

# Parent Refusal of Topical Fluoride for Their Children



## Clinical Strategies and Future Research Priorities to Improve Evidence-Based Pediatric Dental Practice

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### KEYWORDS

- Fluoride refusal • Fluoride hesitancy • Preventive care decision making
- Topical fluoride • Fluoride • Oral health inequalities • Children • Caries risk

### KEY POINTS

- Topical fluorides are one of the few evidence-based preventive treatments available and are especially important in preventing dental caries in high-risk children.
- Parent topical fluoride refusal is a growing clinical and public health problem that may contribute to growing pediatric oral health inequalities in the United States.
- The determinants of topical fluoride refusal are complex and multifactorial. Potential solutions include patient-centered social and behavioral interventions that can be easily implemented within clinical settings.
- There are immediate clinical and community-based strategies that can improve parent-provider communication about fluoride and educate the public about the importance of various fluoride modalities.
- Public health researchers need to develop fluoride refusal screening tools, diagnostic instruments, and evidence-based strategies to help parents make optimal preventive dental care decisions for their children.

### INTRODUCTION

In the early 1900s, Frederick McKay discovered the oral health benefits of fluoride when he observed that individuals exposed to naturally fluoridated drinking water in Colorado Springs, Colorado were significantly less likely to develop tooth decay.<sup>1</sup> Laboratory studies later confirmed his clinical observations. Since then, topical fluorides have become the cornerstone of prevention in dentistry. Fluoride is available in a variety of modalities each with varying concentrations: drinking water fluoridated

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at 0.7 ppm; over-the-counter toothpastes and mouthwashes; foams, gels, and varnishes provided by health providers during dental and medical visits; and prescription-strength toothpastes, drops, or tablets. Fluorides prevent tooth decay by promoting remineralization and inhibiting demineralization of enamel.<sup>2-5</sup> Fluoride is recommended as part of a comprehensive tooth decay prevention program for high-risk children.<sup>6-8</sup> Regular exposure to fluoride is safe, even for young infants.<sup>9,10</sup>

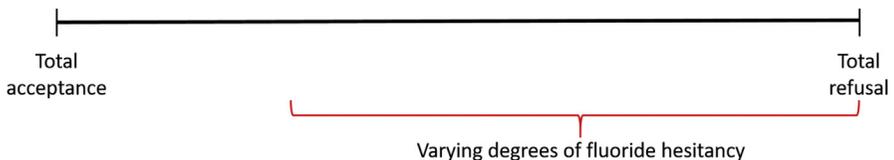
Even though fluoride is effective and safe, recent data showed that 13% of parents refused fluoride treatments for their child during a preventive dental or medical visit.<sup>11</sup> Even more parents are fluoride hesitant, meaning that they may accept fluoride for their children but have unresolved concerns. These are a concern from an evidence-based perspective because fluoride is one of the only preventive treatments available for caries prevention. The growing phenomenon of fluoride refusal has implications for the way in which clinicians communicate with parents about fluoride so that parents can make optimal preventive health care decisions for their children.

This article includes a discussion of conceptual issues related to fluoride refusal, including definitions and measurement-related gaps. Next, the author reviews the relevant scientific literature to identify potential factors related to fluoride refusal. This information forms the basis for recommendations on clinical strategies that can be incorporated into practice and future research priorities related to building on stronger scientific evidence base to manage and address fluoride refusal in clinical settings.

### ***Defining and Conceptualizing Fluoride Refusal***

The author defines fluoride refusal as any instance in which a parent has refused, attempted to refuse, or considered refusing professional fluoride therapy for their child in a health care setting because of concerns about the necessity, safety, or consequences of fluoride. The author emphasizes the behavioral, cultural, or social origins of fluoride refusal behaviors rather than developmental or economic causes. Thus, fluoride refusal excludes reasons like a parent refusing because their young child does not like the taste (developmental) or the inability to pay for fluoride treatment when a parent would otherwise accept it (economic).<sup>12,13</sup>

Fluoride refusal is typically conceptualized as a binary behavior. A parent brings their child into clinic, is presented with the option of fluoride, and makes a decision to either accept or refuse fluoride. However, similar to the continuum-of-addiction model used to describe smoking,<sup>14</sup> fluoride refusal is positioned at one end of a continuum that ranges from complete acceptance of fluoride with no reservations to complete refusal with no desire to change one's mind (Fig. 1). Somewhere in the middle of this continuum are hesitant parents, regardless of whether they accept fluoride, with some degree of concern. Parents who refuse fluoride are considered hesitant, but not all hesitant parents refuse fluoride. Studies on parent preferences regarding preventive care have reported that most parents accept fluoride, but there are some



**Fig. 1.** Continuum of fluoride hesitancy behaviors.

parents with concerns.<sup>15,16</sup> These findings support the continuum model. For simplicity, when the author uses the term “fluoride refusal” in this article, it incorporates the concept of hesitancy.

### ***Fluoride Refusal Measurement Gaps***

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Although broad measures on the acceptability of preventive dental care for children exist,<sup>17</sup> none specifically focus on fluoride. The continuum model indicates the need for 2 types of measures, neither of which currently exist. The first is a screening tool to identify parents who are fluoride hesitant. A screening approach is similar to the process of screening for behavioral health conditions in primary care.<sup>18</sup> Screening tools exist to identify vaccine-hesitant parents. For example, the Parent Attitudes toward Childhood Vaccines is an 18-item measure that addresses beliefs about vaccine safety and efficacy, attitudes, and trust in health providers.<sup>19</sup> The value of a screening tool is that it could help clinicians identify parents who refuse fluoride as well as parents who may accept fluoride for their child but retain some degree of hesitancy. Hesitant parents may be at risk for eventually becoming parents who refuse fluoride. The second is a diagnostic instrument to assess the reason or reasons a parent is hesitant about fluoride. Diagnostic data are critical in developing a logic model of the problem, which describes a problematic health behavior of interest and is a precursor to developing strategies to address the problem behavior based on the underlying reason or reasons for the behavior.<sup>20</sup>

A logic model of the problem, in turn, is needed to develop a logic model of change, which lays out the necessary steps in a causal chain of events that are expected to result in behavior change, in this case reducing fluoride hesitancy and improving fluoride acceptance.<sup>20</sup> There may be a need for multiple logic models because fluoride refusal is a complex, multifactorial health behavior. Multiple logic models form the basis for chair-side interventions tailored to parents based on the specific reason or reasons a parent refuses fluoride.<sup>21</sup>

### ***Reasons for Topical Fluoride Refusal***

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The origins of fluoride refusal in the United States are traced back to water fluoridation opposition by the John Birch Society during the Soviet era.<sup>22</sup> As such, most relevant studies in the dental literature focus on community resistance to water fluoridation, for which limited knowledge and risk-benefit misperceptions are the main determinants.<sup>23</sup>

There are only 3 publications on topical fluoride refusal. Two publications reported that parents of children with autism spectrum disorders have a higher likelihood of refusing topical fluoride during dental visits.<sup>24,25</sup> Only one other study to date has identified factors related to topical fluoride refusal.<sup>11</sup> In a 3-clinic study in Washington State, fluoride refusal was significantly associated with vaccination refusal.<sup>11</sup> Fluoride refusal was more common among parents under the age of 35 years and those with a college degree.<sup>11</sup> The implication of this study was that a potential strategy to reduce fluoride refusal was to address vaccine refusal. However, subsequent analyses found that different behavioral and social factors were related to vaccination and fluoride refusal behaviors, indicating that different solutions are needed to solve these related problems separately (Carpiano R, Chi DL, unpublished data, 2017).

The association between vaccination and fluoride refusal highlights the relevance of the vaccine literature in identifying the potential causes of fluoride refusal. Similar to topical fluoride, there are more parents who are hesitant about vaccines than those who refuse vaccines.<sup>26</sup> Parent attitudes and beliefs about health are important

determinants of vaccine hesitancy. Most common is the belief that vaccines are unsafe and lead to conditions like autism spectrum disorders,<sup>27</sup> which parallel concerns about fluoride. Many parents believe vaccines are no longer necessary.<sup>28–30</sup> These beliefs are spread through social networks, the media, and anti-vaccine Web sites, where information seeking may be compromised when the parent's primary goals are control and certainty over perceived risks.<sup>31–36</sup> Low health literacy influences the way parents understand and process information about vaccine necessity, safety, and risks.<sup>37</sup> Studies have also found that vaccine refusal is bimodal, with the highest rates present at the highest and lowest ends of the income spectrum, and that the reasons for refusal are different for these 2 groups.<sup>38</sup> Other factors include religious beliefs, a desire for autonomy, and concerns about the true intent of vaccines (ie, financial interest of pharmaceutical companies, government conspiracy).<sup>39–46</sup> These factors have led to a growing number of vaccine-hesitant parents.<sup>19</sup>

Another potential cause of fluoride refusal is rooted within the dental profession and relates to the provision of fluoride treatment that may not always be based on a child's risk for developing caries. A recent *Cochrane Review* reported caries-prevention benefits associated with fluoride varnish in children and adolescents.<sup>5</sup> The studies in this systematic review focused on high-risk children, as is the case with almost all published fluoride trials. However, not all low-income children are at high risk for caries. This means that recommendations for fluoride should be based on risk, but there is little evidence that this is what actually occurs in practice. Thus, the potential problem is dentists who indiscriminately recommend fluoride varnish for all children regardless of risk. The phenomenon of fluoride refusal in higher-income parents may be a response to recommendations for fluoride treatment when there is little perceived need for fluoride. Fluoride refusal behaviors may also occur in lower-income parents, who may feel disempowered during dental visits because of perceptions that dental offices discriminate against lower-income families.<sup>47</sup> Reactance, a concept from psychology that describes parent responses to influences perceived to constrain behaviors (eg, a dentist telling a parent "all children get fluoride, therefore you should do it"), could help to explain fluoride refusal behaviors.<sup>48</sup>

### ***Fluoride Refusal and Oral Health Inequalities***

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Although topical fluoride refusal behaviors may occur equally among high- and low-income families, the consequences associated with these behaviors affect the children differentially. Children from low-income families may be harmed disproportionately when they do not receive fluoride because many of these children are at high-caries risk. Children from high-income families who do not receive fluoride oftentimes benefit from other protective factors such as healthier dietary behaviors. Thus, the sociodemographic determinants of fluoride refusal have the potential to lead to increased inequalities between children from higher- and lower-income families. This narrative is consistent with data that fluoride refusal is bimodal—with the highest rates among the lowest- and highest-income families.<sup>11</sup>

### ***Evidence-Based Interventions***

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Once the epidemiologic factors related to fluoride refusal are identified and the relevant logic models are developed, this information can be used to develop tailored chair-side interventions. Although fluoride refusal is multifactorial, it is likely that the reasons can be classified into 4 or 5 typologies, similar to empirical typologies identified in alcohol use and exercise participation.<sup>49,50</sup> Evidence-based intervention approaches can be developed based on each typology to comprehensively address fluoride refusal. For instance, a reactance-based typology might require a behavioral

approach that involves shared decision making and consensus building,<sup>51</sup> whereas a fatalism-based typology might focus on emphasizing the possibility of preventing tooth decay and boosting parent self-efficacy to make decisions that increase the odds of disease prevention.<sup>52</sup> Such interventions are developed mainly for parents who refuse fluoride, but can also be delivered to parents exhibiting any degree of fluoride hesitancy. Behavioral informatics-based approaches, which take advantage of technologies and electronic algorithms, could be adopted to deliver precision interventions.<sup>53</sup>

### ***Clinical Strategies***

Evidence-based strategies to manage fluoride refusal behaviors in clinical settings have yet to be developed. In the meantime, there are 10 clinical and community-based strategies to help improve communication with parents about topical fluoride and reinforce the importance of fluoride to the public (**Box 1**):

1. *Acknowledge fluoride refusal is a problem.* Some dentists and health professionals may not recognize that there are a significant number of parents concerned about fluoride.<sup>11</sup> These concerns form the basis for fluoride refusal behaviors during preventive health care visits.
2. *Assess parents' knowledge, beliefs, and attitudes about fluoride.* In the absence of validated screening tools that can identify parents who are likely to refuse fluoride, it is important to screen for these behaviors at the start of the preventive visits.<sup>54</sup> Parents should be asked open-ended, nonjudgmental questions<sup>55</sup> that provide an opportunity for starting a conversation about fluoride, like "Fluoride is the sticky stuff dentists paint on children's teeth to prevent cavities. Do you have any questions for me about fluoride?".
3. *Incorporate caries risk into discussions with parents during preventive visits.* Before any recommendations are made about the need for topical fluoride, dentists should explain the child's caries risk to the parent.<sup>56</sup> Anticipatory guidance should be tailored to specific risk factors that manifest in a child and is the starting point to either recommend fluoride (for high-risk children) or explain that fluoride is

#### **Box 1**

#### **Ten clinical and community-based strategies to help improve topical fluoride-related communication with parents and reinforce the importance of fluoride**

1. Acknowledge fluoride refusal is a problem.
2. Assess parents' knowledge, beliefs, and attitudes about fluoride.
3. Incorporate caries risk into discussions with parents during preventive visits.
4. Obtain information about why a parent refuses fluoride.
5. Provide parents a tailored explanation of why topical fluoride is important.
6. If a parent continues to refuse fluoride, discuss alternative fluoride sources and behavioral strategies.
7. Maintain open communication.
8. Accept that some parents will continue to refuse fluoride.
9. Communicate with local health professionals to reinforce the importance of fluoride.
10. Engage in public health advocacy.

- not needed at this time (for low-risk children). Low-risk children should not receive fluoride treatment because there is no added health benefit.<sup>57</sup>
4. *Obtain information about why a parent refuses fluoride.* For parents who refuse topical fluoride treatment, pro-fluoride sales pitches should be avoided. Rather, parents should be asked open-ended, respectful questions about the reasons that motivated the parent's decision to opt out of fluoride, like "I respect your decision. Can you tell me some of the reasons that helped you to reach the decision to skip fluoride for your child today?". Listening is a key factor and will help to build trust with a fluoride-hesitant parent.<sup>58</sup> Let the parent speak and avoid interrupting.
  5. *Provide parents a tailored explanation of why topical fluoride is important.* It is helpful to provide a tailored explanation of why fluoride is important based on the unique set risk factors associated with each child. For instance, white spot lesions on the child's teeth should be pointed out to the parent, with a description on how fluoride helps to prevent white spots from turning into cavities that require fillings.<sup>59</sup>
  6. *If a parent continues to refuse fluoride, discuss alternative fluoride sources and behavioral strategies.* To ensure that high-risk children not receiving professional fluoride are protected from caries, it is important to discuss alternative sources of fluoride that could be used at home, like fluoridated toothpastes and rinsing with fluoride mouthwashes.<sup>8</sup> Twice-daily brushing with fluoride toothpastes should be stressed. Some parents who refuse fluoride during dental and medical visits may be open to use of at-home fluoride products. Other parents avoid all fluoride-containing products. In these latter cases, anticipatory guidance should be framed in the context of the caries balance.<sup>60</sup> If fluorides are not part of the prevention armamentarium, then it is critical for parents to understand that reducing dietary sugars and acids becomes even more critical in managing caries risk.<sup>61,62</sup>
  7. *Maintain open communication.* Some parents need to engage in multiple discussions over time before reconsidering their decision to refuse fluoride. Trust is an important aspect of parent decision making. Building trust involves continuity of care, reassurance that the provider respects a parent's health care decisions, and partnership-building communication style.<sup>63</sup> Asking parents for permission to discuss fluoride at future appointments is one way to maintain open communication.<sup>55</sup> It is important to document conversations with parents so that future interactions can be framed appropriately without repeating information and highly sensitive topics can be avoided.
  8. *Accept that some parents will continue to refuse fluoride.* Despite repeated attempts at behavior modification, some parents will continue to refuse fluoride. It is important to maintain open communication with parents, monitor the child's caries risk, and incorporate findings from risk assessment into anticipatory guidance. Consistent with professional guidelines from medicine regarding parents who refuse vaccines,<sup>64</sup> fluoride-refusing families should not be dismissed. Some children whose parents refuse fluoride start as high risk but may gradually become low risk (eg, secondary to dietary modification). In these cases, it is important to acknowledge the observed improvements in behavior and the change in caries risk and explain that professional fluorides are not needed as long as healthy behaviors and low-caries risk status are maintained.
  9. *Communicate with local health professionals to reinforce the importance of fluoride.* During discussions with parents who refuse fluoride, clinicians may learn about health professionals in the community who are misinforming parents about fluorides.<sup>65</sup> It is helpful to arrange times to meet with these colleagues and discuss the continued importance of fluoride using similar strategies one would use chair

side with fluoride-hesitant parents. Some health providers believe caries rates have reached such low levels that fluorides are no longer necessary. Providing continuing education at medical association meetings can help spread the message that fluorides are important for high-risk children and that all children and adults benefit from lower levels of fluoride found in fluoridated toothpastes and drinking water. The issue of appropriate, risk-based supplementation can also be discussed with professionals who prescribe fluorides to children.<sup>66</sup>

10. *Engage in public health advocacy.* It is also important to educate the public about the importance of fluoride, especially fluoridation of community water supplies. Many individuals are not aware that tooth decay continues to be the most common disease in children and adults. Public advocacy can take place in the form of community outreach events at parent teacher association meetings, editorial pages in newspapers, and education aimed at city council members and state and federal lawmakers.<sup>67</sup>

### **Research Priorities**

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There are 4 main research priorities in building the scientific evidence base to address fluoride refusal. First, there is a need for basic epidemiologic research to identify the behavioral, social, and cultural causes of fluoride-refusal behaviors. Second, knowledge about the causes of fluoride refusal should be used to construct fluoride-refusal typologies, each of which will involve a different approach to address fluoride refusal. Testing of these various typology-based approaches in research settings will lead to 4 or 5 approaches that can be combined into a preliminary intervention and tailored to parents based on the specific reasons for fluoride refusal. Third, reliable and valid tools need to be developed that will allow researchers to assess the efficacy of interventions aimed at increasing acceptability of fluoride among parents of high-risk children. These tools can eventually help clinicians identify parents who are likely to refuse fluoride and the reason or reasons for refusal. These tools should be patient-centered (eg, acceptable to patients, nonjudgmental, easy to read and understand) and brief so they can be incorporated into busy clinical settings. Administering these tools electronically could help clinicians with documented and tracking these data in the electronic health record. Fourth, after demonstrating that tailored approaches work in research settings, these programs should be broadly scaled and disseminated into clinical practice.

In conclusion, the growing number of parents who refuse topical fluoride in clinical practice warrants attention from dental professionals and the scientific community. In the short term, there are clinical and community-based strategies available to improve communication with parents about fluoride and educate the public about the importance of fluoride. In the longer term, there is a need to develop measures to identify parents who are likely to refuse topical fluoride and to uncover the reason or reasons for topical fluoride refusal. The goal of this research is to develop evidence-based strategies that can help parents make better preventive dental care decisions for their children, reduce dental disease in high-risk children, and reduce oral health inequalities.

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