How to Communicate With Vaccine-Hesitant Parents

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KEY WORDS

vaccine safety, health care providers

ABBREVIATIONS

HCP—health care provider
AAP—American Academy of Pediatrics

MMR—measles-mumps-rubella

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abstract

Development of safe and effective vaccines is one the greatest medical triumphs. However, despite high immunization rates in the United States, 85% of health care providers (HCPs) will have a parent refuse a vaccine for his or her child each year. HCPs have the greatest influence on a parent's decision to vaccinate his or her child. To effectively communicate with vaccine-hesitant parents, HCPs must first understand the concerns of parents regarding immunization and understand influences that can lead to misinformation about the safety and effectiveness of vaccines. HCPs should establish an open, nonconfrontational dialogue with vaccine-hesitant parents at an early stage and provide unambiguous, easily comprehensible answers about known vaccine adverse events and provide accurate information about vaccination. Personal stories and visual images of patients and parents affected by vaccine-preventable diseases and reports of disease outbreaks serve as useful reminders of the need to maintain high immunization rates. Ongoing dialogue including provider recommendations may successfully reassure vaccine-hesitant parents that immunization is the best and safest option for their child. Pediatrics 2011;127:S127-S133

Immunization is a safe and effective preventive health measure that has saved numerous children from death or serious sequelae from vaccinepreventable diseases and is one of the greatest medical triumphs. Despite these facts, immunization remains an emotional issue for many parents. The media may focus on perceived vaccine dangers despite absence of scientific data to support the claims. The availability of information that is not always accurate makes it difficult for parents who seek information from a variety of sources to separate fact from fiction and can lead some to refuse vaccines by using the "first, do no harm" principle. Physicians and other health care providers (HCPs) have a responsibility to provide guidance to parents. A thorough understanding of parental concerns, including what influences the perceptions of parents, is a necessary prerequisite for effective communication between HCPs and concerned parents.

UNDERSTANDING PARENTAL CONCERNS

Characteristics of Vaccine-Hesitant Parents

The National Immunization Survey in 2003-2004 revealed that more than 28% of parents have allowed their child to be immunized while being doubtful that it was the correct thing to do (9%), delayed a vaccine (13%), or refused a vaccine (6%).1 American Academy of Pediatrics (AAP) surveys have shown that up to 85% of pediatricians annually encounter parents who refuse some or all vaccines.2 Despite these figures, immunizations rates in the United States have reached record levels. Contemporary studies have revealed that unvaccinated children are more likely to be white, have parents with higher levels of education and higher salaries, and have a mother who is married and lives in a state that

allows philosophical exemption from school immunization laws.3-5 whereas underimmunized children often have characteristics that reflect social and economic inequalities rather than true vaccine skepticism.6,7

Categorization of parental attitudes about vaccines is difficult because of the complex interaction of educational, societal, personal, and other factors that influence the formation of these attitudes. In their study, Gust et al⁸ identified 5 categories of parents: "immunization advocates" (33%), who strongly agree that vaccines are necessary, safe, and important; "go along to get alongs" (26%), who agree that vaccines are necessary and safe; "health advocates" (25%), who agree that vaccines are necessary but are less sure about their safety; "fencesitters" (13%), who slightly agree that vaccines are necessary and safe; and "worrieds" (3%), who slightly disagree that vaccines are necessary and strongly disagree that they are safe. Parents in these categories differ in their relationships with their HCPs and their belief that HCPs have their child's best interest at heart; worrieds are most skeptical about the latter. Other studies have revealed that even among parents with serious concerns regarding immunization, the greatest influence in the ultimate decision about immunizing their child is their child's HCP1,9,10 and that one-third of all parents want more information about vaccines.11

What Are Vaccine Concerns of Parents?

Since the advent of variolation (vaccination) in the 18th century, the concept of inoculation to prevent disease has seemed counterintuitive to some people. Benjamin Franklin, a prominent early antivaccination campaigner, regretted his skepticism about vaccination after his 4-year-old

son died from smallpox, writing, "I long regretted bitterly, and still regret that I had not given it to him by inoculation. This I mention for the sake of parents who omit that operation, on the supposition that they should never forgive themselves if a child died under it. my example showing that the regret may be the same either way, and that, therefore, the safer should be chosen."12

Although parental vaccine concerns vary according to knowledge and personal experience, the underlying premise remains remarkably constant: fear that vaccines (and/or their additives) are unsafe, will give the immunized person the infection against which they are designed to protect, or that somehow getting the "natural" disease is healthier. 1,2,7,9,13-15 The latter viewpoint has gained popularity as vaccines have reduced disease incidence and disease-associated mortality; the devastating consequences of polio, pertussis, and measles are not apparent. 16 Parents (and HCPs) also may have a tendency to selectively grade individual diseases in terms of their importance; studies have revealed, for example, that some parents are skeptical of the need for varicella vaccine. 1,9,13 In addition, as the vaccine schedule becomes more comprehensive and complex and has the ability to protect against more diseases in the first few years of life, some parents worry about the number of injections a child may receive at a single visit, and others are concerned that the immune system is "overloaded," a view that has been refuted scientifically.¹⁷ Because parents have a diversity of concerns about vaccines, it is imperative that HCPs individualize each parent's set of concerns and guard against making erroneous assumptions about their attitudes and about specific concerns.

The Media Perspective

A common misconception among HCPs is that because scientific studies consistently demonstrate that vaccines are safe and effective, this message should be obvious in media coverage, but this is not always the case. Most print and broadcast media do not set out to promote an antivaccine agenda. However, information on the Internet is not subject to the same constraints. Some Internet sites aim to capture a target audience by providing information in a form that attracts attention, is comprehended easily, and disregards scientific validity, ensuring that the story is not "balanced." Achieving that balance requires highlighting benefits and risks of provaccine and antivaccine viewpoints within a limited time frame, typically a few minutes for broadcast media. Thus, a small, discredited study that links the measlesmumps-rubella (MMR) vaccine to autism in 12 children¹⁸ may receive air time or column space equal to that of the many large-scale population-based studies or lengthy court judgments that have proven that no such association exists. 19-24 Communicating the truth behind the science also is complicated, because definitive studies often use scientific language and terms that are familiar to physicians and scientists but are confusing for parents who are trying to process the information.

The power of anecdotal experiences or "sound bites" supplemented by visual imagery also should not be underestimated.²⁵ A 30-second clip of a child allegedly damaged by vaccines exploits every parent's worst fears and is more compelling than clips that detail the reduced incidence or elimination of infectious diseases of which many parents have never heard, much less seen. These impressions supplemented by stories parents may have heard or read on the Internet may be-

come more memorable and lead parents to believe that vaccines are harmful. The flip side to this is that the popular media is reactive. While the first episode of a 2008 fictional ABC series, *Eli Stone*, featured a trial lawyer fighting for the little guy and convincing a jury that a mercury preservative in a vaccine caused a child's autism, outbreaks of measles across the United States²⁶ may have influenced storylines in *Law and Order* and *Private Practice* in 2009, when measles directly or indirectly caused the death of unvaccinated children.

ADDRESSING PARENTAL CONCERNS

Establish Honest Dialogue

Although time-consuming, establishing nonconfrontational dialogue regarding immunization from the first HCP-parent interaction, including provision of Vaccine Information Statements, is invaluable. It is important for HCPs to listen carefully to identify parental beliefs surrounding immunization, which allows them to target education appropriately.27 Parents are attempting to make the best decisions on behalf of their children, a task made more difficult by many potentially conflicting sources of information. Parents may be more fearful of committing harm (giving an unsafe vaccine) than allowing harm (taking a chance that their child will develop a disease). In addition to the broader categorizations of vaccine-hesitant parents,8 Halperin²⁸ identified 5 groups of vaccine-hesitant parents. The uninformed but educable seek information to counter an antivaccination message; the misinformed but correctable are not fully aware of the benefits of vaccines; the well-read and openminded have explored the provaccine and vaccine-hesitancy messages and want to discuss the issues and put them in an appropriate context; the convinced and contented are strongly

vaccine hesitant but want to demonstrate their willingness to listen to the other side of the argument; and the committed and missionary want to convince the provider to agree with their arguments against vaccination. The first 3 groups are likely to be amenable to information and respond positively to HCP dialogue, whereas the latter 2 groups are unlikely to ever change their position, although repeated, respectful discussion and experiences possibly may make their beliefs less entrenched over time.

Acknowledge That Vaccines May Be Associated With Adverse Events and Balance That Against Disease Risk

Once an HCP has identified the concern, most parents will be amenable to targeted education and discussion, which must be done with sensitivity and should be done while acknowledging the difficulties of decisions for parents and without overstating the benefits or understating the risks.²⁹ Despite a vaccine prelicensure and postlicensure process designed to evaluate vaccine safety and efficacy, no vaccine is completely without adverse events or 100% effective for all children.³⁰ Acknowledging this fact is important in establishing credibility and dialogue with parents.27 However, the vast majority of reported adverse events attributable to vaccines are minor and self-limited (eg, injection-site reactions, transient low-grade fever) and should be placed in their proper context for parents who may find the potential for adverse events to be worrisome. Most adverse events are no more troublesome than the effects of the normal rough-and-tumble experiences encountered by the average toddler or school-aged child. Serious adverse events from an individual vaccine can occur, but these events are exceedingly rare.

Parents should be assisted in understanding that rarely occurring risks associated with vaccines need to be weighed against the risks associated with the natural infection. For example, the risk of encephalopathy from measles vaccine (1 in 1 million) is 1000 times less than the risk of encephalopathy from natural measles and similar to the risk of acquiring subacute sclerosing panencephalitis after natural measles infection.30 Measles outbreaks have occurred recently in the United States,26 and the risk of acquiring measles can be 35 times higher in unvaccinated people.31

Specific Parental Concerns

The most pervasive vaccine concern or "myth" that an HCP is likely to encounter is the alleged link between vaccines and autism. The authors of a review of this topic discussed in detail the 3 suggested hypotheses to substantiate this link. The initial concern arose from a 1998 case series in which the authors hypothesized that the combination MMR vaccine damaged the intestinal lining and allowed encephalopathic proteins to cross to the bloodstream and brain. 18 Since the publication of that report, the results of numerous large-scale population-based studies have consistently shown no association between MMR vaccine and autism, and case-control studies have revealed an absence of gastrointestinal tract disease and autism after MMR vaccine. 19-24 In February 2010, the Lancet retracted the 1998 report.18

The second hypothesis is that thimerosal, a vaccine preservative that contains 49% ethylmercury, led to mercury toxicity and to increased diagnosis of autism as the immunization schedule expanded. The biological plausibility of this hypothesis is

questionable,³² given that the clinical features of mercury poisoning differ substantially from those of autism, and the ethylmercury in thimerosal differs from naturally occurring methylmercury. The Food and Drug Administration Modernization Act of 1997 called for the US Food and Drug Administration to review and assess the risk of mercury-containing foods and drugs.33 As a precautionary measure, thimerosal as a preservative was removed from all vaccines administered to infants in the recommended childhood immunization schedule in the United States except for some influenza vaccines.33 Subsequent studies in Denmark, Sweden, Canada, the United Kingdom, and the United States that examined populations over many decades revealed no relationship between thimerosal and autism.34-43 The incidence of autism increased in Denmark, Canada, and California after thimerosal was removed from vaccines.39-41 The Institute of Medicine rejected a causal association between MMR vaccine or thimerosal and the development of autism.⁴³

Another hypothesis is that multiple vaccines overwhelm the immune system and trigger a neurologic response that causes autism. Scientific considerations against this hypothesis include the following: the immune system has the capacity to respond to multiple antigens simultaneously and is not overwhelmed by vaccines. In addition, mild or moderate illness does not interfere with an infant's ability to generate protective immune responses to vaccines, vaccinated children are not more likely to develop infections with other pathogens than unvaccinated children, and infants encounter fewer antigens in vaccines today than they did 40 to 100 years ago. 17,44-46 Other important observations not consistent with the vaccinesand-autism hypothesis are that autism spectrum disorders are complex inheritable disorders that involve multiple genes and demonstrate great phenotypic variation, the subtle evidence in some children that autism is present from early infancy, and that the expression of the autism genes may be influenced by environmental factors that occur in utero during fetal brain development.47-49

The HCP who encounters vaccine concerns such as those outlined above has a difficult task in acknowledging that these issues do concern people and that recommendations are based on the best available science and in the best interest of the child. It may be useful in this scenario to observe some simple rules for effective communication,25 which involve giving the scientific facts by using direct, unambiguous language rather than hiding behind "jargon" or qualified statements that are, of necessity, inherent in every study but are unlikely to reassure a concerned parent. Some suggested responses to common concerns and questions can be found at the Web sites listed in Table 1. The Centers for Disease Control and Prevention, in partnership with the AAP and the American Academy of Family Physicians, has developed "Provider Resources for Vaccine Conversations With Parents" (www. cdc.gov/vaccines/spec-grps/hcp/ conversations.htm). Materials include communication tips on having productive conversations about immunization; current vaccine-safety information, including answers to common questions and summaries of research; and disease-specific fact sheets. This information can be downloaded and provided as handouts to parents and used to initiate a dialogue about vaccines during prenatal, newborn, and other health care visits. HCPs can sign up for e-mail updates as new resources are posted on the site.

TABLE 1 Recommended Online Resources

Organization Albert B. Sabin Vaccine Institute Allied Vaccine Group American Academy of Family Physicians American Academy of Pediatrics American Academy of Pediatrics Childhood Immunization Support Program American College of Physicians American Immunization Registry Association American Medical Association American Nurses Association Association of State and Territorial Health Officials Association of Teachers of Preventative Medicine Baby 411 Canadian Paediatric Society Centers for Disease Control and Prevention Center for Vaccine Awareness and Research, Texas Children's Hospital Vaccine Resource Library Every Child by Two Families Fighting Flu

Global Alliance for Vaccines and Immunization
Group on Immunization Education, Society of Teachers and
Family Medicine
Health on the Net Foundation
Infectious Diseases Society of America
Immunization Action Coalition
Institute for Vaccine Safety (Johns Hopkins University
Bloomberg School of Public Health)
Institute of Medicine

Meningitis Angels
National Alliance for Hispanic Health
National Foundation for Infectious Diseases
National Institutes of Allergy and Infectious Diseases
National Medical Association
National Meningitis Association
National Network for Immunization Information
Parents of Kids with Infectious Diseases
Vaccine Education Center (Children's Hospital of Philadelphia)
US Food and Drug Administration
World Health Organization

www.sabin.org www.vaccine.org www.familydoctor.org www.aap.org www.cispimmunize.org

Web-Site Address

www.acponline.org
www.immregistries.org
www.ama-assn.org
www.nursingworld.org
www.astho.org
www.astho.org
www.windsorpeak.com/baby411
www.caringforkids.cpc.ca
www.cdc.gov/vaccines
www.vaccine.texaschildrens.org

www.path.org/vaccineresources www.ecbt.org www.familiesfightingflu.org www.gavialliance.org www.immunizationed.org

www.hon.ch www.idsociety.org www.immunize.org www.vaccinesafety.edu

www.iom.edu/Global/Search.aspx?q=
immunizations&output=xml_no_dtd
&client=default_frontend&site=
default_collection&proxyreload=1
www.meningitis-angels.org
www.hispanichealth.org
www.fld.org
www.fld.org
www.nmanet.org
www.nmaus.org
www.immunizationinfo.org
www.pkids.org
www.yaccine.chop.edu
www.fda.gov/cber/vaccines.htm
www.who.int/en

in the context of high background immunization rates. In addition, research is ongoing to develop tailored immunization materials that may be helpful in improving immunization rates in certain groups of vaccine-hesitant parents. 52,53

Ensure Ongoing Communication

Despite the best efforts of HCPs, parents occasionally may elect to delay or refuse vaccines for their children. Although in this situation alternative immunization schedules may seem like an attractive option for HCPs, deviation from the recommended childhood and adolescent immunization schedule should be used only when other options have failed and not as a substitute for establishing communication or targeted education. As stated by Offit and Moser,⁵⁴ these alternative schedules are not founded in science, are cumbersome, encompass multiple HCP visits and thereby increase the likelihood of noncompliance, and, most importantly, leave children unnecessarily vulnerable to acquiring serious, potentially fatal vaccinepreventable diseases. The AAP's Committee on Bioethics does not recommend discontinuing care for families who refuse or delay immunization.²⁷ Rather, the HCP should reopen a nonconfrontational dialogue, continue to discuss risks and benefits of immunization during subsequent patient encounters, and document these discussions during each visit. The committee advises against more serious action in the majority of cases, saying that "[c]ontinued refusal after adequate discussion should be respected unless the child is put at significant risk of serious harm (as, for example, might be the case during an epidemic)." HCPs in this situation may be concerned about the medicolegal implications for themselves should an unvaccinated child contract a vaccine-preventable disease. The AAP has developed

Provide Other Information Resources

Just as anecdotes and visual imagery are used to great effect by the antivaccine lobby, parents should be aware of similar stories that highlight the dangers of refusing vaccination. These stories are available in publications from reputable sources and online, where parent advocacy groups describe serious consequences of not vaccinating or from organizations that specialize in vaccine education (Table 1). Supple-

menting this information with posters advocating immunization in waiting areas or examination rooms also may be helpful. Although these items are no substitute for effective communication between concerned parents and HCPs, they help raise awareness of the consequences of refusing immunization, such as outbreaks with sometimes fatal outcomes of diseases such as pertussis, measles, and *Haemophilus influenzae* type B.^{26,50–52} It is fortunate that these outbreaks are not common

guidelines regarding appropriate techniques and sample documentation to cover this eventuality.⁵⁵ In addition, guidance for best practices that should be included in any public health risk and communication plan is available.⁵⁶

CONCLUSIONS

Most HCPs will encounter vaccinehesitant parents in their practices. HCPs should try to understand individual parental concerns and the media influences that shape them so that these concerns and fears can be addressed. Because HCPs are the most important influence on a parent's final decision on immunization, establishing ongoing, nonconfrontational dialogue from the initial HCP-parent interaction is essential when dealing with vaccine-hesitant parents. Evidencebased data can be used to address the specific fears and concerns of parents. Information should be communicated by using unambiguous. easily understood language. The serious consequences of not vaccinating should be highlighted both by data showing that vaccinepreventable diseases are a constant threat and by using the experience and stories of patients and parents affected by these diseases. Parentfriendly literature and guidance to online resources that explain the value of vaccination should be provided in the HCP's office. The issue

should be addressed and documented at subsequent visits to ensure parents that vaccination following the AAP/American Academy of Family Physicians/Advisory Committee on Immunization Practices childhood immunization schedule is recommended.

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How to Communicate With Vaccine-Hesitant Parents

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