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“It’s Like 1998 Again”: Why Parents Still Refuse and Delay Vaccines

Jiana L. Ugale

Seattle Children’s Research Institute, Seattle, WA, USA

Heather Spielvogle

Seattle Children’s Research Institute

Christine Spina

University of Colorado School of Medicine and Children’s Hospital Colorado

Cathryn Perreira

University of Colorado School of Medicine and Children’s Hospital

Ben Katz

Seattle Children’s Research Institute

See next page for additional authors

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Authors

Jiana L. Ugale, Heather Spielvogle, Christine Spina, Cathryn Perreira, Ben Katz, Barbara Pahud, PhD
Amanda F. Dempsey MD, Jeffrey D. Robinson PhD, Kathleen Garrett MA, MPH Sean T. O'Leary MD, and
MPH Douglas J. Opel MD

“It’s Like 1998 Again”: Why Parents Still Refuse and Delay Vaccines

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Jiana L. Ugale¹, Heather Spielvogel, PhD¹, Christine Spina, MSPH², Cathryn Perreira, MA², Ben Katz¹, Barbara Pahud, MD, MPH³, Amanda F. Dempsey, MD, PhD^{2,4}, Jeffrey D. Robinson, PhD⁵, Kathleen Garrett, MA², Sean T. O’Leary, MD, MPH^{2,4}, and Douglas J. Opel, MD, MPH^{1,6} 

Abstract

We conducted a qualitative study from 2018 to 2019 to update the reasons why US parents’ refuse or delay vaccines. Four focus groups and 4 semi-structured interviews involving 33 primary care pediatric providers were conducted in Washington and Colorado. A thematic analysis was conducted to identify themes related to reasons for parental refusal or delay. Five predominant themes were identified: (1) vaccine safety, (2) relative influence of information sources, decision-makers, and timing, (3) low perceived risk of contracting vaccine-preventable disease, (4) lack of trust, and (5) religious objection. Vaccine safety was the theme mentioned most frequently by providers (N=45 times by 26 providers) and religious objection to vaccination was referred to the least (N=6 times by 6 providers). Provider-reported reasons for parental refusal or delay of childhood vaccines in 2018 to 2019 remain similar to those reported in previous studies.

Keywords

vaccines, public health, health communication, vaccination refusal, vaccine-preventable diseases

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Introduction

Although vaccines represent one of science’s greatest achievements, parental refusal or delay of childhood vaccines continues to diminish their impact on individual and public health. Vaccine hesitancy, “an expression of concern or doubt about the value, need for, or safety of vaccines or vaccination,”¹ has recently been declared a top 10 threat to global health by the World Health Organization.² The prevalence of vaccine hesitancy in the US was recently estimated to be 6.1%.³ At its extreme, parental vaccine hesitancy can lead to the refusal of all vaccines; more commonly, it manifests as the refusal or delay of some but not all vaccines.^{4,5}

Vaccine safety concerns, low perceived risk of contracting a vaccine-preventable disease (VPD), and lack of trust in vaccination information have been consistent reasons for parental refusal or delay of childhood vaccines reported by both parents and providers.^{1,5-10} However, most of this research is over 5 years old and national outbreaks of VPD, frequently

spurred by the intentionally unvaccinated,¹¹ continue to occur.^{12,13} To ensure that interventions designed to mitigate vaccine hesitancy remain responsive to reasons for vaccine hesitancy, it is critical to periodically assess reasons for vaccine refusal or delay to identify new or developing reasons. The primary objective of this study was to update the reasons why parents refuse or delay vaccines.

¹Seattle Children’s Research Institute, Seattle, WA, USA

²University of Colorado School of Medicine and Children’s Hospital Colorado, Aurora, CO, USA

³University of Missouri-Kansas City, Kansas City, MO, USA

⁴University of Colorado Anschutz Medical Campus, Aurora, CO, USA

⁵Portland State University, Portland, OR, USA

⁶University of Washington School of Medicine, Seattle, WA, USA

Corresponding Author:

Douglas J. Opel, MD, MPH, Seattle Children’s Research Institute, 1900 Ninth Avenue, M/S: JMB-6, Seattle, WA 98107, USA.

Email: douglas.opel@seattlechildrens.org



Methods

We conducted 4 focus groups and 4 individual semi-structured interviews (SSI) in 2 US states (Washington and Colorado) between November 2018 and July 2019 as part of a larger study to design and evaluate a provider vaccine communication strategy to increase childhood vaccine uptake.¹⁴ We utilized both a focus group and SSI format to leverage the primary benefits of each: focus groups, though logistically challenging to coordinate, enabled interactive dialog between all participants that could facilitate identification of a more complete range of reasons for parental refusal and delay, while SSIs, though not able to foster this interaction, were easier to organize. These 2 states were chosen because each ranked in the highest quintile among US states in 2015 to 16 with respect to the proportion of parents claiming non-medical exemptions for their child from required school-entry vaccines.¹⁵ We used convenience sampling to invite practicing pediatric providers (MD, DO, NP, and PA) within each state to participate. Participating providers were restricted to those who were actively practicing in pediatric primary care.

The focus groups and SSIs were conducted iteratively. Two focus groups occurred initially (1 in each state), followed by 4 SSIs in Washington, as well as 2 final focus groups (1 in each state). Focus groups were conducted in person with 5 to 11 pediatric providers present at each meeting, while SSIs were completed in-person or over the phone with an individual pediatric provider. The first in-person focus groups took place in November 2018, SSIs occurred between April and May 2019, and the final in-person focus groups occurred in July 2019.

We used a standardized moderator guide developed by study personnel for both the focus groups and SSIs. Both guides included questions pertaining to participants' experiences in communicating with parents about childhood vaccines and, specifically, the common reasons parents were currently citing when refusing or delaying childhood vaccines (Table 1). Focus groups and interviews were conducted by study investigators (D.J.O., S.T.O., and K.G.). Each participant received a \$100 gift card at completion as a thank you for participation. All focus groups and interviews were audiotaped and transcribed.

We conducted a thematic analysis of the transcripts with inductive coding to identify themes related to reasons for parental refusal or delay of childhood vaccines.¹⁶ To develop the coding scheme, 2 investigators (J.L.U. and B.K.) independently reviewed 2 focus group transcripts and met to discuss identified themes. Disagreements in identified themes were reconciled in consultation with a third investigator (D.J.O.). A revised coding scheme was then developed by 2 investigators

(J.L.U. and D.J.O.). One investigator (J.L.U.) subsequently applied the revised coding scheme to all transcripts. Identified themes were then discussed and finalized with the senior investigator (D.J.O.). We assessed the frequency of identified themes using descriptive statistics.

Ethics Approval and Informed Consent

Study activities were approved by the Colorado Multiple Institutional Review Board (COMIRB Protocol 17-1274). Verbal consent was obtained from participants prior to the start of the focus group or interview.

Results

There were 33 total participants in the focus groups and SSIs. In Washington, there were 15 participants from 8 practices, and in Colorado, 18 participants from 2 practices. Most (N=29) participated in the focus groups.

We identified 5 predominant themes relating to parental refusal or delay of childhood vaccines: (1) vaccine safety (defined as parental concerns regarding the potential physical harm that the composition and the frequency of administration of vaccines may impose on their child); (2) relative influence of information sources, decision-makers, and timing (defined as reasons pertaining to parent decision-making roles, information sources used, and timing of vaccination); (3) low perceived risk of contracting a VPD (defined as reasons regarding parental perception around the low probability their child will contract disease); (4) lack of trust (defined as parent's lack of trust in their provider and/or the government); and (5) religious objection to vaccination (defined as parental religious concerns regarding vaccines) (see Appendix A). Each theme had several sub-themes (Table 2).

Parental concerns about vaccine safety was the theme mentioned most frequently by providers (N=45 times by 26 providers). The relative influence of information sources, decision-makers, and timing was the second most mentioned theme (N=14 times by 11 providers). Low parental perception of their child contracting a VPD, as well as lack of trust in the government or their child's provider were each mentioned 9 times, each by 6 providers. Parents having a religious objection to vaccination was referred to least (N=6 times by 6 providers).

Vaccine Safety

Vaccine safety concerns manifested in several different ways (Table 2). For instance, providers reported that mercury was one of the ". . . more generalized things

Table 1. Focus Group and Semi-Structured Interview Moderator Questions.

Number	Question
1	What experiences have you had yourselves with talking with parents about vaccines? What do you struggle with most?
2	What are the common reasons your patients' parents are wanting to refuse or delay vaccines?
3	How has your vaccine communication changed for you in your practice over the years?
4	What communication techniques do you use and find most effective in communicating with hesitant parents to accept vaccines?

Table 2. Illustrative Quotes for Themes and Subthemes.

Theme	Subthemes	No.	Quote	
Vaccine safety	Vaccine quality and contents	1	"I've done all of my research and there are all of these chemicals and this specific chemical, I don't even know which chemical they are talking about. . .they worry about those kinds of things." (WA FG 1, Participant 4)	
		2	"Well the flu vaccine isn't very good." (CO FG 1, Participant 14)	
		3	"Oh, I'm concerned about the additives." (SSI 3, Participant 20)	
	Health-related consequences	4	". . .I have odd resistance to HPV vaccines from parents because of some vague complications and rumors that they heard about what has happened in Australia which I asked one mom to send me the information because I have heard it now from multiple places although I've never heard of what the chronic fatigue issues, rheumatologic issues. . .those are the sorts of things I have heard." (WA FG 1, Participant 2)	
		5	"Yeah, they're still there that [vaccination] causes developmental issues." (SSI4, Participant 21)	
		6	"It's causing autoimmune diseases in late adolescence and adulthood." (SSI 4, Participant 21)	
		Unnatural/overwhelming for body	7	"And [his] mom asked me, 'isn't this going to be too much for his body to handle? Putting all of this in?'" (CO FG 1, Participant 15)
			8	"It just seems like a lot, isn't it just too much, I want to give their immune systems time to develop." (CO FG 1, Participant 17)
			9	". . .it's not natural and we were fine without them." (WA FG 1, Participant 5)
			10	". . .the concern about overwhelming the immune system and that doesn't feel right to them." WA FG 1, Participant 5)
	Incomplete/inadequate data	11	". . .don't believe that these chemicals are appropriate for our child." (WA FG 1, Participant 5)	
		12	". . .but I feel like a lot of people told me lately that there's been no studies, or only short studies on safety of vaccines." (CO FG 2, Participant 27)	
		13	"This vaccine hasn't been studied in people like me." (WA FG 2, Participant 32)	
		14	". . .we're not getting anywhere with this until I research this more and I want you to pull out specific data." (WA FG 2, Participant 30)	
Relative influence of information sources, decision-makers, and timing	Parent claims to have all the information needed for decision to refuse/delay	15	"[Parent] said 'I've done my research, I don't want anyone to talk to me about shots. Don't bring up the subject.'" (WA FG 1, Participant 6)	
		16	". . .the ones who say 'I know a lot, I've read a lot.' And they won't tell you what they've read or know. And you're stuck." (CO FG 1, Participant 12)	

(continued)

Table 2. (continued)

Theme	Subthemes	No.	Quote
		17	“...where the mother does not want to make the decision without the husband there. . .” (WA FG 1, Participant 4)
	Need to consult family member who isn't present	18	“So sometimes I hear, ‘well I can't make this decision without my husband’ for instance.” (WA FG 1, Participant 1)
		19	“I need to talk to my husband. . .” (CO FG 1, Participant 17)
	Parental promise and convenience	20	“...where the mother does not want to make the decision without the husband there. . .” (WA FG 1, Participant 4)
		21	“I promised him no shots today.” (CO FG 1, Participant 17)
		22	“The one I've been getting recently is ‘oh we're going on vacation, so we'd rather wait. We don't want them to be fussy.” (CO FG 2, Participant 27)
	Discordance	23	““We have a plane trip tomorrow, I cannot deal with that.” (CO FG 2, Participant 27)
		24	“Usually it's the mom saying ‘I'm not getting it because dad doesn't want it but dad won't come in and talk to you.’” (WA FG 2, Participant 30)
		25	“I had a dad the other day hold up a sheet of paper that had the questions that his wife had written out for him. And at the bottom in capitals it said, ‘No HPV, No Immunizations.’ And he's like, ‘See? I'm like, ‘I'm not going there today. I'll talk to mom next time.’” (CO FG 1, Participant 14)
Low perceived risk of contracting VPD	Due to limited exposure to susceptibility factors	26	“...parents that say, ‘my child's not going to be exposed much because they're in a daycare of this size.’” (CO FG 1, Participant 12)
		27	“I feel that there are religious families that see it as more for promiscuous kids.” (WA FG 1, Participant 3)
	Due to proximity to outbreak	28	“I think a lot of families think that they can only get it (HPV infection) from like sex.” (WA FG 1, Participant 2)
		29	“I've asked [parents] what their thoughts were about the outbreak. . . many of them seemed like they'd already talked it through. . . and had come to some narrative about based on where they live that it was unlikely their child would be exposed.” (SSI 2, Participant 19)
Differential risks among VPDs		30	“...when measles hit Disneyland, there was an uptick in people who wanted their measles vaccine. Pertussis never seems to do it. I spend a lot of time telling people ‘yes there is pertussis, yes there is pertussis.’” (CO FG 1, Participant 17)
		31	“Mom only insisted on one vaccine. Wants to talk with provider. What is the most important one?” (SSI 1, Participant 18)
Lack of trust	Lack of established relationship with provider	32	“...at 2 months and you don't have the rapport with them and they decline for whatever reason.” (WA FG 1, Participant 4)
		33	“I think one of the things is that we start vaccinating at 2 months and if they are not an established family and have not done a meet and greet with you and they have seen 1 or 2 other people you don't have the street cred that you might have later.” (WA FG 1, Participant 3)
	Government mis-/distrust		34
35			“...it could be that for the African families, similar to the eastern European families, depended on government distrust.” (WA FG 2, Participant 31)
Religious objection	Usage of porcine products	36	“...far more refusal from patients presenting as Muslim and saying. . . that it is because it has pork. . .” (WA FG 1, Participant 1)
		37	Moderator: “...And the gelatin among Muslim families. . .” Participant: “Yeah. So that's something we hear from time to time. . .” (SSI 4, Participant 21)
	Usage of aborted fetal cells	38	“I think I have a hard time with like the silly concerns. The aborted fetal cells, like the ones where I guess I just need to do more research.” (CO FG 2, Participant 27)
		39	“You know or like the super right-wing Christians, born from aborted-fetal cells.” (WA FG 2, Participant 29)

that [parents] really fear. . ." and that they often receive questions such as ". . .well what about the formaldehyde. . .?" Providers mentioned that purported links between vaccines and rheumatologic conditions, chronic fatigue syndrome, developmental issues, and autoimmune diseases were also of concern among some parents (Table 2—Quotes 4-6). Some providers noted that they had parents who ". . .referenced an article they read off Facebook," related to vaccine safety or say, ". . .I was reading on Facebook that these are dangerous and they can cause autism." Several other providers expressed that the purported link between vaccination and autism was still a concern among parents, stating, for instance, "it's still really autism," that leads to vaccine refusal or delay, and that parents have ". . .old school worries about MMR and autism. It's like 1998 again." Aside from specific ingredients and health-related consequences, it was noted that parents often believed that there are "too many vaccines" and "it's just too much for their immune systems." Some providers also expressed that some parents believed data on vaccine safety are incomplete or inadequate (Table 2—Quotes 12-14).

Relative Influence of Information Sources, Decision-Makers, and Timing

Reasons pertaining to decision-making roles, information sources used, and timing of vaccination were also suggested by participating providers to be important factors associated with refusal or delay. For instance, providers noted that parents who claimed to ". . .know a lot. . .read a lot," or who say "I've done my research. . ." often refuse counseling from them and refuse or delay one or more vaccines. The need to consult their partner was also an important factor, with providers citing ". . .I can't make this decision without my husband," and "I need to talk to my husband. . ." as parental reasons for vaccine refusal or delay. Additionally, lack of agreement about a specific vaccine or vaccination in general among partners was a common reason for refusal or delay (Table 2—Quotes 24, 25). Providers mentioned that keeping a promise to their child of no shots was important to parents, as was avoiding potential side effects for upcoming activities or travel (Table 2—Quotes 21-23).

Low Perceived Risk of Contracting Vaccine-Preventable Diseases

Participating providers suggested that low perceived risk of contracting a VPD was often due to perceptions that their child was not susceptible to contracting a VPD.

For instance, providers noted that parents often refused or delayed the human papillomavirus (HPV) vaccine because their child did not currently engage in any sexual contact (Table 2—Quote 33-35). It was mentioned that vaccines like hepatitis B were also refused as a parent believed that their ". . .kid's not having sex or doing any drugs." (Table 2—Quote 35). A provider also reported that refusal or delay has stemmed from the parental belief that ". . .based on where they live. . .it was unlikely their child would be exposed" to a VPD (Table 2—Quote 36). Parental beliefs that some VPDs are more severe or likely to be contracted, such as measles over pertussis, were reported to lead to alternative schedules or complete refusal (Table 2—Quotes 37, 38).

Lack of Trust

Providers noted that parental lack of trust due to an undeveloped relationship with the child's parent led to refusal or delay. At 2-month well visits, providers mentioned that they "don't have the rapport with them" or the "street cred that you might have later." (Table 2—Quotes 32, 33). Providers reported that government mistrust led to refusal too and was most common among their "African families" and eastern European families (Table 2—Quotes 34, 35).

Religious Objection

Providers noted that the usage of porcine products and "the fear. . .that fetal cells may have been used" in the development of vaccines led to refusal as some parents' religious beliefs lead them to consider vaccines as contaminated (Table 2—Quotes 36-39).

Discussion

In this qualitative study conducted in high vaccine hesitancy geographic locations, we sought to update the reasons for parental refusal or delay of childhood vaccines. We found that concerns about vaccine safety continue to serve as the predominant reason for parental refusal or delay of childhood vaccines. The process in which a parent identifies and solidifies decisions around vaccination was also frequently mentioned by providers as common reasons related to refusal or delay. Religious reasons against vaccination were not as frequently mentioned by providers.

The purported link between vaccination and autism was frequently cited as a common safety concern among parents. Although information and educational resources are available to parents¹⁷ that highlight

rigorous population-based studies that have found no association between autism and vaccination,¹⁸ this purported link between vaccination and autism persists. Alternative interventions that focus on vaccine safety should be developed to address hesitancy and debunking myths as well as training providers on different communication skills to effectively discuss parental safety concerns during visits.

Low perceived risk of contracting VPD was also mentioned as a common reason for parental refusal or delay. It should be noted that this study was conducted prior to the COVID-19 pandemic. Given that infectious disease outbreaks can influence health-related attitudes and behaviors,^{19,20} the prevalence of this reason for refusal or delay, in particular, may change as a result of COVID-19 and deserves further study. Regardless, our study still offers a snapshot of common reasons parents

refused or delayed childhood vaccines that can serve as a pre-COVID-19 comparison for future studies.

The strength of this study lies in the inclusion of pediatric providers from multiple clinics in 2 states, enhancing the representativeness of our findings. However, it is limited by its qualitative design, which precluded a true quantitative assessment of reasons for vaccine hesitancy. It also is limited by the use of provider-report for reasons of parental refusal or delay rather than report from parents themselves.

Conclusions

Vaccine safety continues to be a common reason reported by providers for why parents refuse or delay childhood vaccines. Interventions designed to reduce parental vaccine safety concerns are needed.

Appendix A. Definitions of Themes and Subthemes.

Themes and definitions	Subthemes and definitions
<p>Vaccine safety: parental concerns regarding the potential physical harm that the composition and the frequency of administration of vaccines may impose on their child</p>	<p>Vaccine quality/contents: concerns regarding the efficacy and the ingredients of vaccines</p>
<p>Relative influence of information sources, decision-makers, and timing: defined as reasons pertaining to parent decision-making roles, information sources used, and timing of vaccination</p>	<p>Health-related consequences: concerns or beliefs regarding consequential effects of vaccines, such as disease, disorder, illness, and pain</p>
<p>Low perceived risk of contracting VPD: reasons regarding parental perception around the low probability their child will contract disease</p>	<p>Unnatural/overwhelming for body: concerns that the number of vaccines is unnecessary and harmful</p>
<p>Lack of trust: parent's lack of trust in provider and/or government</p>	<p>Incomplete/inadequate data on vaccine safety: belief that data on vaccine safety is incomplete or inadequate</p>
<p>Religious objection: parental religious concerns regarding vaccines</p>	<p>Parent claims to have all the information needed for decision to refuse/delay: parent believes they possess sufficient knowledge to make informed decision and thus does not desire any more information or counseling from provider</p>
	<p>Need to consult family member who isn't present: parent would like to consult their partner before proceeding with vaccine(s)</p>
	<p>Parental promise and convenience: parent does not want to backtrack a promise to child or does not want child to experience side effects during upcoming travel or child activity</p>
	<p>Discordance: lack of agreement among partners regarding vaccinating child</p>
	<p>Due to limited exposure to susceptibility factors: believes child will not contract disease because exposure to susceptibility factors is considered insignificant</p>
	<p>Due to proximity to outbreak: believes child will not contract disease because the outbreak is a considerable distance away from child's everyday environment</p>
	<p>Differential risks among VPDs: parent assigns different degrees of risk to VPDs and chooses to get vaccinated for the disease(s) that is perceived to be the worst or most likely to be contracted</p>
	<p>Lack of established relationship with provider: parent is untrustworthy of provider as their relationship has yet to develop</p>
	<p>Government mis-/distrust: parent is untrustworthy of government and thus the information that is being passed along to providers</p>
	<p>Usage of porcine products: vaccines such as MMR contain gelatin, which is considered impure by some religious individuals</p>
	<p>Usage of aborted fetal cells: vaccines such as Varicella are grown in fetal embryo fibroblast cells, which is a practice considered impure by some religious individuals</p>

Author Contributions

Drs. Opel, O’Leary, Dempsey, Pahud and Robinson made a substantial contribution to the concept or design of this study. All authors were involved in the acquisition, analysis, or interpretation of the data; drafted or revised the article for important intellectual content; approved the version of the article to be published; and agree to be accountable for all aspects of this work.

Declaration of Conflicting Interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: At the time this study was conducted, Children’s Mercy received grant funding from GlaxoSmithKline (GSK), Pfizer, and Merck for which Dr. Pahud is an investigator. Dr. Pahud received honoraria from Pfizer, GSK, Seqirus, and Sanofi Pasteur for service on advisory boards and non-branded presentations related to vaccines. Dr. Dempsey served on Advisory Boards for Merck, Pfizer, and Sanofi Pasteur. Dr. Dempsey did not receive research funding from these companies. All other authors declare that they have no conflict of interest.

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ORCID iD

Douglas J. Opel  <https://orcid.org/0000-0001-7021-191X>

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