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Assent and Dissent in Pediatric Progressive and Critical Care

Mary Frances D. Pate

University of Portland, pate@up.edu

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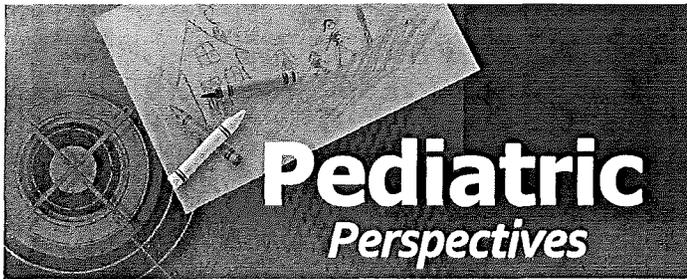
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Mary Frances D. Pate, RN, DSN, CNS
Department Editor

Assent and Dissent in Pediatric Progressive and Critical Care

Mary Frances D. Pate, RN, DSN, CNS

My wish is that doctors and nurses talk to me (7-year-old).^{1(p298)}

Not long ago, medical decisions were made exclusively by physicians with the philosophy that “doctor knows best.” This thinking has evolved over time, as the current evidence-based literature supports a model of decision making in which health care providers engage in collaborative partnerships with patients and families. Unfortunately, strategies for communicating with pediatric patients may be a neglected part of health care provider education.² A lack of this important competency may be a barrier to building trusting partnerships with patients admitted to pediatric progressive and critical care units and their families. Intentional skill building in pediatric communication is vital, so that children feel comfortable in the care of the providers.^{2,3} Although evidence supports collaborative partnerships between pediatric patients and health care professionals, some providers and pediatric researchers still think that it is best not to engage children in the assent process, as assent is nonbinding and provides no authority to proceed.⁴ Note that the literature supports a moral and ethical obligation to communicate with children, and that the principle of self-determination applies not only to adults but also to children.² The purpose of this column is to consider communication with pediatric patients as it relates to assent and dissent in progressive and critical care, and to reflect on the ongoing journey toward respect for the individual capabilities and competencies of children.⁵

Assent

Doctors should be able to tell you what is going to happen before it happens, not after (11-year-old).^{1(p297)}

Much of the conversation about pediatric consent and assent has occurred as it relates to the implementation of pediatric health care research. Much less has been written that guides providers in clinical practice. The concepts of pediatric consent and assent have been confusing to health care providers, which has led to the use of the terms interchangeably, but they are not the same. Consent for medical treatment/procedures by minors is governed by regulations, differs from state to state, and must be followed.⁶ Assent, on the contrary, refers to the expression of approval or agreement, such as a nod of the head.⁷ A misconception persists that assent is a type of “second consent,” which it is not.⁸ It simply allows the pediatric patient to have an appropriate level of involvement in the decision-making process by

Mary Frances D. Pate is Associate Professor, School of Nursing, University of Portland, 332 Buckley Center, 5000 N Willamette Blvd, Portland, OR 97203 (pate@up.edu).

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which he or she will be affected.⁸ Engagement with the patient even when his or her input will not determine a final decision provides the child with a feeling of self-control, which can serve to lessen fear. Health care providers should be reminded that children's assent always should occur in tandem with parental permission,⁹ and that children should never be forced to participate in the assent process against their will.

In 1995 (with reaffirmation in 2006), the American Academy of Pediatrics Committee on Bioethics stated that pediatric patients should not be excluded from health care decision making without persuasive reasons and should be allowed to participate in decision making commensurate with their level of development. The Committee wrote that these collaborations should continue and develop over time, so that at some point the pediatric patient can assume full decision-making responsibilities.^{9,10} Although health care providers may want a specific age range as a guide to determine competence for assent, pediatric research has shown that age has no relationship to competence in this area.^{3,11}

The lack of direction from the literature related to clinical practice adds to the confusion surrounding when assent for procedures is appropriate and how to assess a child's readiness for such. Because each child is a unique being, an individualized assessment should be completed with a broad view toward the patient's developmental, cognitive, psychosocial, cultural, and contextual realities.⁶ Health care providers should note that the ability for a child to provide assent is a fluid process. That is, as a pediatric patient's health improves or deteriorates, additional assessment should be completed to confirm the ability to provide assent.

The American Academy of Pediatrics also stated that assent to care should be obtained only when reasonable (Table 1). Although assent is not a binding contract, it is an attempt to show respect for the patient, satisfy the need to be informed about illness or treatments, decrease fears, and give the patient an opportunity to develop competencies for providing informed consent later in life,¹² which is a way to allow participation by those not legally entitled to informed consent. Health care professionals should understand that the request for assent should not be a "smoke and mirrors" activity, which in reality only gives a child the right to agree with the providers.¹² In a classic publication, Bartholome¹³ reminds those caring for children that it would be cruel and unethical

Table 1: Parental Elements of Assent^a

It is hoped that these elements will assist the child to achieve a developmentally appropriate awareness of the nature of their condition.

A child's view should not be requested unless the perspective will be weighed seriously. If no option exists, do not present one or deceive the child.

1. Lets the child know what to expect with test and treatments.
2. Assesses the child's understanding of the situation and factors influencing the child's response (including whether there is inappropriate pressure to accept testing or therapy).
3. Solicits an expression of the child's willingness to accept the proposed care.

^aSource: American Academy of Pediatrics.^{9,10}

to allow a pediatric patient to think that there were alternatives to the adult viewpoint when there was none, or to only seek assent for non-essential treatments/care to avoid dissent.

Dissent

My wish is for children to get a say (12-year-old).^{1(p299)}

Upon admission to a pediatric progressive or critical care unit, patients most likely will be experiencing physical and psychological stress. An imbalance of power between adults and pediatric patients may provide added stressors, especially if children are not allowed to participate in collaborative decision-making processes and are forced against their will to comply.

Children may appear irrational if they do not agree with health care providers, but adults are not held to a defined standard of rationality.^{9,10} When pediatric patients express dissenting views, the dissent should be respected and carry considerable weight, especially if the treatment/procedure is not essential or can be deferred without significant risk.^{9,10} If a patient is not at risk for harm, time should be provided to obtain more information and have questions answered and concerns addressed. The voice of the child should be weighed as equal with adults and considered with an open mind. When appropriate, treatment/procedures should be postponed to allow time for further conversation, consideration, and possible assent.¹⁴ Manipulating, coercing, or forcing children to provide assent should be avoided.^{9,10}

Proceeding Without Assent

The literature suggests that painful procedures and the perception of being assaulted by health care providers may be more distressing to children than a diagnosed illness.^{15,16} I have had the experience of walking into pediatric patients' rooms only to find a health care employee poised with a needle about to obtain blood from a sleeping child. Pediatric health care providers must attempt to understand such behavior, so that it can be changed, and advocate for policies to prevent such dismissal of a child's feelings. Children may be afraid of painful procedures, but one would assume that patients would also find it difficult, maybe even more so, not being told what was happening to them.

Team members who participate in activities that are against the wishes of the patients in their care may feel stressors and question the ethical nature of such an activity.¹⁷ This moral distress may increase for the health care providers if the patients might be deemed competent to be in collaborative partnerships about personal health care.¹⁸ Holding down or restraining a pediatric patient for the sake of expediting a procedure should not be done and is unethical.¹⁷ Little research has been done about the impact of restraint on children,¹⁸ and one might wonder if the use of the word "clinical holding" for medical procedures¹⁹ versus the word "restraint" is a way of making the activity more palatable to health care providers.

In the event of an impasse where no alternative course of action can be reached, health care providers should acknowledge forced treatments as disrespectful and apologize for any forced interventions.¹³ This approach shows respect for the feelings of children and may allow them to "forgive" the intrusiveness.

Discussion

Children are not human becomings, they are human beings.^{20(p100)}

Health care professionals may think that a discussion of assent and dissent is inappropriate for patients admitted to pediatric progressive and critical care units. This hesitancy may be due to the acute nature of the setting, or the belief that children may not have the capacity to assent in these types of units. However, children move along a continuum of illness during admission to these areas just as adults do, and the latter population is allowed to participate in decision-making processes as health improves. Pediatric providers must consider if there is an

evidence-based reason for this alternative standard for children.

More research is needed about child assent in general, as one study of pediatric health care professionals revealed that there was a substantial lack of knowledge about correct terminology related to consent and assent and that some clinicians did not agree with the American Academy of Pediatrics' policy statement on this topic. The study found that some clinicians thought educating the pediatric patient was appropriate, but seeking agreement with the child was not an important part of assent in the clinical area.¹²

Conversations related to assent in pediatric progressive and critical care must continue, as many questions are unanswered. Operational definitions of the terms *consent* and *assent* are needed to provide clarity and understanding among health care providers in these settings. Criteria for when assent is appropriate need to be developed along with guidance on strategies for implementation in the patient population. The impact of the diversity of culture and language in the United States related to consent and assent also needs to be explored for alternative viewpoints and understanding.²¹ Research focused on the knowledge, attitudes, and use of assent by health care providers should continue. Most importantly, all steps along the journey should incorporate the perspectives of patients and families about assent in pediatric progressive and critical care as these individuals collaborate in complete partnership with the health care team.

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