Trainee Involvement in Advancing Pediatric Shared Decision-making

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Our next patient was one of many affected by a persistent upper respiratory tract infection during my subinternship. As I listened to the dense, coarse crackling throughout both of her lung fields, the 4-month-old girl launched into another coughing fit. Given her lack of improvement, our team felt strongly that she would benefit from continued observation and supportive care. In the midst of discussing our plan with the family, the mother interrupted, stating firmly, “For the past 4 days, you have ordered test after test, treatment after treatment, and we have gone along with it. But now, we want to take her home. Does our opinion even matter?”

After the parents reluctantly agreed with our treatment plan, I walked out of the room wondering, “Did their opinion matter? Could the mother’s frustration stem from our failure to adequately communicate all the aspects of her child’s illness? Did we attempt to balance parental goals of care with what we considered medically necessary?”

Shared decision-making is a concept in which health care providers, patients, and their families collaborate to determine what medical course of action is best for the patient. Proper implementation of shared decision-making involves the following 2 critical components: (1) informing patients and their families of the nature of the patient’s illness, including the risks and benefits of potential therapies, and (2) actively engaging them in the medical decision-making process, ensuring that patient and family preferences are both acknowledged and incorporated into the care plan. In its policy statements, the American Academy of Pediatrics has increasingly recognized shared decision-making as a medium through which families can become more engaged in their children’s care.

The benefits of shared decision-making (such as improved patient understanding of medical options, better medication adherence, and increased satisfaction with the physician-patient relationship) have been clearly demonstrated in adult medicine. The pediatric literature is comparatively sparse but promising. Advanced care planning guidelines developed for adolescents with terminal illnesses have helped elucidate patient values and enhance provider-patient communication. It also has been shown that parents engaged in shared decision-making in the treatment of otitis media are less likely to opt for antibiotics and are more satisfied with their care.

Despite these advances, pediatric shared decision-making is difficult to implement. Consider the first component of the process: the education of both parents and children regarding a child’s illness. Parents with low health literacy were found to be more satisfied with their care when more time was spent in the education process. Other studies have shown that parents who are more informed tend to have better medication adherence. Despite this, many providers fail to give families the information they need to make informed choices.

To cite: Gaw CE. Trainee Involvement in Advancing Pediatric Shared Decision-making. Pediatrics. 2017;140(3):e20171772

Dr Gaw conceptualized this manuscript, drafted the initial manuscript, and reviewed, revised, and approved the final manuscript as submitted.

DOI: https://doi.org/10.1542/peds.2017-1772
Accepted for publication May 31, 2017

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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FINANCIAL DISCLOSURE: The author has indicated he has no financial relationships relevant to this article to disclose.

FUNDING: No external funding.

POTENTIAL CONFLICT OF INTEREST: The author has indicated he has no potential conflicts of interest to disclose.
literacy may be unequipped to understand the rationale behind the care provided to their children. Similarly, a child’s understanding of his or her own care is affected by multiple factors such as age, emotional maturity, and education level. With limited time for each patient encounter, providing effective family education can be a complex task. As a result, parents or children may leave a visit without completely understanding the instructions regarding their plan of care and are thus unable to follow them effectively. Families who are not completely informed regarding a medical course of action may be unable to weigh the social or emotional consequences of testing or treatment.

Even if children and their guardians are adequately informed, challenges still exist in incorporating their values into the decision-making process. Many medical decisions in both outpatient and inpatient settings, ranging from checking vitals to antibiotic selection, are initiated by the provider and implicitly accepted by families. Although families typically do not object to provider-driven decision-making, the number of medical decisions in which they have a voice can be relatively small. Furthermore, in pediatrics, the patient may have even less input because his or her guardian is often the one with the legal authority to make medical decisions. Inadequately promoting autonomy in pediatric care may lead to feelings of disenfranchisement and marginalization among parents and children. Consequently, some patients and families may attempt to reestablish control over the care process, which can manifest as noncompliance, patient-provider decisional conflicts, or refusal of care.\(^{11}\)

Compared with provider-driven care, shared decision-making offers additional benefits, thus warranting its wider adoption in pediatrics. Given that both healthcare and sociocultural factors may prevent the effective implementation of pediatric shared decision-making, a multifaceted approach involving education, advocacy, and further research would be required to identify and address these barriers.

Pediatric trainees are a powerful and largely untapped resource in furthering pediatric shared decision-making. In most healthcare settings, trainees have more face-to-face time with patients than senior or supervising providers. Additionally, some trainees express a specific interest in using education or advocacy to address the social determinants of health. These are the same factors that affect the ability of families to effectively engage in shared decision-making.

How can interested trainees implement and practice shared decision-making with their patients?

One potential strategy is for trainees to use decision aids, which are tools that use interactive, plain language and patient-directed questions to highlight the comparative benefits and risks of specific treatment options. Several publicly available, pediatric-specific decision aids have been developed by the Cincinnati Children’s Hospital Medical Center that cover topics from medication choice in juvenile idiopathic arthritis to options for anticoagulation therapy.\(^{12}\) For example, the decision aid on anticoagulation therapy asks a patient or family to choose the statements with which they identify, such as, “I can swallow pills every day” versus “I can give myself shots.” Other statements elucidate additional preferences regarding food restrictions, medication monitoring, common side effects, and cost.

Multiple studies have demonstrated how decision aids can improve patient knowledge, reduce decisional conflicts, and encourage active participation in care.\(^{13}\) Trainees can employ these tools to elicit family values on important medical and social factors related to treatment as well as to confirm understanding of provider instructions. Furthermore, decision aids provide a framework with which to approach patient communication and education. Although clinical scenarios may vary, trainees can apply the methods and techniques used in decision aids in broader medical practice.

Regardless of their interests, trainees can find a niche in which they can actively participate in improving collaborative decision-making between providers and families. For those interested in education or advocacy, initiatives related to healthcare access, parental health literacy, and family empowerment in medical settings are all crucial to improving a family’s ability to engage in the shared decision-making process. Trainees interested in research or quality improvement can become involved in validating preexisting tools, such as decision aids, or in the development of novel interventions. Most importantly, for every pediatrician-in-training, simply recognizing the divide that children and their parents face in the patient-provider relationship can help us all become more conscientious care providers.

Although our 4-month-old patient continued to improve, I could not help but feel that our medical team had missed an opportunity to incorporate family preferences into our medical decision-making process. In this instance, shared decision-making could have provided us a means to develop a care plan that addressed the concerns of our patient’s family while still permitting us to provide the necessary medical care. In the era of patient-centered care, shared decision-making will become increasingly important in empowering patients and families in a care process that has been led...
traditionally by physicians. And trainees can play an integral role in advancing shared decision-making in pediatrics. We cannot expect every parent or child to be involved in every decision or to understand all diagnostic and therapeutic options at the level of a medical professional. We can, however, find new ways to connect biomedical science with human emotion and clinical acumen with family values to help patients and parents become more engaged in their care.

ACKNOWLEDGMENT

Special thanks to Allison L. Rhodes for her thoughtful review of this article.

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Trainee Involvement in Advancing Pediatric Shared Decision-making
Christopher E. Gaw
Pediatrics 2017;140;
DOI: 10.1542/peds.2017-1772 originally published online August 8, 2017;

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*Pediatrics* 2017;140;
DOI: 10.1542/peds.2017-1772 originally published online August 8, 2017;

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