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Mary Frances D. Pate

University of Portland, pate@up.edu

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Pediatric *Perspectives*

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

Collaborative Partnerships With Patients in Pediatric Progressive and Critical Care

Mary Frances D. Pate, RN, DSN, CNS

A national conversation has been ongoing about collaborative partnerships with patients as they relate to personal health care discussions and decision making, with little focus on how these partnerships might apply to the pediatric population. Some health care providers may feel that this type of collaboration is not applicable to children (including adolescents) admitted to progressive and critical care because of patient acuity. Would this same perspective be held if the patients were adults?

In 1989, the United Nations Convention on the Rights of the Child provided a standard related to the rights of children and is the most widely ratified international human rights treaty to date.^{1,2} The convention established the rights of children as equal to the rights of adults.³ Most laws related to the pediatric population in the United States are focused on protections, whereas few laws focus on rights,³ which may be because children are expected to be obedient rather than autonomous.⁴ Although the convention's principles are not legally binding, as health care providers who embrace excellence, we should consider these international norms. The purpose of this column is to consider the implications of pediatric patients as collaborative partners during their stays in progressive and critical care units and address opportunities for engagement.

Competencies of Children

In the United States, adulthood is assigned to a person according to age by legal statute. This designation assumes competency unless proven otherwise.⁵ Children, regardless of their level of individual maturity, are considered by law to be incompetent and dependent in regard to health, when in fact they may be able to make reasonable decisions, but be legally incompetent.⁵ The autonomy and competence of children develop over time, not from reaching an arbitrary age, but through social and personal experiences.³

As with adults, children need to understand their illness, the necessity of treatment, proposed interventions, risks, benefits, alternatives, and the implications to them and their families related to treatment or nontreatment.⁶ This level of competence cannot occur without collaborative partnerships, including education and information sharing. If health care providers are committed to authentic collaboration with children, then the past minimalist approach to providing information for this population needs to evolve.⁶

Some people think that children are not rational beings; however, adults are not required to be rational about their health care choices.^{7,8} When adults make

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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choices that do not coincide with health care providers' recommendations, these choices are still accepted because adults are viewed as competent. Adults are allowed to choose unwisely, whereas children are not. Children may make decisions in different ways than adults, which does not make children's decisions "wrong" or less rational. Children may lack language skills to express thoughts in an articulate manner, but this shortcoming does not make them incompetent.^{9,10} Confusion over where the boundary lies between an incompetent young person and a competent adult may be a barrier to collaboration with children for some health care providers¹¹ (Table 1).

In the Best Interests of the Child

The Supreme Court affirms the rights of parents to make medical decisions for children according to the standard of best interests. However, no definition of "best interests" or guiding principles about the actual application in practice has been offered.⁵ One question to be considered is, "When best interest is discussed in relation to health care for children, whose best interests are being considered?" Health care providers may have personal or professional interests to avoid family conflict or to make sure that clinical guidelines or protocols are followed.¹⁴ Parents may have cultural, religious, contextual, or sociopolitical values they want considered that may not reflect the values of the patient.⁵ Children may have interests that encompass more than health care.¹¹ For instance, health care providers may want to remove a pediatric patient from the home if family members refuse to provide the prescribed regimen. Although removing the child would possibly improve his

or her health care interests, removing the patient from the security of a family would most likely not be in his or her overall best interests.

Divergent views about children's best interests also can be seen in pediatric research. For example, adult researchers regard the collection of blood samples as "minimal risk," whereas many children are very frightened of needles. The perceptions of risk⁴ and best interests can differ between adults and young people.

Collaboration With Children: Parental Perspectives

Some parents may feel that children do not have the right to collaborate with the health care team, and that adults are the final authority. Some adults may have trouble taking the views of children seriously, as they may not have been treated with this degree of respect themselves as children.¹⁵ Children who have the ability to express personal health care views may not be heard if adults are unwilling to listen.¹⁶

Conversely, some parents may feel strongly that children should participate in health care conversations but still may have reservations about decision making. Parents may be concerned about the outcomes of "wrong" decisions, and the responsibility of participation may cause added stress for the child.¹⁷

Collaboration With Children: Health Care Provider Perspectives

Health care providers may have perspectives that are influenced by outdated theories of child cognitive development, without serious critique of the information.¹⁸ Unfortunately, for children, showing competence is more difficult than showing incompetence, and young people who

Table 1: Barriers to Collaboration With Children^a

1. Quiet children may not agree but may not speak up either.
2. Parental belief that health care providers "know best."
3. Lack of adult realization of the need to stand back to allow young voices to be heard.
4. Alternatives to procedures are rarely presented, leading parents/young people to believe that there are no alternatives.
5. Health care professionals may not know how or have the skills to partner with children and families, or they may not understand what a tripartnership might look like.
6. Health care provider fears that children will feel that health care responsibilities have been transferred to them, producing further stress for the child.
7. Lack of skills to partner with children in different ways, at varying developmental stages and ages.

^aFrom Dixon-Woods et al¹² and Runseon.¹³

are engaged and informed may be dismissed as precocious or outliers.⁴ Some health care providers may find it difficult to cope with children who are knowledgeable about their care and can question them. They also may believe that collaboration with these patients should be based on parental approval.¹⁷

Adults may have an easier time with children consenting to care than refusing care.⁶ In instances in which pediatric patients are deemed to be competent collaborators, they may be easily deemed incompetent and irrational if they do not agree with the health care team.^{12,18} Older paradigms of competency are associated with cognitive capacity, rationality, and age. Newer paradigms take into account the experiences the child has had with an illness.⁶ Health care providers should acknowledge the individual competencies of children versus comparing them with adults. Seeing young people in this way can help health care providers assist children to develop the needed competencies to be collaborators. Members of the health care team may need to build skills related to listening and collaborating with children (Table 2).

Pediatric progressive and critical care units are seeing more patients with chronic and long-term conditions,¹⁷ and many of these patients have definite preferences about how care is provided. These young patients have the potential to develop high levels of competence related to their illness and care.¹⁸ Children who have long-term conditions are usually more informed than those with acute or emergent conditions.⁴

Collaborations With Children: The Patient's Perspective

Little information exists about the views of children, as their perspectives have not been widely published. Available research reveals that young people find it difficult when involved in conversations related to their personal health care because questions are directed to adults in the room.¹⁷ Pediatric patients want to be consulted, involved, and respected as having opinions about their care and treatment. When treated in this manner, these patients were happier, reassured, and felt treated as a person with rights. Children whose opinions were sought and were not told what to do felt more adult-like.¹⁷ Clearly, children want information and

Table 2: Strategies for Listening, Collaborating, and Partnering With Children^a

1. Advocate for collaboration with children with the interdisciplinary team.
2. Provide information and clarification for children. Information gathering is a coping strategy for them, and the better children are informed, the better partners they have the potential to be.
3. Allow Internet access when possible to allow children to seek out information in an anonymous way, with a nonjudgmental entity.
4. Avoid making assumptions or judging the values of children.
5. Avoid rushing to interpretation of the concerns of children; explore their concerns further.
6. Avoid finishing the thoughts/sentences of children or acting as an interpreter.
7. Allow children to share views fully about plans for their health care.
8. Ask and answer questions honestly and authentically.
9. Be aware that quiet children may not speak up, yet they may not agree with planned care.
10. Allow children to have discussions with neutral parties not involved in the provision of care (eg, friend, child life therapist, or spiritual support).
11. Provide privacy and confidentiality, and avoid questioning children in front of groups of adults.
12. Provide collaborative dialogues, not top-down, hierarchical interactions.
13. Allow children the opportunity to think in peace and quiet.
14. Understand that children may provide answers to placate adults that do not reflect their personal views.
15. Allow children to make mistakes and change their minds (just like adults do).
16. Be aware that listening is not the same as understanding. Clarify with the child to see whether perceptions are correct.

^aFrom Dixon-Woods et al¹² and Runseon.¹³

seek it as a coping strategy. Clinicians should note that some pediatric patients may prefer not to be involved in discussions and decision making. These preferences should be respected and accommodated.

Patient- and Family-Centered Care and Children

The practice of patient- and family-centered care in the pediatric population can strengthen family confidence and increase the competence of patients to take on more responsibility about personal health care. This competence can assist children through the transition from the pediatric to the adult health system.¹⁹ One core principle of patient- and family-centered care is the empowerment of each child and family to discover strengths, build confidence, and make choices and decisions about personal health.¹⁹ I hope that interventions to facilitate such collaboration will be considered (Table 3). Be aware that health care providers and parents given adequate time can think of “persuasive reasons” for excluding young persons from collaborations.¹⁵

The American Academy of Pediatrics Committee on Hospital Care and the Institute for Family-Centered Care¹⁹ recommend that parental presence during rounds be standard practice in pediatric hospitals. Groups such as The Joint Commission, the Institute for Healthcare Improvement, and the Institute of Medicine emphasize the importance of patient and family collaboration with the health care team to enhance communication and improve patient safety, assuming that this collaboration includes children.

Mutual goal setting during rounds can enhance parental connections to the child, assist in an increased understanding of health care

processes and procedures, and demonstrate a commitment to mutual interdependence by all parties.^{22–24} These daily collaborations provide time for the child and family to gain information and clarification.

Families having experience in rounds identified communication as the most important aspect for them and were appreciative of being respected as full team members.²³ The assumption is that children desire the same inclusion. Excluding the confident, informed voices of pediatric patients from the conversation silences an important perspective.⁴

Discussion

Clearly, intentional, authentic processes for incorporating collaborations with pediatric patients are needed. This need should not be confused with asking children to make decisions independently. Children can distinguish “having their say, from having their way.”^{9(p35)}

Health care decisions should be made after consultation with the patient and family. If major differences of opinion persist between the health care team and patient and family, an ethics committee consultation may be appropriate. In the event that the health and life of the child is in jeopardy, legal action may need to be taken.¹⁹

Participation of all team members in health care matters may assist children in the long term to develop skills for the future. In the short term, allowing collaboration may allow a sense of control over the illness and hospitalization.¹³ Competence does not occur overnight, so encouraging skill development by starting with low-risk decisions can assist in the maturation process.¹¹ Collaborations will need to be documented in the patient’s record to show that the views of the child are taken into account.

Table 3: Opportunities for Collaboration With Children^a

1. Hospital child advisory councils.
2. Designing and planning of pediatric facilities.
3. Development of patient educational materials directed toward children versus adults.
4. Interdisciplinary rounds.
5. Acting faculty for graduate and undergraduate pediatric health care programs.
6. Quality improvement and safety teams.
7. Policy and procedure development.
8. Pediatric research program agenda setting.

^aFrom Dixon-Woods et al,¹² American Academy of Pediatrics Committee on Hospital Care, Institute for Family-centered Care,¹⁹ MacNaughton et al,²⁰ and Institute for Family-Centered Care.²¹

Dr William G. Bartholome, a longtime advocate for the voice of children, wrote before his death, “I would propose that children and adolescents should always be included in health care decision-making to the extent of their capacity and willingness to do so, ie, that they should never be excluded.”^{15(p981)} I hope that treating young people with this degree of respect will create and sustain long-term relationships with the health care system, which will benefit them with positive health outcomes.

Evidence-based outcomes concerning partnerships with pediatric patients in health care collaboration and decision making are lacking. Research is needed about children’s views and experiences of being informed and trusted by parents and the health care team.⁴ For authentic collaboration to occur, all parties must have a sense of trust. Children must know that they will be respected by adults when they attempt collaboration; both groups will make mistakes in this process, but that does not mean collaboration should not be attempted.⁴

Stifling the involvement of pediatric patients in decision making may influence later abilities, identities, and well-being.²⁰ Health care providers should reflect on the possibility that they have played a part in stifling the participative capacities of children in the past. In collaborative partnerships with young people, the power relationship can be viewed as a seesaw, where each side takes the lead according to the circumstance.²⁵ This view is congruent with that of the AACN Synergy Model for Patient Care,²⁶ in which the needs of patients and families influence and drive the characteristics or competencies of nurses and the entire interdisciplinary team.

Varying levels of comfort and competence among health care team members related to collaborations with children exist. Some may feel that a concrete age range is needed as a guide to determine when collaboration with pediatric patients should occur; however, age is only a number, and competence needs to be assessed just as it would with adult patients. Providers will need to reflect on the steps needed in their institutions and professionally to fully implement collaborations with pediatric patients and families. Patient care processes and unit flow also may need to be modified to accommodate the enhanced level of communication.

Note that children also have the right *not* to collaborate with the health care team. The

provider’s role is not to push for participation because of a desire for patients to gain independence in health care collaborations.¹⁰ The American Academy of Pediatrics has recognized that the perspectives of children, along with those of parents, are essential elements of high-quality clinical decision making and that these individuals are integral members of the health care team.^{7,8,19} Health care providers should hear the voices of children and their families, as the literature has established that outcomes are improved with collaboration.¹⁹

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Providing Adult and Pediatric Care in the Same Unit: Multiple Considerations: Erratum

In the Pediatric Perspectives column that appeared on pages 117–120 of the April–June 2013 issue of *AACN Advanced Critical Care*, the order of authors was incorrect due to an error that occurred during production. The correct order of authors is as follows:

Laura M. Ibsen, MD
Pamela M. Conyers, RN
Mary Frances D. Pate, RN, DSN, CNS

REFERENCE

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