**CHALLENGING CASE: FAMILY RELATIONSHIPS AND ISSUES**

**Parental Refusal to Immunize a 2-Month-Old Infant***

**CASE**

At a 2-month health supervision visit, Monica’s pediatrician was surprised by her mother’s wish to withhold immunizations. At prior encounters with her parents, including a prenatal visit, the meeting after Monica’s birth, and the 2-week health supervision visit, there was no indication that standard immunizations would be refused. Monica’s parents informed her pediatrician that the potential side effects from the immunization led them to think that their healthy child should not be immunized. After talking with other parents in the neighborhood, watching a television program on “children who were brain damaged after getting their shots,” and looking at several web sites for parents on the Internet, they concluded that it was safer to withhold the immunizations. “Monica is so healthy. . . . why give her shots that may make her very sick?”

Monica was the first child born to these college-educated parents who had been married for 5 years. The pregnancy was full term and notable for two transient episodes of spotting in the first trimester. Both parents looked forward to Monica’s birth. There were no perinatal problems, breast feeding was successful with an appropriate weight gain, and the physical examination was normal.

The pediatrician explained to the parents that she understood their concerns. “Most of the things we give children for prevention or treatment of disease may be associated with possible side effects. In the case of immunizations, the chance of a serious side effect is much less than the risk that Monica might acquire one of the diseases we can prevent with an immunization. I have seen a few unimmunized infants who were hospitalized with a very serious case of whooping cough, one of the diseases we can prevent by immunizing Monica.”

The parents thanked the pediatrician for the information and agreed to read several pamphlets about immunizations. The pediatrician observed that her interchange with the parents was cordial but stressful, for both herself and Monica’s parents. As the parents left the office, she wondered if there was a more effective way to talk about immunizations with parents who refuse to immunize their children.

These skills form the foundation for a therapeutic relationship with children and their parents. Pediatricians and other child health clinicians are often challenged by either misinformation or preformed ideas about health and health care that guide some parents to deny needed care to their children. The office visit with Monica’s parents requires significant skill in order to discover common grounds for a discussion of the parents’ beliefs and knowledge while opening up an opportunity to redirect their decision to withhold immunizations. The pediatrician’s knowledge about the benefits and risks of vaccines must be blended with effective communication skills to insure a good outcome.

Three clinicians have been invited to comment on this challenging case. They represent primary care, public health, and a family-focused approach to pediatric clinical encounters. **Dr. Bret Pickering** is Director of the Pediatric Primary Care Clinic at the University of California San Diego. As a teacher and generalist, he discusses the experience of the primary care clinician. **Carolyn Beth Mazzella** is an Assistant Surgeon General and Chief Nurse Officer in the United States Public Health Service. Her work focuses on methods to maximize immunization levels for children through community-based programs. **Dr. Lane Tanner** is Director of Developmental and Behavioral Pediatrics at the University of California San Francisco. He has contributed significantly to our understanding of the doctor-patient relationship in the medical encounter by emphasizing ways to engage and empower families in the therapeutic process.

**Dr. Martin T. Stein**

Informative and therapeutic communication skills are essential elements in all clinical encounters.

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disconcerting especially when there is no prior discussion regarding immunization refusal. Prenatal visits are perfect opportunities to begin these discussions. Giving future parents immunization schedules and information before giving any vaccines may help alleviate parental anxiety towards vaccination. Next, the pediatrician must be knowledgeable about known side effects and their incidence, be honest and respectful of parents’ concerns, and discuss with parents the reasons for their refusal.

This case illustrates the ever increasing concern parents have regarding vaccine safety and the risk of adverse events. Chen and Hibbs, who reviewed these issues in depth, stated, “The art of handling vaccine safety concerns and vaccine risk communication has emerged as an increasingly important skill for health care providers.” Effective vaccine risk communication relies on the understanding of a few key concepts. First, people perceive risk differently based on their knowledge and life experience. Every pediatrician should be very knowledgeable regarding vaccine safety and associated risk. We are the experts parents turn to. Information, however, is not limited to just the vaccine package insert. Parents want to discuss the information they read in the media, hear from friends and family, or find on the Internet. It is incumbent upon the pediatrician to know the lay literature in order to help parents properly evaluate and interpret what is being stated about vaccine risk. A relationship of trust is also essential in communicating knowledge; without it, even the most compelling explanations will fail. Families who lived through the 1950s polio epidemics and pediatricians who have seen *Haemophilus influenzae* type b (Hib) meningitis will advocate for these vaccines much more passionately than today’s newly trained pediatricians who have not seen the ravages of these infections. Conversely, a family friend who has suffered an adverse event from a vaccine will provoke an unwaveringly negative position. These life experiences dramatically affect risk communication and decision making.

The next key concept of risk communication is that certain risks are more acceptable than other risks. For example, the risk of not vaccinating and potentially getting a disease is more acceptable than the risk of the potential adverse event after vaccination. Frequently people will prefer the risk associated with doing nothing over the risk associated with doing something. Also, people may perceive a vaccine to be less risky if it protects against a disease with which they are familiar, like polio, as opposed to a disease, like Hib, which may be quite foreign to them. Another aspect of risk communication is how the issue is framed. Concentrating on the positive fact that most people do not suffer adverse effects instead of the negative fact that a few do may communicate the idea of a more acceptable risk.

Finally, according to Chen and Hibbs, “risk communication is an interactive process that requires active listening and discussion.” Pediatricians need to be empathetic, patient, and have an open mind when listening to parents’ concerns regarding vaccines. If parents do refuse vaccines, the pediatrician should suggest an office visit to just discuss vaccine issues and bring additional resources to give the parents at that visit. Parents should be encouraged to bring any information they have that supports their concerns so that the subject can be evenly addressed. Parents should also be reminded that immunizations will be offered at subsequent well child visits. These subsequent discussions should be done in a nonjudgmental fashion to keep the tone of communication positive, but they should serve as reminders of the importance of pediatric immunizations.

**Resources for Professionals and Parents**

Readers may obtain additional information from the following resources:

5. CDC Immunization Hotline: 1-800-232-2522 (English); 1-800-232-0233 (Spanish)

**REFERENCES**


**Dr. J. Lane Tanner**

In this age of expanding information, blind trust in medical protocols is increasingly a thing of the past. In Monica’s case, her parents have become alarmed by information gleaned from the media, the Internet, and other parents about the potential for harm connected with immunizations. This is by now a familiar scenario to pediatric clinicians, and it illustrates a problem that is sometimes effectively resolved simply by explaining the relative risks that attend the choice to immunize or not. For Monica’s parents, however, the physician’s advice and urging was not sufficient, and the encounter was deemed stressful on both sides by the pediatrician. This dilemma has become commonplace enough that in its 25th edition, the American Academy of Pediatrics’ *Red Book* has for the first time included the section “Risk Communication,” which addresses the issue of parent questioning and refusal of immunizations.¹

The challenge in this case largely revolves around the physician’s capacity to stretch her role, from educator and expert in diseases of children to supportive inquirer, resource, and parent ally. This phy-
The physician has already demonstrated a major first ingredient of this role shift in her recognition of the unfinished and not-wholly-adequate aspects of the encounter. Her discomfort with the parents’ response to her good advice has signaled the need to shift into a “different gear,” that is, to become curious about how and why they think and feel as they do. We know from the presentation that the parents are expressing anxiety over the baby’s well-being. Thus, our clinician needs to better understand the roots of the anxiety, to listen and explore, and, for the time being, to suspend her mission to educate and exhort.

It seems safe to assume that these first-time parents are grappling with a wide range of major adjustments, individually and in their marriage, while attempting “to do everything right” for Monica. Even within this completely normative context, pediatricians should be aware of the barrage of potentially frightening vaccine-related information and misinformation that many new parents must contend with. Even the Centers for Disease Control and Prevention’s “Vaccine Information Statements,”2 which the National Childhood Vaccine Injury Act requires pediatricians provide to parents, may seem overwhelming because, at the 2-month visit, parents must absorb information on the side effects of, not one, but five different vaccines (DtaP, IPV, Hep B, Hib, and Pneumovax).

Beyond this first confrontation with an invasive medical procedure and amidst the usual maelstrom of family change brought about by a new baby, we would want to know if these particular parents carry special anxieties for their child.3 Perhaps the episodes of spotting during the first trimester set in motion some particular fears regarding the baby’s vulnerability. Was a miscarriage predicted? What more should the pediatrician know about their experience with the pregnancy? Were there difficulties with conception or a family history of ill effects of medical treatments? Do the parents have religious or philosophical objections? What advice or cautions have they received from extended family members, especially their own parents?

To explore these and other possible issues, I would envision our pediatrician closing the described visit with a statement along the following lines: “You have real concerns about the immunizations . . . Why don’t I give you a few weeks to read through the materials and think about this matter. Then I’d like to see both of you back for a follow-up, just to focus on this issue . . . because it is an important one.”

The essential ingredient of the follow-up meeting would then be the physician’s stated intention to listen and understand the parent’s concerns, starting with such inquiries as: “Tell me more about what you have heard,” and “What of that has really caught your attention?” This may be enough of an “opener” to encourage the parents to describe the personal meaning of immunization risk to their doctor. If appropriate, the doctor may want to further probe with such questions as: “Have there been past experiences in your family in which medical treatments (including immunizations) went badly?” and “Have you had particular worries about your baby’s well-being up to now?” Family interviewing skills, including active listening, a nonjudgmental approach, and a genuine empathy for the parents’ position and perspective are essential during this encounter.4

Attitudinally, the physician must avoid the trap of taking the parents’ reluctance as a criticism of her own expertise or feeling obliged to become the champion of immunizations (and medical science generally). Rather, her understanding that this situation represents a very real dilemma for the parents and her expressed intention to support them in their process of decision making provide the platform for bringing this issue to a well-considered resolution. This does not mean that the physician eschews her advocacy for immunizations. Her position needs to be expressed clearly and the reasons given in understandable terms. If the parents’ reluctance to immunize continues, she will want to realistically forecast the future problems attendant on this decision, including not only the real risks to Monica’s health, but also the burden to them as parents in knowing of her increased vulnerability to serious infection.

Can the pediatrician maintain a strong position in this matter and still serve as an active elicitor of the parents’ feelings and fears? Yes! In most cases, I would expect the parents to be grateful for such an opportunity for exploration as described above, given the significance of the decision they are being asked to make. The physician’s act of outreach to the parents will speak most eloquently to them that her intention is to base their newly developing relationship on trust, understanding, and honest discussion, and that they can expect this from her in all of their future encounters.

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REFERENCES

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Monica’s parents present a dilemma for her pediatrician, one that is increasing in complexity and frequency. Her parents are motivated by health concerns demonstrated by their behavior, education, and participation in health decisions that impact their child. These are the characteristics that every clinician desires in their patients. However, those same parental characteristics have enabled a choice against immunizing Monica.
Vaccines are one of the great achievements of biomedical science. We now administer 15 to 19 doses of vaccines by 18 months of age against 11 childhood diseases, and newer vaccines are on the horizon. The increasing complexity of vaccine schedules fuels parental resistance compounded, at times, by a blissful ignorance and misunderstanding. It is unlikely that Monica’s parents have ever seen a case of polio, measles, or diphtheria, and they may believe that those diseases no longer exist in the United States. The success of public health initiatives has created a sense of security with no visible threats. Concurrently, the development of pharmacological agents and technology has enhanced a confidence in curative medicine that minimizes prevention and personal responsibility in health care. Our health environment is severely challenged by this complacency.

Additionally, the rapid emergence of new knowledge and new sources of knowledge and communication strategies contribute to “info-clutter.” Pseudoscience is pervasive in some communities, coupled with a naive reliance on computerized information sources. Who has the correct information? Just as we need to maintain a healthy skepticism toward everything we read in the newspaper, we need to evaluate and examine critically materials available through the Internet. Who is the author, what are the credentials of the source of information, and can the information be validated and replicated? Health professionals must help Monica’s parents find and evaluate materials as part of an informed decision-making process.

Informed consent about adverse reactions to vaccines is another clinical challenge. Monica’s mother’s concerns are real, although they are out of proportion to the risk. The demand for the intense education about potential adverse effects and the plethora of informed-consent forms have given some parents the impression that serious vaccine-related side effects are more common than what we know from well established prevalence data. The public debate about an individual’s right to know and how we meet that need without enhancing anxiety has not found a satisfactory balance. Risk communication is a genuine clinical challenge.

How can we effectively approach Monica’s parents and give them the useful information to change their decision? When we learn about “selling” strategies, one of the first lessons is to not denigrate the competition. Monica’s parents must trust their child’s clinician—a difficult task to accomplish in the average 8- to 13-minute office visit. The clinician must enter into a partnership with Monica’s parents, respect their education, communicate with them in a clear manner about the scientific facts, and be accessible when they raise questions or bring new ideas to the discussion.

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Web Site Discussion

The Challenging Case was posted on the Developmental-Behavioral Pediatric web site and the Journal’s web site . The following questions were asked: How would you assist a primary care pediatrician who has experienced this clinical encounter? What could she have said to the parents to encourage acceptance of immunizations? What interview techniques may have lessened the stress or encouraged a more therapeutic dialogue? The response was extraordinary in that this case recorded the largest number of web site commentaries to date.

Gary Feldman, M.D., (Case Western Reserve University, Rainbow Babies and Children’s Hospital, Cleveland, Ohio) writes: This has been a common encounter in my previous primary pediatrics practice. The parents are often young and it is their first child. Although mostly unspoken and well concealed, their defensiveness toward the medical profession is present. They want the best for their child and don’t want to “mark” them with artificial interventions.

Acknowledging their strong nurturing motive, their desire for minimal interference, and for nature to take its course minimizes their defense. Adopting a collaborative stance with the parents is helpful. I gently point out that proactive intervention is ubiquitous in life and is proportional to the degree of potential danger—for example, using sunscreen, even with the preservatives and other unnatural ingredients, to prevent sunburn or the use of seat belts to prevent serious injury and death. Similarly, what about preventing the unexpected, but life-threatening, illness?

Lyn Laborel, M.D., (Private Practice, Tarzana California) comments: A parent may look you in the eye and say, “No” to your best advice about what their infant needs! We can choose to hear it as a personal attack on our competence, or as a declaration of their stubborn ignorance, and miss a wonderful opportunity to build a relationship with them for the sake of their child.

My initial approach is one of careful active listening. I make it clear that this is very important and that we need to talk. I shift my body language, sit down in a chair, and give every signal that I have time and that I am ready to listen and value what they have to say. I usually begin by reminding them that my philosophy is that my role is that of an advisor. They are the parents and they make the decisions; they want what is best for their child and they bear the responsibility for those decisions. They hired me to give them the best advice I have, to partner with them in finding solutions that fit with what is best for their family.

I acknowledge how difficult it is to make decisions with so much conflicting information in our media-intensive world with so many experts telling parents what to do. I would ask Monica’s parents to “help me to understand your reasons for not immunizing your baby.” I don’t debate but rather listen and give
opportunity to be heard. I respond carefully at this point avoiding the point-counterpoint of debate. At the same time, I let them know that I have heard these same concerns from other parents who have come to different conclusions. The specific responses to parental concerns (e.g., pertussis and brain damage, “polio isn’t around any more,” or “my kids are healthy”) are not usually a challenge for pediatricians. What is difficult is maintaining a respectful attitude toward parents that makes it clear that we understand how hard it is to make these decisions. I also point out that the only way that their children will be safe from most of these devastating illnesses is if other children take the immunizations that they are declining.

We cannot respond to Monica’s parents by just handing out brochures or telling scary stories about disease in unimmunized children (they’re already pretty scared). We must acknowledge the emotional conflict behind the reluctance to immunize and use it to build a bridge of communication for the benefit of the child.

Susan Romeo, M.S., N.P., (Pediatric Nurse Practitioner, Child Care Health Consultation, Primary Care Pediatrics, Utica, New York) adds: In a situation such as that described with Monica and her parents, I begin by thanking the parents for raising the issue with me personally. I appreciate their willingness to enter into discussion with me and reinforce them for that.

I would direct the clinical interview with Monica’s parents in the following ways in order to lessen the stress and encourage a more therapeutic dialogue:

1. Ask yourself whether you truly believe that parents have the right to determine their child’s care. Consider where you as a clinician place this issue in relation to blood transfusions, abusive parents, etc. Knowing where your own line is drawn is critical to handling the situation in a nonconfrontational manner.

2. Giving the parent license to disagree with you and let you know when they feel coerced levels the playing field, but realize that ultimately the health care provider is still viewed as an authority figure, so don’t abuse the privilege.

3. Give voice to the parents’ own growth, development, and prior history. Watching mothers of 2-month-old babies hover anxiously over their children as they receive vaccines is enough to appreciate the intensity of parental emotional attachment with their baby at this moment. Acknowledge it and bring it out for self-examination.

4. Consider putting a face to vaccine-preventable disease. Recommend a parent-friendly web site (see Dr. Pickering’s references above).

5. And finally, keep lines of communication open. Positively reinforce any evidence, no matter how small, of the kind of interaction and decision making you would like to see. If these parents have trouble with you, they will likely have the same trouble with another primary care provider.

Sometimes it is an opportunity to help parents grow as well.

Edward Christophersen, Ph.D., (Children’s Mercy Hospital, Kansas City, Missouri) writes: I have found from clinical experience and from reading some of the literature on persuasion and attitude change that you can get a lot further if you make a carefully thought out point to a parent, but then do not push for closure. The parent’s defenses immediately come in if you turn it into a debate. However, if you make your point the first time, and drop it, you can return to the point at a later visit when the parent isn’t as defensive.

I guess I really learned this strategy by having two adolescents. Prepared to argue with almost any point that you make (with regard to such things as their friends, smoking, or drinking), they can’t really do so if we never let it turn into an argument. It gives them a chance to think about it without pressure.

I find that revisiting the issue several times, without pushing, is often the most effective strategy. There’s a great article that discusses parent resistance, from an empirical perspective: Patterson GR and Chamberlain P (1994): A functional analysis of resistance during parent training therapy. Clinical Psychology: Science and Practice, 1, 53–70.

Ronald Marino, D.O., M.P.H., (Winthrop University Hospital, Mineola, New York) writes: I have little to add to the discussion except that I believe that as a child advocate I have a responsibility to do the best I can to assure the health and well-being of my patient. Having a medical home is better than not. With the exception of immunizations, these children receive the benefits of all the other aspects of good health supervision, anticipatory guidance, and developmental surveillance. I give the counseling approach my best shot; however, many of these parents have clearly decided before they come to the office that their child will not be immunized.

Daniel P. Kohen, M.D., (Behavioral Pediatrics Program, University of Minnesota, Minneapolis, Minnesota) comments: For me the bottom line is the same as it is for any clinical encounter. The three most important things to do are Rapport, Rapport, and Rapport. No knowledge, wisdom, or list of references will take the place of that. Acknowledging the parents’ commitment to their child to do the best they know how and honoring their thoughtfulness and courage in bringing up a controversial subject are essential—e.g., “I’m glad you brought this up, and I’ll bet you knew it would not be a popular perspective to take, but I’m glad you did, so we could talk about it together. Please help me understand what led you to the decision you have made so far.” Saying “so far” lets them know that you believe that perhaps there is room for flexibility without hitting them over the head with the notion that somehow you have the right answer to which they have to ultimately adhere.

However, having said that, there remains the question, “Isn’t this a public health issue?” It is essential that parents know that by not immunizing their chil-
children they place other children at risk, ergo the public health consideration. We might ask, “Is failure to immunize your child against life-threatening illnesses medical care neglect?” I’m not talking about the force of doctors’ wills or about dishonoring individual patient’s and parents’ belief systems. I’m wondering about the “public good.” Is the issue under discussion limited to a matter of value conflicts? Does the unthinking/unreasoning infant have a “right” to be protected against life-threatening illnesses that is a more important right than his or her parents’ right and obligation to choose presumably in their best interests. And who decides?

Dr. Martin T. Stein

This challenging case generated one of the most lively discussions yet among clinicians who have participated in the Developmental and Behavioral Pediatric web site. Comments reflect a wide range of clinical experiences and points of view. Many of the ideas in the commentaries from Drs. Pickering and Tanner, Assistant Surgeon General Mazzella, and the web site participants suggest an opportunity for further studies that may clarify the most effective communication skills and therapeutic approaches for these challenging clinical encounters.
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