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Childhood Immunization: When Physicians and Parents Disagree

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KEY WORDS

immunization, health knowledge, attitudes, practice, physician-patient relations, treatment refusal

ABBREVIATIONS

MMR—measles, mumps, and rubella

CAM—complementary and alternative medicine

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abstract

Persistent fears about the safety and efficacy of vaccines, and whether immunization programs are still needed, have led a significant minority of parents to refuse vaccination. Are parents within their rights when refusing to consent to vaccination? How ought physicians respond? Focusing on routine childhood immunization, we consider the ethical, legal, and clinical issues raised by 3 aspects of parental vaccine refusal: (1) physician counseling; (2) parental decision-making; and (3) continuing the physician-patient relationship despite disagreement. We also suggest initiatives that could increase confidence in immunization programs. *Pediatrics* 2011;128:S167–S174

Phoenix, a 24-month-old boy, is brought in by his mother for his annual well-child physical examination. The physician notices that the child has yet to receive vaccination against measles, mumps, and rubella (MMR) and reminds his mother of the need to have her son immunized. The mother is hesitant and states that she has heard of the links between MMR and autism. Citing several recent cases of measles in the community, the physician stresses the need for the MMR vaccine to protect the young child, because they may be in the midst of a measles outbreak. He tells her that mortality rates range between 1 and 3 of every 1000 cases and that acute encephalitis, which may cause permanent brain damage, occurs in ~1 of every 1000 cases.¹ The mother counters that her chiropractor has discussed the issue of vaccination with her, including the topic of vaccination safety. In addition, the chiropractor discussed immune function and noted that treatments such as spinal manipulation and nutritional supplements, although not an alternative to vaccination, may optimize her son's natural immune function. The physician is frustrated and tells her that he is not comfortable with continuing care for Phoenix if she chooses not to listen to his professional advice. The physician wonders what he could have done differently to avoid this impasse.

Routine childhood immunization is important to both individual and public health. It is strongly promoted by the World Health Organization and by governments, public health authorities, and health professions worldwide.^{2,3} A majority of parents have their children vaccinated. However, persistent concerns about the safety and efficacy of vaccines, and whether immunization programs are still needed, have led a significant minority of parents to refuse vaccination. Are parents within their rights when refusing to consent to vaccination? How should physicians respond?

In this we article focus on routine childhood immunization. Other types of vaccine may raise different considerations, depending on data about risks, benefits, and long-term effectiveness, goals of the vaccination program, and other factors, but they are beyond the scope of this article.⁴⁻⁸ We consider the ethical, legal, and clinical issues raised by 3 aspects of our scenario: (1) physician counseling; (2) parental decision-making; and (3) deciding whether to continue the physician-patient relationship despite disagreement.

ETHICS

Communication and Counseling

There is more than one way to understand parents' views about immunization.⁹ Some parents have virtually no information, and when provided with data about harms and benefits, they usually (anecdotally) give permission for their child to be vaccinated. Other parents may have limited information or incorrect information that can be corrected by the physician, and yet others have a great deal of information and a firm philosophical stance that immunization is not what is best for their child. There are also divisions between complementary and alternative medicine (CAM) practitioners and some physicians about the merits and risks of vaccination.

Physicians' ethical duty is to assess how much information parents have and to explore the values and beliefs that underlie their views about immunization. Physicians should then fill in gaps in parents' knowledge about potential benefits and harms associated with both immunization and choosing not to immunize and make an evidence-based medical recommendation. It is then the parents' choice.

Parental Decision-Making

Parents have a duty to make decisions in the best interests of their children.

Diekema and the American Academy of Pediatrics Committee on Bioethics have noted that the risks to an unimmunized child living in a well-immunized community are low (although not as low as the risks when the child is immunized). Presumably, then, a decision to decline immunization may be tolerated. In their clinical report they contrast this case with the example of a child with a deep and contaminated puncture wound who may suffer serious harm if not given a tetanus vaccine.^{10,11} Such cases, which could be categorized as needing acute care, can be distinguished from immunizations, which would be considered preventive care.

Deciding Whether to Continue the Physician-Patient Relationship

Many physicians encounter parents who refuse vaccines for their children.¹² Are these physicians ever ethically justified in rejecting these families from their practice? What reasons might they offer for this decision?

One reason might be their concern for other children in their practice (eg, that nonimmunized children might expose other patients to disease). This is a real concern, but there may be other children in the practice who have not been immunized for medical reasons or for whom immunizations failed. To protect their patients during outbreaks, physicians should organize their practices to minimize risk of exposure, which would be the best way of protecting their patients and providing care to all who need it (including those who are not immunized). Another reason that physicians might wish to exclude particular families from their practice is because the families' values and beliefs differ to a great extent from the physicians', and they are not comfortable with families who choose to reject their professional advice. However, parents may accept or reject

physicians' professional advice, including and beyond that related to immunization, and still make good decisions regarding the health of their child. Respectfully disagreeing with parents while continuing to treat their child provides an opportunity for the physician to build trust and perhaps ultimately change the parents' views about immunization.

As a general rule, physicians should continue to care for children even when their families reject immunization.^{10,11} However, if a physician truly believes that he or she cannot continue to provide care for a family, he or she may end their relationship only after another physician has assumed responsibility for the patient or the parents have been given reasonable notice that the physician intends to terminate the relationship.^{10,13}

LAW

Counseling and Informed Consent

Health care providers are legally obliged to obtain informed consent before treating a patient. They must disclose all material information about the treatment, its risks and benefits, the alternatives (including nontreatment), and associated risks and answer patients'/parents' questions.^{14,15} Treating without consent, including vaccination, can give rise to civil liability, professional discipline, and even criminal liability.¹⁶ When advising parents, health care practitioners should provide full and complete information about the diseases targeted and the risks and benefits of proceeding with immunization or refusing it.

Parental Obligations

When children are not yet able to decide about treatment, then according to common law and in statutes that govern both consent to health care and child welfare, their parents or guardians are authorized to act as

their substitute decision-makers and consent to or refuse treatment on their behalf, absent demonstrated neglect or unsuitability.^{17,18} Parents and guardians are to make decisions in the child's best interests.^{17,19,20} However, determinations about what constitutes "best interests" will differ and are affected by value systems, religious and other beliefs, perceptions of risk and benefit, and other considerations. In recognition of these variations, the law allows parents considerable leeway in their decisions, provided that they, as the Supreme Court of Canada has stated, "do not exceed the threshold dictated by public policy, in its broad conception,"¹⁷ a standard that depends heavily on factual circumstances, medical expertise, and community values.^{21,22}

In the United States, all states have school-entry immunization requirements, although specifics vary among them.²³ As of 2010, all states permit medical exemptions, 48 permit religious exemptions, and 20 allow personal-belief exemptions.²⁴ School immunization is not mandatory in all countries. For instance, in Canada, only 2 provinces (Ontario and New Brunswick) require proof of immunization for specified diseases before first-time admission to school,* and exemptions are available on medical grounds and on grounds of religious belief or conscience.^{25,26} However, children who have not been vaccinated can be excluded from school during outbreaks of vaccine-preventable diseases.^{25,27} In addition, public health legislation generally authorizes required vaccination in the case of an epidemic or threatened epidemic of a communicable disease, but again, medical, religious, or conscience-based exemptions are allowed.^{28,29} Thus, common law and stat-

*Ontario imposes similar requirements for entrance into nurseries and preschools (see O. Reg. 262 made under the Day Nurseries Act, RSO 1990, c. D.2).

utory frameworks leave parents discretion to decide about consenting to routine childhood immunizations. In one of the few Canadian legal cases in which the parents' decision was challenged, the court held that refusing routine immunization did not provide sufficient grounds for state intervention.³⁰ If parents disagree about immunization, however, Canadian courts have tended† to find in favor of the parent who wants vaccination because it is in children's best interests.³¹ Otherwise, a legal challenge to a parent's decision is unlikely to be successful unless there is evidence of a greater need to protect either the child or the community from vaccine-preventable infectious diseases than is generally present with routine childhood vaccinations.³² For instance, in *Children's Aid Society of the Region of Peel v T.M.C.H.*, the court authorized vaccination, despite parental refusal, of a newborn whose mother was a hepatitis B carrier.³³ Similarly, in the United States, the American Academy of Pediatrics Committee on Bioethics has noted that when immunization rates are high and disease prevalence is low, the risk to others from small numbers of unimmunized children "does not usually pose a significant-enough health risk to others to justify state action."^{10(p1430)}

Deciding Whether to Continue the Physician-Patient Relationship

Parents of young patients are entitled to refuse treatment, even if strongly recommended by physicians, provided that doing so does not result in serious risk to the life or health of the child.^{17,20} Physicians can discontinue professional services to a patient but, in

†See *Chmiliar v Chmiliar* (2001), A.J. No. 838, 2001 ABQB 525 (Q.B.) (parents disagreed about vaccination; 10-year-old son ordered vaccinated; 13-year-old daughter found not able to make voluntary decision because of influence of mother's irrational fears, but vaccination not ordered because not in her best interests, given her age and opposition).

keeping with their professional obligations, must not abandon the patient. Regard should be had to the legislation, regulations, and policies in the jurisdiction in question if the physician plans to sever the relationship. Generally, if initiated by a physician, the patient or parents must at least be given reasonable opportunity to arrange alternative services.^{10,34,35}

Considering No-Fault Compensation

The Manitoba Law Reform Commission noted that “[p]arents are persuaded to place great reliance in the integrity and safety of the routine childhood immunization system and to expose their healthy children to it,” protecting not only that child from disease but also contributing to the protection of the whole community.³⁶ However, establishing legal liability for vaccine-related injury through a civil lawsuit is difficult; most such claims fail.^{5,27,37,38} The United States and England have implemented administrative compensation systems for vaccine injury^{39–43}; in Canada, only Quebec has done so.^{44–46} Although benefits available are broad, the need to establish a causal link between the vaccine and the harm suffered still limits eligibility.^{47,48} Administrative compensation systems can be structured with less stringent eligibility requirements than needed to establish civil liability and potentially compensate more claimants.^{49–54} No-fault compensation in those rare instances when serious injury occurs could ease concerns about participating and redress harm.

CLINICAL RESPONSE

Counseling and Education: Communicating With Patients and CAM Practitioners

In 1998, a now infamous study linked the MMR vaccine to autism.⁵⁵ The study was retracted by almost all of the co-authors,^{56,57} several comprehensive re-

views concluded that autism is not linked to MMR,^{58–60} and the medical journal that published the study retracted it.^{61,62} In addition, the physician/lead author Andrew Wakefield and 2 co-authors were the subject of professional misconduct proceedings. In 2010, England’s General Medical Council concluded that charges against Dr Wakefield of conducting invasive research on children contrary to their best interests and without ethics approval, presenting results in a dishonest and irresponsible manner, and others had been proven. Another hearing concluded that these actions constituted serious professional misconduct, and the council banned him from practicing medicine.^{63,64} Despite this history, the scientific community in Britain has had little success combating misinformation about MMR in the media and has seen the number of children who receive the MMR vaccine plummet.^{65,66} The rates of immunization are reaching a point at which that if these levels persist, the United Kingdom might once again face epidemics^{67–69} and/or the reemergence of endemic measles,⁷⁰ which is a harrowing prospect that seems more grim when considering the potential ripple effects throughout the rest of Europe and even North America.^{71,72} These statistics also suggest that health care professionals and public health agencies have not yet learned how to communicate effectively with parents about immunization. The occurrence of vaccine-associated adverse events cannot be denied,^{73,74} but they are rare, and given the overwhelming evidence in favor of immunization, medical authorities widely accept that vaccines provide safe, cost-efficient, and highly effective protection against infectious diseases. Most parents recognize that immunization is important for their children’s well-being, but a significant number of them are also concerned about vaccine safety.⁷⁵ This negative view of

vaccination is particularly prevalent among parents who also use CAM.^{23,76–78}

Because it becomes even more difficult to communicate the importance of immunization when a physician’s professional opinion is contradicted by a CAM practitioner, it is important to examine their views (in this scenario, chiropractors). Chiropractic is among the most frequently used CAM practices and one of the most established CAM disciplines in North America.^{79–81} The Canadian Chiropractic Association “accepts vaccination as a cost-effective and clinically efficient public health preventive procedure for certain viral and microbial diseases, as demonstrated by the scientific community.”⁸² Nonetheless, surveys of chiropractors have revealed that many of them still have misgivings about the safety of immunization.^{83–87} One would assume that a way to increase acceptance of vaccinations would be education and discussion with CAM practitioners. However, a randomized trial by Wilson et al⁸⁸ revealed that neither evidence-based teaching nor presentations from polio survivors changed chiropractic students’ perceptions of immunization. In fact, the provaccine presentations may have even strengthened antivaccine attitudes, which suggests a need for different and unique educational strategies. One reason for this failure may be that educational programs have not addressed practitioners’ concerns, such as questions regarding safety of adjuvants and preservatives used in vaccine preparation. Learning about CAM practitioners’ questions and answering them could assist in assuaging their concerns.

Ultimately, physicians must inquire about their patients’ and parents’ beliefs in a respectful manner, maintain an open and understanding relationship with families, and use their role in

providing continuing care as an opportunity to educate families and continue discussion. The best place to start such conversations may be reminding the family that physicians and parents share a common goal: the best interests of the child. However, when there is no evidentiary basis for parental refusal of a particular vaccine or when the evidence establishes parental beliefs about a vaccine to be untrue, physicians should make those facts clear. Parents who are unwilling to consent to vaccination may be prepared to accept a compromise (eg, vaccination with a single component of a multivalent vaccine, staggered doses, adjusted scheduling). Although some physicians find this contentious, because it is not in keeping with current guidelines, others argue that some vaccination is preferable to none.^{89–93}

RECOMMENDATIONS

Parents, while taking medical advice and statistical information about risks, benefits, and likelihood of harm into account, are not making a decision about an aggregate group but about an identifiable life—that of their child, whom they are charged to protect. They want to do their best to do so responsibly. However, people perceive and weigh risk differently.⁹⁴ In addition, even after discussion, some parents may feel that they do not receive sufficient information about the risks and benefits of vaccines and the risks

of illnesses they are intended to prevent.⁵⁶ These observations help explain the lack of confidence in childhood immunization programs that underlies some parents' decisions not to vaccinate.

1. In advising parents, health care practitioners should provide full information in clear language about the risks and benefits of immunization and the diseases targeted^{10,95–98} and information on the efficacy and risks of alternatives, including vaccine refusal. Information needs to be presented in a way that best supports informed decision-making, which ensures that parents have the necessary foundation for making sound decisions.^{99–105}
2. Physicians and other clinicians should tell parents when their beliefs about the vaccine in question are unsupported or disproved by evidence.
3. Physicians can discontinue professional services to a patient but must comply with applicable legal and ethical requirements when severing the relationship. Patients and parents are entitled to refuse treatment that a physician recommends; however, not every such disagreement should result in physicians discharging patients and families from their practices.
4. Educational programs for CAM practitioners about vaccines and

the diseases targeted should be developed, potentially through relevant educational institutions, regulatory bodies, and professional associations.

5. Public educational campaigns should also disseminate this information widely.
6. Policy-makers should consider reforming compensation systems to introduce no-fault compensation if a child should suffer a vaccine-related injury.

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