th>Strongly Agree, No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparation time is reasonable</td>
<td>1 (2)</td>
<td>6 (14)</td>
<td>6 (14)</td>
<td>24 (55)</td>
<td>7 (16)</td>
</tr>
<tr>
<td>Preparation materials are helpful</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>2 (5)</td>
<td>21 (48)</td>
<td>21 (48)</td>
</tr>
<tr>
<td>Faculty development is adequate</td>
<td>0 (0)</td>
<td>4 (9)</td>
<td>8 (18)</td>
<td>21 (48)</td>
<td>11 (25)</td>
</tr>
<tr>
<td>Residents are engaged</td>
<td>0 (0)</td>
<td>1 (2)</td>
<td>2 (5)</td>
<td>24 (55)</td>
<td>17 (39)</td>
</tr>
<tr>
<td>TBL makes topic clinically applicable</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>6 (14)</td>
<td>16 (36)</td>
<td>22 (50)</td>
</tr>
<tr>
<td>I prefer TBL to lecture</td>
<td>1 (2)</td>
<td>1 (2)</td>
<td>8 (18)</td>
<td>14 (32)</td>
<td>20 (45)</td>
</tr>
</tbody>
</table>

*N = 64 (44 responders).*

Individual Readiness Assurance Test (iRAT)

Joe is a 9-year-old boy with metastatic rhabdomyosarcoma, whose medical team assesses that his prognosis is likely grim, but are willing to offer continued treatment. After many multidisciplinary discussions, Joe’s parents decide to leave the hospital for end-of-life care at home. However, when he decompensates prior to discharge, Joe’s parents reverse his do-not-resuscitate, do-not-intubate status, and ask for invasive interventions including surgery. A surgical consult is requested and a new chemo/induction protocol is initiated, though the consulting oncologist does not believe it will be successful. A nurse requests an ethics consult, noting that Joe has voiced a strong desire to return home. (Adapted from Olszewski and Goldkind, 2018.)

1. According to the AAP, the ethical course of action for the attending physician in this case includes which of the following:
   a. Soliciting Joe’s assent for surgical interventions
   b. Soliciting Joe’s assent for chemotherapy and radiation
   c. Refusing to offer suboptimal interventions (i.e. chemo).
   d. Offering an apology to Joe not following his wish to return home
   e. Following the parents’ wishes without soliciting Joe’s assent
Joe is a 9-year-old boy with metastatic rhabdomyosarcoma, whose medical team assesses that his prognosis is likely grim, but are willing to offer continued treatment. After many multidisciplinary discussions, Joe’s parents decide to leave the hospital for end-of-life care at home. However, when he decompensates prior to discharge, Joe’s parents reverse his do-not-resuscitate, do-not-intubate status, and ask for invasive interventions including surgery. A surgical consult is requested and a new chemo/induction protocol is initiated, though the consulting oncologist does not believe it will be successful. A nurse requests an ethics consult, noting that Joe has voiced a strong desire to return home. (Adapted from Olszewski and Goldkind, 2018.)

1. According to the AAP, the ethical course of action for the attending physician in this case includes which of the following:
   a. Soliciting Joe’s assent for surgical interventions
   b. Soliciting Joe’s assent for chemotherapy and radiation
   c. Refusing to offer suboptimal interventions (i.e. chemo).
   d. Offering an apology to Joe not following his wish to return home
   e. Following the parents’ wishes without soliciting Joe’s assent
Discussion

Joe is a 9-year-old boy with metastatic rhabdomyosarcoma, whose medical team assesses that his prognosis is likely grim, but are willing to offer continued treatment. After many multidisciplinary discussions, Joe’s parents decide to leave the hospital for end-of-life care at home. However, when he decompensates prior to discharge, Joe’s parents reverse his do-not-resuscitate, do-not-intubate status, and ask for invasive interventions including surgery. A surgical consult is requested and a new chemo/induction protocol is initiated, though the consulting oncologist does not believe it will be successful. A nurse requests an ethics consult, noting that Joe has voiced a strong desire to return home. (Adapted from Olszewski and Goldkind, 2018.)

1. According to the AAP, the ethical course of action for the attending physician in this case includes which of the following:
   a. Soliciting Joe’s assent for surgical interventions
   b. Soliciting Joe’s assent for chemotherapy and radiation
   c. Refusing to offer suboptimal interventions (i.e. chemo).
   d. Offering an apology to Joe not following his wish to return home
   e. Following the parents’ wishes without soliciting Joe’s assent
Application Exercise

Megan is 8 years old with Li Fraumeni syndrome. She had a bout with leukemia when she was 6 and, at the time, underwent induction and consolidation protocol. She reported that treatment was incredibly difficult for her, physically and mentally. She cried frequently upon arrival to the cancer center and it often took a long time to calm her enough to begin treatment. Two weeks ago she was diagnosed with stage 2 rhabdomyosarcoma. Her parents want the standard chemo and radiation protocol, but Megan is resistant. Her pediatric oncologist, Dr. Bhadavia, is hesitant to force her. In a conversation with Megan’s primary pediatrician, he notes “Megan has been aware of her autosomal condition since age 6. She is a highly intelligent and perceptive little girl. When first diagnosed with leukemia, she asked me whether she would just keep getting cancer for the rest of her life.” Megan’s parents have been unwavering in their requests for aggressive care. Dr. Bhavadia reports broaching the subject of hospice/palliative care with them, given the marginal 5-year survival rates and the underlying autosomal condition, and they reacted with hostility. Upon Megan’s refusal of treatment for her current condition, her parents privately told Dr. Bhavadia, “one way or another, she’s getting treated or you’ll have a legal problem on your hands.”
Application Exercise

In the case of Megan, which of the following is the most ethical course of action?

a. Do not solicit Megan’s assent, but treat her on the basis of her parents’ wishes.
b. Do not solicit Megan’s assent, but refuse to offer treatment (against her parents’ request), because of the low marginal survival rates.
c. Solicit Megan’s assent, but treat her even if she dissents, on the basis of her parents’ requests.
d. Solicit Megan’s assent, and refuse to treat her if she dissents, against her parents’ requests.
e. Solicit Megan’s assent, but treat her even if she dissents, on the basis of her parents’ requests, but apologize to her for doing so.