ETHICS ROUNDS

A 6-Month-Old With Vaccine-Hesitant Parents

abstract

Many primary care pediatricians find vaccine hesitancy to be one of the most frustrating situations that they face. Parents who refuse to vaccinate their children implicitly call into question an intervention that most pediatricians see as one of the safest and most effective health care interventions of all time. Many pediatricians respond by refusing to care for children whose parents refuse vaccines, and some may consider that the parent’s refusal warrants referral to child protective services. We present a case in which a pediatrician faces this dilemma, with responses from pediatricians in academia and private practice. Pediatrics 2014;133:526–530

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KEY WORDS
vaccines, ethics, parental rights, law

ABBREVIATION
AAP—American Academy of Pediatrics

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Many primary care pediatricians find vaccine hesitancy to be one of the most frustrating situations that they face. Parents who refuse to vaccinate their children implicitly call into question an intervention that most pediatricians see as one of the safest and most effective health care interventions of all time. Many pediatricians respond by refusing to care for children whose parents refuse vaccines, and some may consider that the parents’ refusal warrants referral to child protective services.

In this month’s ethics rounds, we present a case that raises this issue. We then ask a group of experts to guide us through the ethically controversial choices. Respondents include Douglas J. Opel, a general pediatrician and bioethicist at Seattle Children’s Hospital; Monica Richter, a pediatrician in private practice in Renton, Washington; Saad B. Omer and Walter A. Orenstein of the Emory Vaccine Center; and Kristen Feemster, an infectious disease specialist at the Children’s Hospital of Philadelphia.

THE CASE

You are seeing a 6-month-old boy for his health supervision visit in your primary care practice. This boy is completely unimmunized at his parents’ request. You explain to the parents, as you have on each of their well-child visits, that their son is at risk for a life-threatening disease. You once again strongly encourage them to immunize their son. They remain steadfast in their refusal because, as they tell you, they strongly believe that the risks of immunization outweigh the benefits. In particular, they are concerned about the safety of vaccines at his young age and believe that their child’s naturally strong immune system will protect him. Recently, you and your colleagues have been seeing a lot of pertussis cases in your practice, and according to the Department of Health, there have been 241 cases of pertussis in children <1 year in your state in the last year. There have been >2000 cases statewide across all age groups, which is a 1000% increase over the previous year and exceeds state-defined epidemic thresholds. As of yet, there have been no deaths from pertussis among children <1 year. What would your next steps be in caring for this child and family?

Response of Dr Douglas J. Opel

This case illustrates the classic ethical tension in public health: weighing the competing values of individual choice and the common good. Pediatric providers are often at the center of this balancing effort. While trying to preserve a therapeutic alliance with parents, pediatric providers must decide at what point it might be ethically justifiable to intervene against parents’ wishes to protect their child’s or the public’s health.

The presumption in US law is to respect parental autonomy and family privacy. Parents are presumed to best understand the needs and interests of their children. Parents are therefore allowed wide discretion in the decisions they make on behalf of their children. But parents’ rights are not unlimited. Those rights can be overridden when they make decisions that place their child’s health, well-being, or life in jeopardy. The benefits and burdens associated with a decision, and importantly, their likelihood of occurring, therefore are central to whether a parent’s decision reaches this harm threshold. To determine whether state intervention to override the parents’ wishes in this case would be justifiable, we must evaluate the benefits and burdens of all possible options to determine whether their refusal poses significant risk of serious harm to the child.

We can begin this evaluation by focusing on the risk. The state is currently amid a pertussis epidemic: 241 cases of pertussis among children <1 year and >2000 cases total have been reported this year in the child’s community. Although these numbers are hard to interpret principally because of underreporting and uncertainty about the total size of the population at risk, the cumulative incidence or an incidence rate offers a reasonable estimate of the level of risk to a child of contracting pertussis. We can develop an incidence estimate by extrapolating from recent pertussis epidemics. In the 2010 California and 2012 Washington State epidemics, the pertussis incidence in children <6 months was 445.9 per 100 000 persons and in children <1 year was 428 per 100 000, respectively. Therefore, the 1-year risk of pertussis during these epidemics was ~0.4%.

Applying this estimate to our case, I would argue that this level of risk, which, even during an epidemic, is <1% risk to a child <1 year old, is not high enough to justify seeking state intervention to interfere with the parents’ wishes. It is hard to argue that a <1% of risk is “significant” when this level of risk approximates the risks associated with the DTaP (diphtheria-tetanus-acellular pertussis) vaccine itself: fever (<1%), hypotonic-hyporesponsive episode (<1%), and seizure (<1%). Risk, however, is only part of the equation: what is the harm associated with pertussis if a child <1 year was to become infected? Children with pertussis suffer harm: ≥50% may be hospitalized, ~25% will have major complications, and ≤1% will die and these risks are highest in the first 6 months of life. However, I would again argue that the level of harm a child is likely to experience is not serious enough to justify intervening against parent wishes. In Washington State, where our nonmedical exemption rate for required kindergarten-entry immunizations is 4.2% (seventh worse in the nation), I am not aware of any case in which the state has compelled a parent to immunize their child against their wishes, in epidemic conditions or otherwise.
There are similar situations where we would likely respect parental refusal of a high-benefit, low-risk intervention because of the overall low risk of serious harm to the child, such as parenteral administration of vitamin K prophylaxis to a term infant. Although I would earnestly explore alternatives (for example, oral vitamin K), I would not compel a parent to give vitamin K to their child. Likewise, I think the most appropriate next step in caring for this unimmunized child would be to explore options to reduce his risk of contracting pertussis, such as ensuring that the parents and close contacts are up-to-date with Tdap (tetanus toxoid, reduced diphtheria toxoid, and acellular pertussis, adsorbed): cocooning may decrease the risk of transmission to the child. I would also ensure that the parents are adequately informed about the symptoms of pertussis.

All this said, it is hard to ignore the burdens an unvaccinated child poses to the community. These burdens can be significant: it cost $175 000 to contain a 2008 measles outbreak in San Diego started by an intentionally unvaccinated boy. Although consideration of these burdens often extends beyond the doctor-parent relationship and ultimately may not tip the balance in favor of limiting parental choice, other societal mechanisms may exist to hold parents accountable for their decisions. If others are harmed by a parent’s decision to refuse to vaccinate his or her child, for instance, perhaps that parent should be held liable.  

Response of Drs Saad B. Omer and Walter A. Orenstein

There are 2 potential types of actions a physician can take in situations in which a family refuses to accept recommended vaccines: (1) decline further care to the family or (2) continue to provide care but use strategies to change their mind about vaccination over time and mitigate effects of non-vaccination. Any decision in this context requires balancing 3 sets of interests: (1) interests of the child whose parents are refusing vaccines, (2) parental autonomy, and (3) interests of other children in the practice.

Vaccines have been one of the most effective preventive tools for infant health. Therefore, vaccination has a clear benefit in protecting this infant from vaccine-preventable diseases, even after accounting for potential adverse events associated with each vaccine. Parental autonomy for children’s health-related decisions is well recognized (although this autonomy is not absolute). On the other hand, if this family is dismissed from the practice, they are likely to find a practice more sympathetic to their position on vaccines. Parents who refuse vaccines tend to seek care from providers who have less faith in vaccine safety compared with health care providers of vaccinated children. If the family seeks care from a physician more sympathetic to their position, there is a lower likelihood of an ongoing conversation regarding vaccine promotion to occur. Many parents who refuse vaccines for their young infants subsequently get their child vaccinated at older ages. In the case of this 6-month-old infant, parents may be more open to vaccination once the child is older. It is in the best interest of the child to continue receiving care from a “pro-vaccine” physician. Furthermore, the provision of some vaccines is better than total non-vaccination, and the pediatrician may be able to convince the family to accept some vaccines. Moreover, for some diseases such as influenza and pertussis, parents who refuse vaccines for their children should be strongly urged to get vaccinated themselves against these diseases to decrease the likelihood of transmission to their infants. Pediatric and family practice clinics have children who are unprotected against vaccine-preventable diseases due to reasons other than vaccine refusal. For example, even for highly efficacious vaccines, some children do not mount a protective immune response (vaccine failures); some children have legitimate medical contraindications; and some children may be too young for vaccination, yet still susceptible (eg, an 11-month-old not yet vaccinated against measles). It could be argued that dismissing an unvaccinated child from a practice is in the interest of other children in the practice because unvaccinated children pose a risk to other children they interact with. However, in this situation, there are fewer restrictive options that preserve the interest of other children in the practice. For example, unvaccinated children could have a separate section of the waiting area. Moreover, they could be restricted to appointment times at the beginning or at the end of a clinic, minimizing their exposure to other children in the clinic. Any burden placed on vaccine-refusing families due to fewer appointment options would be reasonable because it does not substantially restrict parental autonomy while preserving interests of children whose parents do not refuse vaccines.

We recognize that many practices may not have space for separate waiting rooms. However, if they do not, unvaccinated children could be asked to wait in their cars until an examination room is available.

Another option to address vaccine refusal in clinical settings is to require that parents sign an informed declination form. These forms outline the rationale for vaccination, risks associated with nonvaccination, adverse events associated with various vaccines, and misconceptions regarding vaccines. Two good templates of such forms have been developed by the American Academy of Pediatrics (AAP) and the Immunization Action Coalition.
There are no studies on the prevalence of such forms in pediatric practices in the United States.

In summary, the overriding concern is what is in the best interests of the child and that interest is in continuing a relationship with the family with the hope over time to convince them to accept vaccination of their child. Discharging the family can compromise the health of the child by funneling the child to a provider who does not believe strongly in vaccines. Moreover, efforts of pediatricians to counsel families need to be reimbursed because discussions require physician time. Insurers should reimburse for these efforts.

Response of Dr Kristen Feemster

When parents refuse some or all of the recommended vaccines for their young child, the pediatrician must balance 3 things: (1) the relationship they have established with the child’s family, (2) a desire to respect the family’s preferences and beliefs, and (3) their desire to provide the best care possible to protect the health of the child. There are only 2 possible responses: to work with the family to encourage immunization or to request the family chose another pediatrician due to this conflict. The parents believe they are making the best decision for their child. You believe that they are refusing one of the most important elements of pediatric care. The AAP recently reaffirmed their recommendations for responding to parents who refuse immunization for their children. The policy statement concludes that “In general, pediatricians should endeavor not to discharge patients from their practices solely because a parent refuses to immunize a child.” Instead, pediatricians are encouraged to maintain the relationship in order to provide a platform for continued communication that could potentially result in a change in belief. I disagree.

Counseling parents is certainly appropriate. They should know that pertussis is actively circulating in many communities and that young infants are at highest risk of severe disease. Sharing this information with real-time data and personal stories could potentially be effective. This approach may help emphasize that the choice to forego vaccination is not between a vaccine and no vaccine, it is between a vaccine and being susceptible to a vaccine-preventable disease. Parents need to know that when children do not get immunized, outbreaks of vaccine-preventable disease follow. This situation has occurred with measles, mumps, varicella, and pertussis in communities throughout the United States and Europe.

Parents should also be informed that vaccines are one of the safest interventions recommended for children. Their approval requires more safety data than any other medication. Millions of vaccine doses are safely administered each year. If a vaccine-associated adverse event does occur, it is most commonly mild; serious adverse events are extremely rare, especially compared with the likelihood of a severe outcome from a vaccine-preventable disease like pertussis. No vaccine or medication is 100% risk free, nor is a decision to leave a child unvaccinated.

If their decision does not change after this information is communicated, I would argue that the pediatrician is compelled to act as an advocate for the infant and the other children in his or her practice. I would discharge this family from my practice. Routine immunization according to the Advisory Committee on Immunization Practices is a standard of pediatric care that offers significant direct benefit to both individual children and the community. As pediatricians, we are obligated to provide the standard of care and protect patients under our care based upon the central tenet of medical practice, “First do no harm.” By not vaccinating this patient, we are playing a role in putting the infant at risk. As such, a pediatrician is justified in telling a family that he or she cannot provide the parents’ decision to leave the child unvaccinated. A pediatrician also has a responsibility to the other children in his or her practice who would be at risk of exposure if this unvaccinated infant develops a vaccine-preventable disease.

To maintain the profound public health impact we have seen from vaccines, immunizations cannot be optional. Accommodating refusals can send a message that vaccines are not really necessary. To confront the strong messages that question vaccine safety and efficacy and result in misperceptions, we must have equally strong messages in support of vaccination. It is important that the pediatrician listen to and acknowledge parents’ beliefs. One of the key contributors to rising vaccine hesitancy is an eroding trust in medicine and public health. If communication from pediatricians is to remain effective, we must do what we can to maintain trust. We cannot address concerns without knowing what they are. But when education and strong recommendations have not worked, action speaks louder than words.

Response of Dr Monica Richter

First, I would advise the parents that it is their decision whether to vaccinate their child. My role is to educate and make recommendations. Then I would ask them if they are open to discussing their decision. If not, then I recommend that they visit reputable Web sites such as those of the AAP or Centers for Disease Control and Prevention for more information. I will also tell them that I feel vaccines are one of the most important medical services that I provide and I will continue to revisit the subject at each visit. Vaccines are safe and effective, and there is no scientific
evidence that they cause autism. If they have any information to the contrary, I would like to review it with them. Then they are asked to read and sign the refusal-to-vaccinate form available from the AAP (revised September 2012). I should note that every nurse in my office reviews the vaccine records and discusses recommended vaccines with each family at each visit, well or sick, before I enter the room. This procedure emphasizes the importance of vaccines, and I know when families are opposed to vaccines as soon as I enter the room.

If the parents are open to discussion, I would then ask them to tell me what they know about the immune system. From there it is easy to explain how the immune system gets stronger after each infection and how vaccines boost the immune system without the risk of disease. I would mention that vaccines are better than medications such as antibiotics or antiviral agents because the benefits of medication only last for as long as you take them, whereas the immunity from vaccines is long-lasting.

Furthermore, prevention of disease is always preferable to treating disease. I would close with stories of children who have died unnecessarily because they were unvaccinated and emphasize the danger of pertussis in children under 1 year. The recent statistics are helpful. In addition, I would add that adults and adolescents often have milder forms of the disease and can expose their child unknowingly. My final statement is about personal experience with meningitis and how we saw several children with meningitis each year before the introduction of the Haemophilus influenzae type b vaccine. The parents usually agree to vaccinate or ask for Web sites with more information.

When parents continue to refuse immunizations, it is often because of cultural reasons (ie, some say, “people in my country do not vaccinate”) or because they know of someone who was reportedly harmed by a vaccine. I do not refuse treatment to these patients but continue to discuss the issue at each subsequent visit and with each subsequent child.

JOHN D. LANTOS COMMENTS

Parental vaccine hesitancy always exists in a semistable equilibrium with outbreaks of infectious disease. When children were dying of H1N1 influenza, and vaccine was in short supply, parents camped out on the steps of public health clinics to get vaccine for their children. When disease is common and deadly, parents want their children to be immunized. As a result, the prevalence of disease goes down. As the prevalence of disease goes down, more people refuse immunizations for their children. They are gambling. The odds are in their favor. At first, most of the kids are fine because herd immunity protects them. As herd immunity wanes, new outbreaks occur. Children die. As a result, more parents again choose to immunize their children. This dynamic has existed since the early days of vaccination. The dynamic will only change as a result of continued efforts at education by pediatricians, policy makers, and parents who have lost the gamble.
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