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Balancing Parental Needs for Physicians' Technical Help With Physicians' Legal Protection

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Electronic cigarettes are not the only noncigarette product associated with increased likelihood of combustible cigarette smoking in AYAs,¹⁵ and advertising receptivity was associated with use of cigars, hookah, and smokeless tobacco in Pierce et al.¹ Similar to e-cigarettes, cigars and hookah are available in youth-friendly flavors, and their use in the adolescent population is appreciable.²

Pierce et al¹ reinforce what we might expect. We have known for decades that advertisements for combustible ciga-

rettes and other health-damaging products (eg, high-sugar foods) are effective in recruiting a new, younger customer base. The same principles apply to noncigarette tobacco products. The marketing of such products in youth-friendly flavors or packaging may enhance the risk of exposure to advertisements that promote use initiation of both noncigarette tobacco products and combustible cigarettes, posing a threat to the public health of this generation of adolescents and young adults.

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Balancing Parental Needs for Physicians' Technical Help With Physicians' Legal Protection

Amanda Rahman, DO; Shetal Shah, MD; Edmund F. La Gamma, MD

It is a confusing world. Technology advances daily, new knowledge gets disseminated instantly, and somehow everyone must make sense of it all. But can we, without expert guidance?

While worldly things evolve rapidly, parenting emotions remain constant. Neonatal intensive care hospitalization is a stressful experience for medically naive parents who serve as a proxy for their infants and must make important decisions



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with lifelong consequences on their behalf. Physicians have a unique and challenging role in this decision-making process. By virtue of their technical expertise, knowledge base, and professional duty, physicians also have a critical role in the lives of these infants. In

the article by Weiss et al¹ in this issue of *JAMA Pediatrics*, the authors question whether physicians and parents understand each other's priorities during the process of medical decision making.

Weiss et al¹ find that the specific circumstances in which families choose to retain decision making authority are matters involving higher risks and long-term outcomes. By contrast, decisions thought to have a direct benefit to their child and any urgent choices are relegated to the physician team. The report has implications for the informed consent process and suggests that both parents and physicians should reconsider the premise of these discussions. Two major questions are raised. First, how are parents best served by the consent pro-

cess? Second, under what situations should physicians obtain consent?

Today, consent legally documents patient/surrogate understanding of the risks and benefits of and alternatives to a therapy and demonstrates that physicians are acting under the legal definition of good faith. The article by Weiss et al¹ considers how patients and physicians might benefit from a consent process that includes a better understanding of when parents desire to cede control of treatments for their child to the physician. The article underscores the importance of information presentation in consent outcomes and the crucial role that context plays in counseling parents. For example, if resuscitation of a fetus of 23 weeks' gestational age is presented as a circumstance in which a high potential of benefit exists, as opposed to a circumstance with a high likelihood of harm, parental responses may differ. The resulting clinical approach may reflect the biases of the medical team rather than accurate parental preferences.

Traditionally, the spectrum of decision making is a continuum composed of 2 extremes: a paternalistic model of health care or an informed decision making process. In the first, the patient is passive, allowing the physician to assume a more authoritative role in decision making. In the second, more autonomous model, the physician shares information but does not share in the decision making.² The parent, serving as a surrogate of the child patient, is responsible for processing physician-provided information and drawing a conclusion, which is then communicated to a physician who acts primarily as an agent of parental preferences.²

Current perspectives argue for a shared decision making model. Notably, this has been endorsed by the American Academy of Pediatrics.³ However, it is likely that clinicians practice shared decision making less often than we think. Tucker Edmonds et al⁴ performed a pilot study of neonatologists' decision making roles in delivery room resuscitation counseling for periviable births, a common scenario in a neonatal intensive care unit. The study found that most physicians, even when explicitly asked what they prefer, continued to give only objective data and were unable or unwilling to provide a recommendation on resuscitation. Strikingly, few physicians asked about the values of the family; in fact, neonatologists tended to force parental autonomy, even when parents did not desire it.

Reasons for this behavior are unclear. One interpretation may be that physicians try to restrain themselves from unduly influencing parental decision making and therefore attempt to use data to sanitize an issue from muddying by emotion or personal beliefs. Simply put, the parents may seek guidance, but the physician is seeking protection from bias and potential legal insulation. Furthermore, physicians themselves may be uncertain or uncomfortable with the weight of these decisions and use the guise of parental autonomy to hide their own insecurity.

Weiss et al¹ also discuss how implications of decisions may affect parental involvement. Their findings show parents want to be involved most commonly in decisions that are highly likely to affect the big picture or in treatment decisions that are potentially dangerous. The authors describe

parental desire for children to survive with the best outcomes, and the tendency for parents to seek involvement in decisions that may impair this goal. However, details of how they achieve this outcome appear less important. To explain via analogy: an airplane passenger may want the pilot to fly the plane to London safely, but the altitude of flight is the pilot's decision. In neonatal health care settings, the focus is on the end result of optimal child health, not on clinical nuances. This is unsettling because physicians often provide many technical details of a choice instead of eliciting what parents actually want from the consent process. Consequently, physician weakness may lie in failing to ask what is important to families, and thus not knowing what decisions matter most to them.

As we see it, the problem lies not in how to conduct a shared decision model, but when it should be used. Advocates argue for using this process when the prospective decision has multiple options, no clearcut right or wrong choice, and consequences for the well-being of the patient or family.⁵ In practice, many routine decisions made by neonatologists fit these criteria but are not shared (eg, advancing feedings from 30 mL to 40 mL). The challenge for the clinician remains in gauging how large, controversial, or influential a decision need to be before it is necessary to formally involve families. Are we consenting for an overall strategic plan, or for all tactical turning points along the way?

In our opinion, another formidable question is to consider how much decision power clinicians are willing to forgo. Is it appropriate to surrender all important decisions to incompletely informed lay personnel? What, then, is the meaning of expert opinion? Shifting the current barometer of decision making too far away from medical control by empowering parental authority over all decisions can have unintended consequences, especially during intensive care interventions. Consider debates over vaccines causing autism or parental refusal to give vitamin K after birth; these were well-intended family opinions that were not based on medical facts. Indeed, these positions may be better characterized as examples of patient/surrogate autonomy unconstrained by medical insight and expertise and, perhaps most disturbingly, exhibiting a lack of trust.

Physicians generally consider the informed consent a legal document, fearing the reality of lawsuits citing absence of informed consent. As a result, all procedures and many decisions require consent. However, the reality is that the informed consent process becomes cumbersome and often falls to the bottom of an already busy to-do list. Instead of being an optimal time to truly discuss goals of care, it becomes a rushed process to get a form signed, which means it is not always informative. In her review, Grady comments on the lack of power of a signature.⁶ Although we consider written consent necessary to truly consider a patient informed, the reality is that a signature is a superficial marker of an apparent understanding and agreement.

There may be some middle ground in how medicine navigates 2 polar models of decision making. If parents feel overwhelmed and incapable of making truly informed decisions, some may prefer a more paternalistic physician role. Parents

can also experience guilt in life-or-death decisions and may desire the physician to make choices, which absolves them of the burden. We argue that while it is important to provide parents data, such data only become information when the physician provides an expert opinion to interpret them and guide the decision making process. A parental desire to be informed by facts must not be misinterpreted as becoming knowledgeable enough to have an expert opinion on a complex topic that they were not trained to manage.

While it may be a long time before we alter the legacy of consenting (or continue making it more complex), the study by Weiss et al¹ serves the purpose of focusing attention on the

topic by providing patient perspective. The study by Weiss et al¹ reminds us that communication with families will continue to be a challenge in the neonatal intensive care unit as patient expectations of autonomy continue to expand and paternalism diminishes in health care. Because a little knowledge can be dangerous, awakening this issue both hinders and helps with the challenge of optimal medical decision making, including a requirement for improved health literacy in our patient population. The solution lies not only in providing black-and-white data, but also in wisely working with parents to identify a shared goal, work toward that goal, and determine which components of care need discussion.

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Should Pediatricians Be More Proactive in Counseling Children About Skin Cancer Risk? Implications of the USPSTF Recommendation Statement

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The most recent issue of *JAMA* includes the updated recommendation statement from the US Preventive Services Task Force (USPSTF) on behavioral counseling to prevent skin cancer.¹ In the same issue is the supporting evidence report and systematic review.² The recommendations differ notably from the 2012 iteration³ in the following ways: (1) counseling for persons with fair skin types is now recommended as early as age 6 months, down from age 10 years; and (2) selective counseling is now recommended for adults older than 24 years with fair skin types. The first of these new recommendations is already well known to pediatricians. Intervening early with parents and appropriate-age children likely helps to shape safe future behaviors and decrease skin cancer risks; not doing so will leave those same children, conditioned to bad habits over the span of their youth, relatively refractory to later education. A broad coalition of stakeholders has endorsed this guidance, including the American Cancer Society,⁴ the Royal

Australian College of General Physicians,⁵ the American Academy of Pediatrics,⁶ the American Academy of Dermatology,⁷ and others.

Nonetheless, these recommendation updates from the Task Force are important to pediatricians for several reasons. First, skin cancer is the most common type of cancer in the United States, and it is increasing in frequency.⁸ Melanoma is the second leading cause of death in patients aged 15 to 25 years.⁹ In my own residency training in the 1990s, I was taught that a child born in the United States had a 1 in 70 chance of developing malignant melanoma. I teach my own residents today that that same risk is closer to 1 in 40. Encouragingly, recent trends have identified a modest decline in pediatric melanoma incidence from 2004 through 2010 after years of 2% to 3% annual increases.¹⁰

Second, the strongest connection between UV radiation (UVR) exposure and skin cancer is in childhood and adolescence. For most individuals, the majority of lifetime UVR exposure occurs prior to age 18 years. There is also some evi-



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