Factors associated with refusal of childhood vaccines among parents of school-aged children: a case-control study.

Abstract

Background  The rate of nonmedical exemptions to school immunization requirements has been increasing, and children with exemptions have contributed to outbreaks of vaccine-preventable diseases.
Objectives To determine why parents claim nonmedical exemptions and to explore differences in perceptions of vaccines and vaccine information sources between parents of exempt and fully vaccinated children.

Design Case-control study.

Setting Colorado, Massachusetts, Missouri, and Washington.

Participants Surveys were mailed to the parents of 815 exempt children (cases) and 1630 fully vaccinated children (controls randomly selected from the same grade and school) recruited from 112 private and public elementary schools. Surveys were completed by 2435 parents (56.1%).

Main Outcome Measures Parental reports.

Results Most children (209 [75.5%] of 277) with nonmedical exemptions received at least some vaccines. The most common vaccine not received was varicella (147 [53.1%] of 277 exempt children). The most common reason stated for requesting exemptions (190 [69%] of 277) was concern that the vaccines might cause harm. Parents of exempt children were significantly more likely than parents of vaccinated children to report low perceived vaccine safety and efficacy, a low level of trust in the government, and low perceived susceptibility to and severity of vaccine-preventable diseases. Parents of exempt children were significantly less likely to report confidence in medical, public health, and government sources for vaccine information and were more likely to report confidence in alternative medicine professionals than parents of vaccinated children.

Conclusion Continued efforts must be made to educate parents about the utility and safety of vaccines, especially parents requesting nonmedical exemptions to school immunization requirements.

Laws requiring immunization for school attendance have contributed to the enormous success of the US immunization program.\(^1\),\(^2\) Smallpox has been eradicated, polio will likely soon follow, and the incidence of most vaccine-preventable diseases (VPDs) has been reduced by 98% to 99% in the United States.\(^3\),\(^4\) All states require children entering school to receive certain vaccines, and all states permit medical exemptions to these immunization requirements. In
addition to medical exemptions, 48 states offer religious exemptions and 19 states offer personal or philosophical exemptions.\(^5\)

Children who have exemptions to these laws are at greater risk for contracting VPDs and transmitting disease to children too young to be vaccinated, persons with medical contraindications to immunization, and persons who do not develop protective responses to vaccines (vaccine failure). Children in the United States with nonmedical exemptions between 1985 and 1992 were 35 times more likely to contract measles than vaccinated children.\(^6\) Children in Colorado with nonmedical exemptions between 1987 and 1998 were 22 times more likely to contract measles and 5.9 times more likely to contract pertussis than vaccinated children.\(^7\) Also, the rate of exemptions in Colorado counties with outbreaks of pertussis was higher than counties that did not have outbreaks of pertussis (4.3% vs 1.5%, respectively; \(P = .001\)).\(^7\)

To sustain high immunization coverage rates, immunization programs must maintain public confidence in the utility and safety of vaccines. Maintaining public confidence in vaccines can be challenging when VPDs have been controlled and attention is focused on reported vaccine-associated adverse events rather than prevention of disease.\(^8\)

An increase in the rates of nonmedical exemptions has been documented during the last decade in several states, including Colorado, Massachusetts, and Oregon.\(^9\) In the 2003-2004 school year, 5.7% of school entrants in Michigan claimed an exemption, and 6 other states reported exemption rates of 3% or higher.\(^10\) Exemptions are not randomly distributed within states. There are geographical regions with exemption rates several times higher than state averages.\(^6\) This clustering of susceptible children contributes to the possibility of outbreaks.

Most studies that have examined the knowledge, attitudes, and beliefs of parents regarding vaccination issues have focused on parents of children younger than 5 years, typically aged 19 to 35 months. Some investigators found no association between parental beliefs and vaccination,\(^11-13\) and others found that contributing to underimmunization were concerns about vaccine safety and efficacy, underappreciation of the risks and severity of disease, and distrust in the health
Most unvaccinated preschool children, however, receive recommended vaccines by school entrance. Studies to date have not followed preschool children through to school entrance, so there has been no distinction between children who are delayed in vaccination and children who remain unvaccinated past school entry. Studies of preschool children revealed variable associations between vaccination status and parental knowledge, attitudes, and beliefs despite fairly consistent findings that barriers to immunization are associated with delays in vaccination. Focusing only on younger children may be insufficient to understand why parents claim exemptions for their children, since it is not possible to distinguish between children with delayed vaccination vs those who remain unvaccinated once in school. Knowing why parents claim nonmedical exemptions is important because the proportion of parents claiming exemptions has been increasing and exemptions contribute to outbreaks of VPDs.

This study was designed to determine why parents of school-aged children claim nonmedical exemptions and to explore differences in the use and perceived credibility of sources for vaccine information between parents of exempt and fully vaccinated children.

Methods

We surveyed the parents of 815 children who, according to school records, were exempt (for any reason, including medical) for 1 or more vaccine antigens required for school entry (based on state laws) and compared them with parents of 1630 fully vaccinated children. Two vaccinated control children in the same grade and school as the case child were randomly selected per case. Children were recruited from 112 private and public elementary schools (grades kindergarten through 5) in Colorado (n = 25), Massachusetts (n = 23), Missouri (n = 34), and Washington (n = 30) that participated in an earlier survey of school immunization personnel and had 5 or more students with exemptions. The earlier study of school personnel sampled 250 schools in each of these 4 states, including 150 schools per state with the highest rates of exemptions, 50 schools with the lowest rates of exemptions, and 50 schools randomly selected from the remaining schools in the state. Up to 13 exempt children were selected per school; if the school had
more than 13 exempt children, 13 were selected randomly to ensure that we sampled a large number of schools and did not exclusively recruit exemptions from a small number of schools with high rates of exemptions. This study was approved by the Committee on Human Research at Johns Hopkins Bloomberg School of Public Health.

**Survey procedures**

Johns Hopkins researchers trained school personnel and nurses in the study procedures and process for random selection. Survey packets were mailed from Johns Hopkins to the school personnel responsible for immunization, who then addressed and mailed survey packets to the selected parents (survey packets were addressed “To the parent of [name of child]”). Parents consented to participate through use of a disclosure letter. Parents were requested to mail an enclosed postcard to the school indicating their willingness to participate in the study; schools then followed up with parents by letter and telephone. Completed surveys were mailed from parents directly to Johns Hopkins. Johns Hopkins researchers did not know the names of the children or their parents, and there were no identifiers on the surveys. Surveys of the parents of exempt children had exemption-specific questions that allowed researchers to identify which surveys were completed by case parents vs controls. These survey procedures allowed the schools to protect the privacy and confidentiality of the children and their parents. Surveys were mailed to Massachusetts parents in February 2002 and to parents in the remaining states in February 2003.

**Survey content**

Parents of exempt children were asked to verify that their child had not received 1 or more of the vaccines required for school entry, whether the child received the complete or less-than-complete number of doses for each vaccine series, and the reasons why they chose to forgo vaccination. Parents who indicated that they did not vaccinate for medical reasons were asked to indicate the medical condition that contraindicated vaccination. All respondents were asked to use a 5-point Likert scale to estimate the probability that an unimmunized child would contract a disease for which vaccines are recommended for elementary school children (polio, measles, mumps, rubella, diphtheria, pertussis, tetanus, *Haemophilus influenzae* type b, hepatitis B, and varicella) during a 10-year period (“impossible” to
very likely"), how serious it would be for an 8-year-old to develop one of these diseases ("not at all serious" to "very serious"), how effective the vaccines are in preventing children from getting these childhood diseases ("not at all protective" to "very protective"), and how safe the vaccine is ("dangerous" to "very safe"). Respondents were also asked to use a 5-point Likert scale ("strongly disagree" to "strongly agree") to indicate their agreement or disagreement to a series of 14 questions relating to key immunization beliefs and who benefits from vaccination (the child, community, physicians, government, or companies that make vaccines: "not at all" to "a great deal"). The same 5-point scale was used to indicate their agreement or disagreement to a series of 11 questions that measured trust in health care professionals and a series of 6 questions that measured trust in government (addressing issues of beneficence, equity, and openness of information); 1 question about whether they or their immediate family members (spouse/partner or children) had used the services of a chiropractor, acupuncturist, or other complementary/alternative medicine (CAM) professional in the past 5 years; 1 question asking about 16 information sources where they received information about vaccines and the quality of sources for vaccine information ("extremely poor source" to "excellent source"); and 1 question about the type of medical professional they considered their child's primary physician to be.

Respondents were asked to identify their age (9 categories, starting with 18-20 years and continuing by 5-year intervals, with ≥61 as the highest), education (6 categories of grade completed: grade 4, grade 8, grade 12 or General Educational Development test, some college, college graduate, or postgraduate), household income (in $10 000 intervals to ≥$70 000), race or ethnic group, their relationship to the child (mother, father, or other), the age of the child, and whether they had other children. Surveys took approximately 30 minutes to complete; a sample is available online.

**Data analysis**

Parents were excluded from the primary data analysis if their child had been listed by the school as exempt but the parent indicated that their child was fully vaccinated or if the parent provided a plausible medical contraindication. The median categories for age, education, and income were determined by combining
all cases and controls. Age was dichotomized into the median (age 36-40 years) or younger vs older than the median. Education was dichotomized into the median (some college) or less vs more education than the median. Income was dichotomized into the median ($60,000-69,999) or less vs greater than the median income. Race was dichotomized into white vs all other races. Logistic regression models were used to compare differences in age, education, income, and race between cases and controls.

General constructs for respondents' assessments of disease susceptibility and severity and vaccine efficacy and safety were created using the respondent's mean scores for all 10 antigens or diseases. A general construct score for trust in health care professionals was created by taking a mean for the 11 questions. A general construct score for trust in the government was created by taking a mean for the 6 questions. The Cronbach statistic was used to measure internal consistency of the scales for trust in health care professionals and trust in government. Construct scores were dichotomized by the lower quartile among all respondents to ease interpretation of results. Logistic regression models were used to compare differences in independent variables between cases and controls. The final model included independent variables that were significant in bivariate analysis.

Answers to key belief questions were dichotomized into "strongly agree or agree" vs all other responses. Perception of benefit from vaccination was dichotomized into "a moderate amount or a great deal of benefit" vs all other responses. Source for vaccine information was dichotomized into "a good or excellent source" vs all other levels. Logistic regression models were used to compare differences in these independent variables between cases and controls.

Results

Twenty exempt children were identified as siblings with different last names when the school addressed the envelopes (before the surveys were mailed), and older siblings were removed from the study to avoid sending a duplicate survey to the same household. Surveys were returned by 391 (48.6%) of the 805 parents of exempt children and 976 (59.9%) of the 1630 parents of fully vaccinated children, for an overall response rate of 56.1% (state range: 50.2%-64.1%).
Of the 391 parents of exempt children identified by the school, 86 reported that their children were fully vaccinated, and an additional 28 provided valid medical contraindications for vaccination. The remaining 277 parents of children with nonmedical exemptions were included as cases in the analyses; 68 children (24.5%) received no vaccines, and the remaining children had antigen-specific exemptions (Figure 1). The most common antigen not given was varicella (n = 147; 53.1% of cases), and the least common antigen not given was polio (n = 45; 16.2% of cases) (Figure 2).

Number of recommended vaccines received for children with nonmedical exemptions (n = 277). Recommended vaccines included diphtheria, pertussis, tetanus, measles, mumps, rubella, polio, *Haemophilus influenzae* type b, varicella, and hepatitis B.
A higher proportion of parents of exempt children were older than the median (aged 36-40 years) compared with parents of vaccinated children (44.0% vs 35.9%, respectively; \( P = .02 \)). Parents of exempt children were more likely to have higher than the median level of education (some college) than parents of vaccinated children (57.6% vs 47.2%, respectively; \( P < .02 \)). Parents of exempt children and parents of vaccinated children were similar in terms of income (40.6% vs 41.1% with a family income greater than the median [\$60,000-$69,999], respectively; \( P = .90 \)) and race (94.5% white vs 91.7% white, respectively; \( P = .14 \)). The mean age of the children selected by the school whose parents completed surveys was 7.8 years. Surveys were completed by mothers (\( n = 1093; 88.5\% \)), fathers (\( n = 115; 9.3\% \)), and a range of other caregivers (\( n = 27; 2.2\% \)) including grandparents, aunts, stepparents, foster or adoptive parents, and legal guardians. Most respondents (\( n = 1061; 87.0\% \)) reported having other children. Respondents reported living in Colorado (\( n = 347; 28.1\% \)), Massachusetts (\( n = 350; 28.3\% \)), Missouri (\( n = 238; 19.2\% \)), Washington (\( n = 296; 23.9\% \)), and other states (\( n = 6; 0.5\% \)), including those bordering the states where schools were selected.

The most common reasons stated for not vaccinating related to perceived vaccine safety, including (not mutually exclusive) that the vaccines might cause harm
(n = 190, 68.6%) and that they might overload the immune system (n = 136; 49.1%). Other reasons given for forgoing vaccination included the perceptions that the child was not at risk for the disease (n = 103; 37.2%), that the disease was not dangerous (n = 58; 20.9%), or that vaccines might not work (n = 36; 13.0%); ethical or moral issues (n = 25; 9.0%); and religious beliefs (n = 25; 9.0%). The ethical and moral issues included use of aborted cell lines, fetal tissue and blood, and animal testing as well as opposition to the requirements. In Massachusetts and Missouri, where nonmedical exemptions are authorized solely for religious reasons, only 8.6% and 22.9%, respectively, indicated religious reasons for forgoing vaccination.

There were several differences in the perception of vaccine benefits between parents of exempt and fully vaccinated children. Parents of exempt children were less likely than parents of vaccinated children to report that children benefit a moderate amount or great deal when fully vaccinated (47.0% vs 95.5%, respectively; odds ratio [OR], 0.04; 95% confidence interval [CI], 0.03-0.06) or that the community benefits a moderate amount or great deal when a child is fully vaccinated (47.3% vs 89.6%, respectively; OR, 0.10; 95% CI, 0.07-0.14). Parents of exempt children were more likely than parents of vaccinated children to report that vaccine companies benefit a moderate amount or great deal when a child is fully vaccinated (94.9% vs 88.8%, respectively; OR, 2.35; 95% CI, 1.30-4.29). Parents of exempt and vaccinated children were similar in terms of perceived benefit of vaccination for physicians (52.4% vs 57.1%, respectively; OR, 0.83; 95% CI, 0.62-1.11) and the government (59.9% vs 59.6%, respectively; OR, 1.01; 95% CI, 0.74-1.39).

The internal consistency of the constructs for trust in health care professionals and trust in the government as measured by the Cronbach’s statistic were .92 and .80, respectively. In bivariate analysis, parents of exempt children were more likely to report low perceived susceptibility to and severity of VPDs, low perceived vaccine efficacy and safety, and a low level of trust in health care professionals and the government compared with parents of vaccinated children in univariate analysis (Table 1). With the exception of trust in health care professionals, all of these constructs remained statistically significant in the multiple logistic regression model (Table 1). A dose-response relationship is suspected between
these constructs and the number of antigens for which a child was exempt (Table 2).

Table 1.

Proportion of Parents With Low Levels of Perception of Key Constructs by Child's Vaccination Status and Adjusted ORs of Child Having a Nonmedical Exemption*

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<tr>
<th>Unadjusted OR of Low Levels of Perception of Key Constructs by Number of Antigens Against Which Child Is Unvaccinated</th>
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Table 2.
Most parents of exempt and vaccinated children agreed with the statement “Children should only be vaccinated against serious diseases” (Table 3), and only a small proportion (5.8%) of parents of exempt and vaccinated children considered varicella to be serious or very serious. Parents of exempt children were more likely than parents of vaccinated children to hold beliefs that questioned the safety and utility of vaccination.

Table 3

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<th>Frequency of Parent Agreeing or Strongly Agreeing With Vaccine-Related Beliefs by Child's Vaccination Status and ORs of Child Having a Nonmedical Exemption*</th>
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Parents of exempt children were more likely than parents of vaccinated children to report use of CAM professionals by their immediate family members (79.6% vs 51.2%, respectively; OR, 3.73; 95% CI, 2.70-5.14). Among respondents who reported family use of CAM professionals, 47.5% reported family use of 1 type, 42.4% reported using 2 to 4 types, and 10.1% reported using 5 or more types of professionals. The most common type of CAM professional used was a chiropractor (83.9%).

Most parents of exempt and vaccinated children reported receiving vaccine information from health care professionals (Table 4). Parents of exempt children were more likely than parents of vaccinated children to report receiving vaccine
information from 11 of the 16 information sources. There were no information sources that parents of exempt children were less likely to use compared with parents of vaccinated children. Parents of exempt children were less likely than parents of vaccinated children to perceive the following sources as good or excellent for vaccine information: health care professionals, professional organizations, pharmacists, health departments, the Centers for Disease Control and Prevention, the Food and Drug Administration, the Institute of Medicine, vaccine companies, and the National Vaccine Information Center (Table 4). Parents of exempt children were more likely than parents of vaccinated children to consider CAM professionals and the organization Dissatisfied Parents Together as good or excellent sources for vaccine information.

| OR of Child Having a Nonmedical Exemption by Parent's Utilization and Credibility of Sources for Vaccine Information |

Parents of exempt children were less likely to report their child's primary health care professional to be a physician (75.8% vs 93.9%; OR, 0.20; 95% CI, 0.14-0.30) and were more likely to report their child's primary health care professional to be a nurse practitioner (7.4% vs 2.7%; OR, 2.90; 95% CI, 1.59-5.28) or CAM professional (11.5% vs 0.3%; OR, 41.77; 95% CI, 12.66-137.78) compared with the parents of vaccinated children.
We were surprised to find that 22% of the parents of exempt children identified by the school reported that their children were fully vaccinated. Possible explanations include that the parent was mistaken about the vaccination status of the child, the child had received the vaccine before the age required by state law and the parent was not willing to have the child revaccinated, the vaccine record was not available at the time of school entry, or the exemption for pertussis was necessary for school entry and stayed on the books as the child advanced to higher grades even though the child was past the age recommended for pertussis vaccination. The high proportion of children with exemptions to only certain vaccines (75.5%) suggests that most parents are selectively choosing vaccines rather than opposing vaccines altogether. Concern about vaccine safety was the most important factor reported by parents who declined vaccination for their children. Many parents appear to use the religious exemption option for nonreligious reasons. For example, in Massachusetts and Missouri, where philosophical exemptions are not allowed, 9% and 23% of nonmedical exemptions, respectively, were reported by parents to be for religious reasons.

Parents of exempt children were more likely than parents of vaccinated children to report low perceived susceptibility to and severity of VPDs, low perceived vaccine efficacy and safety, and a low level of trust in the government. However, parents of vaccinated children also held beliefs that questioned the safety and utility of vaccination: 20.3% were concerned that children get more immunizations than are good for them, 32.2% were concerned that a child’s immune system could be weakened by too many vaccines, and 10.8% reported that it is better to develop immunity from natural disease than from vaccination, although at lower rates than parents of children who were not fully vaccinated. These data are similar to findings by Gellin et al\textsuperscript{22} for the same questions in the general population and indicate the need for additional educational interventions for parents. The parents of children considering exemptions should be targeted with extra effort to provide them with accurate information from sources that they trust.

Parents of exempt children were more likely than parents of vaccinated children
to report receiving vaccine information from a wide range of information sources, including medical and public health authorities. However, these parents were less likely than parents of vaccinated children to consider medical and public health authorities to be good or excellent sources for vaccine information. Parents of exempt children gave more credibility to CAM professionals for vaccine information and were more likely to report family use of CAM than parents of vaccinated children.

Parents of exempt children who use CAM professionals and/or consider these people to be the child's primary health care professional may have been influenced by these individuals to forgo vaccination. It is also possible that although parents with alternative life views may have been more likely to use CAM professionals and/or consider them to be the child's primary health care professional, discuss vaccine issues with them, and consider them credible sources, they would not have vaccinated their children regardless of these interactions. Some parents may be turning to CAM professionals and nurse practitioners because pediatricians and family physicians are unwilling to care for children who are unvaccinated. A recent study found that up to 10% of physicians refused to care for children whose parents refused vaccination. Studies are indicated to determine if the refusal of health care professionals to care for these children contributes to increased use of CAM professionals, who may influence parents to forgo vaccination, or if the parents seek out alternative professionals before being refused care. Emphasizing the importance of vaccines to CAM professionals may be beneficial.

The credibility ratings among parents of vaccinated children for the National Vaccine Information Center (82.2% believed it was a good or excellent source) were much higher than for Dissatisfied Parents Together (15.2% believed this was a good or excellent source), the former name for this organization. Most parents of vaccinated children (97.5%) had not used the National Vaccine Information Center as a source for vaccine information. The high credibility rating given to this source may be due to the new, more neutral name.

Demonstrating associations between beliefs and immunization status cannot determine causality. Further studies are indicated to determine how parents develop perceptions of vaccine-associated risks and benefits, how they identify
sources of information, and how they resolve conflicting information and make vaccination decisions.

This study has the potential for nonresponse bias; parents of exempt children were less likely to complete the survey than parents of vaccinated children. If bias exists, it likely results in an underestimation of many of the constructs measured, since persons who do not recognize the utility and safety of vaccination would be less likely to complete an immunization survey. We were unable to compare child or parental characteristics between participants who completed surveys and those who refused; no information was collected for refusals, and the investigators were blinded to the names of respondents. Care should also be used in generalizing from this study to the entire nation; parents were selected from 4 states, which did not include a southern state, where religion may play a greater role in the avoidance of vaccines. Additionally, home-schooled children were not included.  

The rates of exemptions are increasing in many states; the concerns of parents with exemptions may also apply to parents who have nonetheless decided to vaccinate their children. To maintain the public health benefit of immunizations, continued efforts must be made to educate the public. Many of the vaccine concerns identified among parents can be addressed through discussions with health care professionals and public vaccine information campaigns. States should consider linking mandatory education to the exemption process.  

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