

Caregivers Who Refuse Preventive Care for Their Children: The Relationship Between Immunization and Topical Fluoride Refusal

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The 2013 Institute of Medicine report *Childhood Immunization Schedule and Safety: Stakeholder Concerns, Scientific Evidence, and Future Studies* provides an up-to-date review of immunization safety for children.¹ This report, along with numerous other publications, indicates that childhood immunizations are safe, have decreased morbidity and mortality by reducing the incidence of serious diseases, and play an important role in population-based disease prevention.²⁻⁴ Similarly, topical fluoride is safe, effective, and prevents dental caries,⁵ the most common disease worldwide.⁶ However, as is the case with all drugs and preventive therapies, immunizations and topical fluoride are not completely risk-free, which can lead to concerns among caregivers regarding preventive care for children.

Most children in the United States receive immunizations as recommended, but immunization hesitancy and refusal among caregivers are growing problems. According to a recent study, 20% of children 6 to 23 months of age did not receive recommended immunizations.⁷ Another study reported an increase in the percentage of immunization-hesitant caregivers from 2.5% to 9.5% between 2006 and 2009.⁸ Overall immunization refusal rates range from 1.6% to 2.4%, and they are known to cluster geographically within school districts, communities, and counties.^{9,10}

More than 90% of pediatricians and 60% of family medicine physicians report having treated at least 1 child whose caregiver had previously refused immunizations.¹¹ Reasons for immunization hesitancy or refusal include concerns about safety and side effects, religious objections, and philosophical or personal beliefs.¹²⁻²⁰ The public health consequences of immunization refusal include outbreaks of life-threatening diseases (e.g., measles,

Objectives. The aim of this study was to examine caregivers' refusal of preventive medical and dental care for children.

Methods. Prevalence rates of topical fluoride refusal based on dental records and caregiver self-reports were estimated for children treated in 3 dental clinics in Washington State. A 60-item survey was administered to 1024 caregivers to evaluate the association between immunization and topical fluoride refusal. Modified Poisson regression models were used to estimate prevalence rate ratios (PRRs).

Results. The prevalence of topical fluoride refusal was 4.9% according to dental records and 12.7% according to caregiver self-reports. The rate of immunization refusal was 27.4%. In the regression models, immunization refusal was significantly associated with topical fluoride refusal (dental record PRR = 1.61; 95% confidence interval [CI] = 1.32, 1.96; $P < .001$; caregiver self-report PRR = 6.20; 95% CI = 3.21, 11.98; $P < .001$). Caregivers younger than 35 years were significantly more likely than older caregivers to refuse both immunizations and topical fluoride ($P < .05$).

Conclusions. Caregiver refusal of immunizations is associated with topical fluoride refusal. Future research should identify the behavioral and social factors related to caregiver refusal of preventive care with the goal of developing multidisciplinary strategies to help caregivers make optimal preventive care decisions for children. (*Am J Public Health.* 2014;104:1327-1333. doi:10.2105/AJPH.2014.301927)

pertussis, rubella), hospitalizations, and threats to herd immunity.²¹⁻²⁷

The dental caries process begins with intake of dietary fermentable carbohydrates, which are metabolized by intraoral bacteria. Over time, these bacteria produce acids that demineralize tooth structure. Topical fluorides are defined as any fluoride source (e.g., fluoridated drinking water, toothpaste, mouth rinses) that promotes remineralization and inhibits demineralization on the tooth surface. Regular exposure to topical fluorides helps to prevent tooth decay.²⁸

Inadequate or irregular exposure to topical fluorides leads to increased risk of dental caries (cavities), which requires dental treatments such as fillings, crowns, or extractions. When left untreated, dental caries can lead to pain, infection, hospitalization, and, in rare cases, death. The social and economic consequences span the life course and include missed school days, poor grades, and teasing or bullying at

school among children and underemployment and lower earnings among adults.²⁹⁻³²

Low levels of fluoride are found in drinking water, toothpastes, and mouth rinses. Individuals at increased risk for dental caries who lack access to fluoridated water can be prescribed fluoride tablets or drops that are taken daily at home.³³ High-risk individuals may periodically have higher levels of fluoride applied to their teeth in the form of fluoride gels, foams, and varnishes during dental or medical visits.

Relatively few studies have addressed fluoride hesitancy and refusal among caregivers. One study examined predictors of fluoride varnish refusal but focused on child behaviors and provider factors as correlates of refusal by children.³⁴ A number of investigations have identified caregiver concerns regarding fluoride safety, particularly among caregivers of children with autism spectrum disorders.³⁵⁻³⁷ Most studies focus on opposition to community water fluoridation.³⁸⁻⁴⁰

Concerns about topical fluoride may stem from the handful of cases of accidental hyperfluoridation of community water,^{41–49} which is extremely rare and most commonly results in temporary nausea and vomiting. Since the 1980s, there have been fewer than 20 incidents of hyperfluoridation across community water systems, which serve 72.4% of the US population.⁵⁰ However, 1 documented death related to water fluoridation was reported in Hooper Bay, Alaska, in 1992. This incident was caused by insufficient system monitoring and an equipment malfunction,⁴⁷ highlighting the importance of proper training and oversight of water hygienists responsible for fluoridating water.

Dental fluorosis, in which the teeth exhibit diffuse, whitish mottling, is a more prevalent side effect associated with fluoride overexposure.^{51–53} Fluorosis occurs with chronic intake of low levels of fluoride during early childhood, particularly when young children brush their teeth unsupervised and ingest fluoridated toothpaste in excess of the amount needed to prevent dental caries.⁵⁴ Topical fluorides provided during dental visits are not known to cause dental fluorosis.⁵⁴

Immunizations and topical fluorides are front-line preventive strategies in pediatric medicine and dentistry. As such, the growing number of caregivers who refuse preventive care for children is a significant public health concern. The links between medical care and dental care use among children^{55–57} suggest that caregivers' refusal of immunizations and refusal of fluoride are related behaviors; however, to my knowledge, no investigations to date have examined this relationship. In this study, the goals were to estimate the prevalence of caregiver refusal of topical fluoride through chart review and survey data and to evaluate the association between immunization and topical fluoride refusal. Such work has important public health implications for developing clinical strategies that can be deployed by medical, dental, and public health professionals to help caregivers make optimal preventive care decisions for children.

METHODS

The study was conducted in 2 phases. The first phase involved a retrospective chart review of data from children younger than 18

years who were patients of record at 1 of 3 dental clinics during 2009 or 2010. Patients were required to have received at least 1 comprehensive oral evaluation (identified through Current Dental Terminology [CDT] 2005⁵⁸ code D0150) or 1 periodic oral evaluation (CDT code D0120) in either calendar year.

The study was based on a convenience sample of children drawn from 3 dental clinics in Washington State: a university-based pediatric dentistry clinic, an urban community health center affiliated with a regional children's hospital, and a private-practice dental clinic in a rural community. Although the 3 clinics were physically located in areas with fluoridated community water, the specific water fluoridation status of each child was unknown.

The second phase involved a prospective survey administered to caregivers of children identified in the chart review. Those surveyed included caregivers who refused topical fluoride for the children in their care (case participants) and those who did not (control participants). Case and control participants were matched on a 1 to 1 basis according to the clinic and the child's age and gender ($n = 1024$).

Survey Development and Administration

A 60-item English-language survey was developed, pretested with 3 caregivers, and modified to improve its clarity and flow. The survey included questions about the child (age, gender, race/ethnicity), caregiver (education), household (income, food security), and immunizations and topical fluoride (history of refusal, acceptance, beliefs about the efficacy of preventive care, ability to obtain care, barriers to care). Surveys were mailed to caregivers, and a \$2 bill was included with each survey as an incentive for participation. After 2 weeks, a trained research assistant contacted caregivers who had not responded by telephone to request that they complete a survey. Caregivers were asked to return the completed survey, mailed a second survey as requested, or offered the option of completing the survey via telephone.

Study Variables

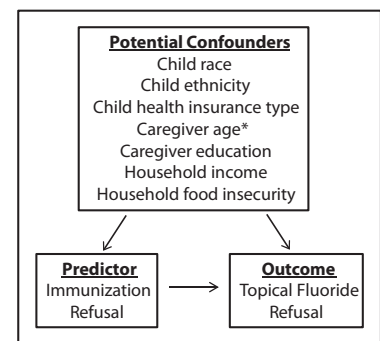
The conceptual model for the study was based on previous work indicating significant associations between preventive medical and dental care use among children.^{55–57} The immunization refusal and medical care use

literatures were used to identify child, caregiver, and household sociodemographic factors that could serve as potential model confounders (Figure 1).

Outcome variables. The primary outcome was caregiver refusal of topical fluoride (yes or no). Fluoride refusal was operationalized in 2 ways with respect to the chart review. In the private-practice dental clinic, fluoride refusal is consistently noted, and charts were manually reviewed for any entries indicating caregiver refusal of topical fluoride. In the case of the other 2 clinical sites, at which there is no consistent charting of fluoride refusal, electronic claims were reviewed to identify children who did not receive fluoride treatment (CDT 2005 code D1201 or D1203⁵⁸) in 2009 or 2010. In the survey, caregivers were asked whether they had ever refused topical fluoride for the children in their care at a dental care visit.

Predictor variable. The predictor variable, measured with a single item, was whether caregivers had ever refused to have their child immunized (yes or no).

Potential confounders. The following child, caregiver, and household sociodemographic factors (measured via the survey) served as potential confounders: child's race (White or non-White), ethnicity (Hispanic or non-Hispanic), and health insurance category (Medicaid, private, or other)⁵⁹; caregiver's age (≤ 35 years, 36–50 years, or ≥ 51 years) and education (\leq high school, some college,



* $P < .05$.

FIGURE 1—Conceptual model depicting the proposed relationship between immunization and topical fluoride refusal among caregivers.

or \geq college)¹⁴; and household annual income (<\$20 000, \$20 000–\$39 999, \$40 000–\$59 999, or \geq \$60 000).⁶⁰

An exploratory confounder was household food insecurity,⁶¹ measured through a 2-item food insecurity screener. The items were as follows: “In the last 12 months, the food that we bought just didn’t last, and we didn’t have money to get more” and “In the last 12 months, we worried whether our food would run out before we got money to buy more.” Children of caregivers who responded affirmatively (“often” or “sometimes”) to both items were classified as being food insecure. The remaining children were classified as being food secure. This 2-item screening instrument has been validated against the US Department of Agriculture’s 6-item instrument and has high sensitivity and acceptable specificity.⁶²

Data Analyses

On the basis of data from the chart review, the prevalence of fluoride refusal was estimated and adjusted to account for multiple children from the same household. Caregiver-reported topical fluoride and immunization refusal rates were estimated from survey data. Modified Poisson regression models were used to evaluate the bivariate relationships between each potential confounder and the predictor and outcome measures.⁶³ All potential confounders that were significantly associated with both the predictor and outcome were included in the final regression model ($\alpha = 0.05$). In testing the study hypothesis, a multiple-variable modified Poisson regression model was used to estimate prevalence rate ratios (PRRs) and 95% confidence intervals (CIs). SPSS was used in conducting all of the analyses.⁶⁴

RESULTS

Of the 1024 mailed surveys, 75 were returned because of an invalid address; in addition, 40 caregivers did not communicate in English, 343 could not be reached by telephone, 155 were not interested in taking part, and 50 were interested but did not return a completed survey. A total of 361 surveys were completed and included in the analyses (35.3% response rate; 39.7% response rate adjusted for invalid addresses and caregivers who did not communicate in English). There

were no significant differences in response rates across the 3 clinics ($P = .09$). However, caregivers of privately insured children were significantly more likely to respond ($P < .001$). Approximately 50% of caregivers cared for privately insured or dually insured (e.g., private and Medicaid) children or children with Tricare (e.g., uniformed services insurance) coverage; 30.3% cared for Medicaid-enrolled children and 33.5% for uninsured children.

Prevalence of Topical Fluoride and Immunization Refusal

The record-based prevalence of topical fluoride refusal was 4.9%. Clinic-specific refusal rates were 1.7% (community health center), 4.0% (private practice dental clinic), and 12.8% (university-based pediatric dentistry clinic). According to the survey data, the caregiver-reported prevalence of fluoride refusal was 12.7%, and the prevalence of immunization refusal was 27.4%.

Bivariate Analyses

The survey data showed that 34 of 94 caregivers (36.2%) who refused immunizations also refused topical fluoride, whereas 11 of 220 (5%) who did not refuse immunizations refused topical fluoride ($P < .001$). Of the 45 caregivers who refused topical fluoride, 34 also refused immunizations (75.6%), and 60 of 269 (22.3%) who did not refuse topical fluoride refused immunizations ($P < .001$).

Of the 7 potential confounders, only caregiver age was significantly associated with immunization and fluoride refusal (Table 1). The prevalence of refusal was greater among caregivers younger than 36 years than among those 51 years or older in the case of both immunizations (PRR = 2.46; 95% CI = 1.23, 4.93; $P = .01$) and fluoride (PRR = 3.25; 95% CI = 1.04, 10.76; $P = .04$). Caregivers of White children had a significantly greater prevalence of immunization refusal than caregivers of non-White children (PRR = 1.67; 95% CI = 1.17, 2.39; $P = .01$). The prevalence of fluoride refusal was greater among caregivers who had completed 4 years of college or more than among those with a high school education or less (PRR = 3.14; 95% CI = 1.15, 8.58; $P = .03$).

Regression Models

In the caregiver age-adjusted regression models, caregiver refusal of immunizations was significantly associated with both record-based and caregiver-reported refusal of fluoride. The prevalence of fluoride refusal based on dental records was 1.61 times as high (95% CI = 1.32, 1.96; $P < .001$) for caregivers who refused immunizations as for caregivers who did not refuse immunizations, and the prevalence based on caregiver self-reports was 6.20 times as high (95% CI = 3.21, 11.98; $P < .001$).

DISCUSSION

This is the first published study, to my knowledge, to examine topical fluoride refusal with an emphasis on assessing the relationship between caregivers’ refusal of preventive medical and refusal of dental care. The findings suggest that fluoride refusal is highly prevalent among caregivers and that refusal of immunizations is associated with refusal of topical fluoride offered to children during dental visits.

The first primary finding is that topical fluoride refusal rates ranged from 4.9% (based on dental records) to 14.6% (estimated from survey data). There are no study data to which these rates can be compared. In this study, the topical fluoride refusal rate based on dental records was not as high as the immunization refusal rate (27.4%) and might appear to be clinically inconsequential. However, at the population level, a 4.9% fluoride refusal rate corresponds to 3.6 million children.⁶⁵ This is a substantial number of children unable to benefit from evidence-based care to prevent dental caries. Furthermore, studies suggest that at least 4 fluoride varnish treatments are needed in high-risk infants to ensure therapeutic levels of caries prevention.⁶⁶ As such, even occasional refusal of fluoride may reduce the overall effectiveness of topical fluoride.

What is unknown from the current study is the extent to which fluoride hesitancy or refusal is a growing health behavior among caregivers as documented in the immunization literature.⁸ Longitudinal studies involving larger samples are needed to monitor population-based trends in caregiver behaviors regarding refusal of preventive dental care for children.

This study did not include an examination of reasons why caregivers refused topical

TABLE 1—Results of Bivariate Analyses Identifying Factors Related to Immunization and Topical Fluoride Refusal: Caregivers of Children in Washington State, 2009–2010

Potential Confounder	Caregiver-Reported Immunization Refusal		Caregiver-Reported Topical Fluoride Refusal	
	PRR (95% CI)	P	PRR (95% CI)	P
Child race				
White	1.67 (1.17, 2.39)	.01	0.92 (0.54, 1.58)	.77
Non-White (Ref)	1.00		1.00	
Child ethnicity				
Hispanic	1.33 (0.88, 2.03)	.18	1.67 (0.87, 3.20)	.13
Non-Hispanic (Ref)	1.00		1.00	
Type of health insurance				
Private (Ref)	1.00		1.00	
Public	1.04 (0.71, 1.51)	.85	0.81 (0.47, 1.42)	.46
Other	1.01 (0.54, 1.89)	.98	0.18 (0.03, 1.29)	.09
Caregiver age, y				
≤ 35	2.46 (1.23, 4.93)	.01	3.25 (1.04, 10.76)	.04
36–50	1.77 (0.90, 3.47)	.1	1.67 (0.53, 5.30)	.39
≥ 51 (Ref)	1.00		1.00	
Caregiver education				
≤ high school (Ref)	1.00		1.00	
Some college	1.45 (0.89, 2.37)	.14	2.17 (0.75, 6.30)	.16
≥ college	1.34 (0.83, 2.16)	.23	3.14 (1.15, 8.58)	.03
Annual household income, \$				
< 20 000 (Ref)	1.00		1.00	
20 000–39 999	1.57 (0.89, 2.74)	.12	2.39 (0.90, 6.34)	.08
40 000–59 999	1.57 (0.85, 2.92)	.15	1.87 (0.61, 5.75)	.28
≥ 60 000	1.40 (0.82, 2.39)	.22	1.83 (0.70, 4.80)	.22
Household food insecurity				
No (Ref)	1.00		1.00	
Yes	0.81 (0.53, 1.25)	.35	0.66 (0.31, 1.40)	.27

Note. CI = confidence interval; PRR = prevalence rate ratio.

fluoride. However, the bivariate analyses indicated that topical fluoride refusal was significantly more prevalent among caregivers younger than 35 years and those with college degrees, the latter of which is consistent with studies on immunization refusal.^{60,67} There are additional reasons a caregiver might refuse fluoride that parallel broader concerns about the safety of community water fluoridation, including potential side effects such as dental fluorosis as well as purported epidemiological associations between fluoride intake and autism spectrum disorders, lower IQs, and other systemic childhood conditions.^{35,68–70}

In this study, 1 in 2 caregivers who refused topical fluoride reported that they were somewhat or very concerned about fluoride, providing preliminary evidence that safety concerns

are related to fluoride refusal. Furthermore, 70% of caregivers who refused fluoride reported their child as having had a history of dental caries, making it unlikely that fluoride refusal is related to a low perceived risk of dental disease. Other potential reasons for refusal include lack of cooperation by children,³⁴ a belief that topical fluoride is ineffective, inability to pay among those who are uninsured, and social norms.⁷¹ Future research should identify the behavioral and social determinants of fluoride refusal with an emphasis on the reasons why caregivers refuse topical fluoride.

The second primary finding is that the prevalence of topical fluoride refusal was greater among caregivers who refused immunizations, which suggests a link between preventive medical and dental care decision-making

among caregivers. A common risk factor approach⁷² would suggest that caregivers' refusal of preventive medical care and their refusal of dental care have similar religious, philosophical, and behavioral etiologies.^{12–20,73} Furthermore, the growing prevalence of immunization hesitancy and refusal may lead to concomitant increases in fluoride refusal behaviors, which has implications for future disease prevention strategies aimed at children. Both immunizations and topical fluoride prevent transmissible diseases, and refusal of preventive care can lead to treatment needs that place additional demands on the health care system.²⁰

The ethical concerns associated with mandating preventive care, eliminating personal belief exemptions, penalizing nonusers of preventive care, or dismissing hesitant families from a practice^{74–78} need to be balanced with the consequences associated with allowing caregivers to refuse preventive care, including threats to herd immunity and increased communicable disease rates. Future studies should continue to expand our understanding of both behaviors and adopt common risk factor models to help develop clinical and public health strategies that optimize disease prevention in children.

This study has multiple public health implications. First, immunization and topical fluoride refusal behaviors may be indicators of broader societal concerns regarding various public health strategies (e.g., community water fluoridation, folic acid supplementation, rice fortification).^{79–83} For example, opposition to water fluoridation has affected a growing number of communities both in the United States and abroad. Yet, there is a dearth of interdisciplinary research on ways to broadly address anti-fluoride behaviors, which is an obstacle to preserving this cost-effective public health strategy.⁸⁴ Second, the population-based health gains that have been secured through preventive strategies such as immunizations and topical fluoride may be at risk, exposing vulnerable children to greater levels of disease.

Third, there is an assumption in health disparities research that improving access to health care services leads to automatic uptake of preventive care. Caregiver refusal of preventive care presents challenges for health professionals regarding how to offset the additional health risks to which a growing number

of children may be exposed. Additional research is needed to improve our understanding of caregiver refusal of preventive care and to identify the social, economic, and policy implications of health care decision-making among caregivers.

In terms of the clinical significance of the current study, previous research has stressed the importance of health providers establishing trust-based relationships with families and conveying information on the benefits of immunizations to caregivers.⁸⁵⁻⁸⁸ Findings from another study indicate that caregivers trust health providers but do not trust the information they dispense regarding immunizations.⁸⁹ There is an immunization behavior continuum with endpoints corresponding to unquestioning acceptance and refusal,⁹⁰⁻⁹² and this is also likely to be the case for fluoride-related beliefs and behaviors. Medical and dental care providers may find it helpful to identify a caregiver's position on this behavioral continuum, which could play a role in delivering tailored strategies such as alternative preventive treatment schedules,¹¹ Web-based approaches,⁹³ participatory communication methods,^{94,95} and motivational interviewing.⁹⁶

Providers encountering caregivers who refuse preventive care may need to postpone attempts to modify caregiver behaviors and revisit these issues during subsequent appointments.⁹⁷ Monitoring a community's position on the behavioral continuum can be helpful in assessing the need for community-level interventions, such as social marketing approaches used to address immunization hesitancy.⁹⁸ Additional behavioral and social science research on ways to address fluoride refusal is needed and could build on existing approaches from the pediatric immunization literature.

Limitations

This study had several limitations. First, the predictor (immunization refusal) assessed whether the caregiver had ever refused immunizations. There was no information available regarding whether the caregiver was hesitant about or refused all immunizations. In addition, caregivers were not asked to specify the types of immunizations refused. Given the wide age range of the study children, caregivers may have refused controversial immunizations (e.g., human papillomavirus) as opposed to

immunizations commonly required for school entry. Future work should adopt validated immunization hesitancy and refusal measures to provide a better understanding of how immunization refusal is related to topical fluoride refusal. There is also a need to develop and validate fluoride hesitancy and refusal instruments. Second, the study was cross sectional, which limits causal inferences. Longitudinal study designs and qualitative data collection methods might be used in the future to better understand the relationship between immunization- and fluoride-related behaviors.

Third, the findings are generalizable only to children from 3 dental clinics in western Washington State. Finally, caregivers of children with private insurance were significantly more likely to have responded to the survey than caregivers with publicly insured or uninsured children. Population-based studies are needed with special efforts devoted to ensuring equivalent response rates from caregivers of various socioeconomic backgrounds, which would improve estimates of refusal rates and the generalizability of study findings. There is also a need to assess the potential for bias associated with mode of survey (e.g., paper vs phone), which also has implications for designing future studies and assessing generalizability of study findings.

Conclusions

Given the importance of preventive care in reducing childhood diseases, it is a public health concern that caregivers' refusal of immunizations is significantly related to their refusal of topical fluoride. This has implications for pediatric medicine and dentistry in terms of increased childhood disease rates, reduced benefits associated with herd immunity, and potential widening of health disparities. Future research should identify the common social and behavioral factors related to caregivers' refusal of various types of preventive care with the goal of developing multidisciplinary strategies to help caregivers make optimal preventive care decisions for children. ■

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Human Participant Protection

The institutional review boards of the University of Washington and Seattle Children's Hospital approved this study. Caregivers provided a waiver of consent in phase 1 of the study and provide informed consent via mail or telephone in phase 2.

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