

Parents of children with autism: Issues surrounding childhood vaccination

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Abstract

Parents of children with autism (PCA) are among those most affected by the controversy surrounding supposed links between vaccines and autism. In this chapter we describe the vaccine attitudes of PCA and their association with satisfaction with their child's healthcare provider. Fifty PCA completed questionnaires on vaccine attitudes, exposure to media discussing links between vaccines and autism ('vaccine-autism media'), and satisfaction with their child's healthcare. These characteristics, as well as autism severity and child cognitive functioning, were examined for their correlation with parents' belief that vaccines caused autism and desire to refuse future vaccination. The majority endorsed vaccines as effective and necessary, yet 56% believed they contributed to autism's cause and 16% would discourage others' vaccination. Nearly 80% discussed concerns with their child's provider and felt they were taken seriously. Attitudes were not associated with parents' demographic characteristics or satisfaction with healthcare, but were associated with trust in health institutions, vaccine safety, exposure to vaccine-autism media, and child's lower cognitive functioning. *Conclusions:* Although parents reported positive communication with providers, doubts about safety and exposure to vaccine-autism media were common. These findings underscore the importance for targeted campaigns addressing PCA's concerns and to mitigate mistrust.

Introduction

Despite increasing evidence of genetic causes of autism spectrum disorder (ASD) (1-3) and an authoritative review rejecting a causal association between MMR vaccination and ASD (4), fear that childhood vaccines play a key role in the etiology of ASD persists (5). In fact, a review by Brown and colleagues (6) identified a significant association between parents' belief that vaccines cause autism and lower vaccine uptake. The controversy continues to attract media attention and many parents remain

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skeptical about the safety of childhood vaccines (7,8). The issue is particularly salient for parents of children with autism (PCA) and, with an estimated ASD prevalence of one in 88 (9), vaccine uptake among this group could have a substantive impact on public health.

Online surveys of parents involved with autism organizations in the US and Canada revealed that 40% of parents believed that vaccines were among the most significant contributory factors involved in their child's autism (10). Many factors play a role in producing these beliefs, including the temporal proximity of childhood vaccination and the manifestation of autism, distrust of governmental agencies, perceptions of the risks posed by vaccine-preventable diseases (VPDs), and information from popular media sources (11). Several studies have suggested that the latter, especially web-based sources, may fuel distrust in childhood vaccinations (12-15); yet, given limitations in extant research, developing interventions to address these influences would be challenging (16).

Healthcare providers are on the frontlines in the debate about vaccines and autism, and can have a substantial influence on decisions about childhood vaccination (17-21). Therefore, it remains critical that healthcare providers offer information to caregivers, and to PCA, as early after diagnosis as possible (17). The purpose of this study was to examine attitudes toward childhood vaccination among PCA. The association between various dimensions of healthcare satisfaction, vaccine attitudes, and child autism severity and cognitive ability was explored, as was exposure to media sources portraying a link between vaccines and autism.

Our study

A convenience sample of PCA were recruited through their participation in randomized controlled trials of a parent-teacher consultation intervention in Kentucky and Indiana (22,23). All children met the diagnostic and statistical manual IV-TR definition of autistic disorder (24) as confirmed by professionally-administered Autism Diagnostic Observation Schedule Modules 1 or 2 (25). Parents (n=79) were

mailed two self-administered surveys assessing their attitudes toward childhood vaccines and their satisfaction with their child's medical care. Fifty parents completed the Parent Satisfaction with Care Questionnaire and 49 completed the Vaccine Attitude Questionnaire (described below). Respondents were not significantly different than non-respondents in terms of child's age, parental education level, income, or race. All study procedures were approved by the University's Institutional Review Board.

Demographic information including child age, gender, race, household income, number of siblings, and parent education level was collected (described in table 1). Measures assessing children's severity of autism (Childhood Autism Rating Scale; CARS) and cognitive ability (Differential Abilities Scale; DAS) were administered by the research team (23). The CARS is a valid and reliable, observational scale comprised of 15 items evaluating behaviors such as social relating, resistance to change, communication, and body use (26). The General Conceptual Ability subscore of the DAS, which has strong internal and test-retest reliability (27), was used to assess children's cognitive ability.

Participants also completed questionnaires assessing their satisfaction with their child's primary healthcare provider (PCP); Table 2 provides example items and coefficient alphas for subscales. The 24-item Parent Satisfaction with Care Questionnaire contained seven subscales and was based on a modification of two established measures for assessing individuals' satisfaction with medical care (28,29). Five subscales examined parents' perceptions of their child's PCP, including his/her informativeness, interpersonal sensitivity, competence to care for a child with autism, and willingness to engage in partnership building with caregiver. Two additional subscales assessed parents' reported accessibility and affordability of healthcare for their child. Response options were arranged on a 4-point Likert scale ranging from strongly agree to strongly disagree.

Parents also completed a 43-item Vaccine Attitude Questionnaire, which was based in part on a study of MMR vaccine attitudes conducted in the United Kingdom (30).

Table 1. Bivariate analyses of parents' (n=50) beliefs toward childhood vaccination and experiences with child's healthcare provider

Correlate	Total mean (SD)	Vaccines contributed to cause of child's autism. (n=43)			Would refuse to vaccinate if there were no penalties. (n=47)		
		Disagree mean (SD)	Agree mean (SD)	p-value	Disagree mean (SD)	Agree mean (SD)	p-value
<i>Demographic and ASD-Related Characteristics</i>							
White - n(%) (n=47)	34 (68.0)	11 (57.9)	18 (81.8)	0.168	28 (71.8)	6 (85.7)	0.657
Mother attended college - n(%) (n=41) ^a	27 (54.0)	10 (66.7)	13 (65.0)	1.000	21 (61.8)	5 (83.3)	0.399
Income greater than \$25,000 - n(%) (n=39) ^b	25 (50.0)	6 (46.2)	15 (75.0)	0.142	20 (62.5)	4 (66.7)	1.000
Child's gender (male) - n (%)	43 (86.0)	17 (89.5)	22 (91.7)	0.806	35 (85.4)	7 (87.5)	0.875
Child's age	5.8 (1.6)	5.4 (1.6)	6.2 (1.6)	0.115	5.8 (1.6)	5.8 (1.7)	0.991
Number of siblings (n=47)	1.2 (1.1)	1.3 (1.3)	1.1 (1.1)	0.625	1.4 (1.1)	0.6 (1.2)	0.094
CARS Score (n=48)	37.7 (8.5)	39.4 (8.4)	37.3 (9.1)	0.455	36.9 (9.0)	41.3 (6.0)	0.194
DAS Score	47.6 (21.2)	50.0 (24.4)	47.3 (20.5)	0.696	51.1 (21.2)	32.8 (13.9)	0.024*
<i>Vaccine Attitudes</i>							
Perception of vaccine safety/efficacy	2.0 (0.5)	2.5 (0.4)	1.8 (0.4)	<0.001 [†]	2.2 (0.5)	1.7 (0.3)	0.002 [†]
Negative consequences of non-vaccination	3.1 (0.5)	3.3 (0.5)	2.9 (0.5)	0.008 [†]	3.2 (0.5)	2.8 (0.7)	0.102
Trust in health institutions	2.3 (0.7)	2.8 (0.6)	2.0 (0.5)	<0.001 [†]	2.4 (0.6)	2.0 (0.7)	0.043*
Vaccine communication with PCP	3.0 (0.7)	3.1 (0.7)	3.0 (0.7)	0.860	3.0 (0.6)	3.0 (0.8)	0.873
Desired autonomy	2.5 (0.7)	2.3 (0.7)	2.8 (0.7)	0.036*	2.4 (0.6)	3.0 (0.6)	0.004 [†]
Sense of responsibility to vaccinate	3.1 (0.6)	3.3 (0.6)	2.9 (0.6)	0.043*	3.2 (0.5)	2.9 (0.7)	0.058
<i>Satisfaction with Medical Care</i>							
Physician informativeness	2.9 (0.7)	2.9 (0.6)	2.9 (0.8)	0.788	2.9 (0.7)	2.9 (0.7)	0.927
Interpersonal sensitivity	3.2 (0.6)	3.3 (0.6)	3.3 (0.5)	0.864	3.2 (0.5)	3.3 (0.5)	0.875
Partnership building	2.9 (0.6)	3.0 (0.7)	3.1 (0.6)	0.691	3.0 (0.6)	3.0 (0.6)	0.846
Perceived competence	2.7 (0.7)	2.7 (0.7)	2.8 (0.7)	0.584	2.7 (0.7)	2.6 (0.7)	0.730
Accessibility of care	2.9 (0.5)	3.0 (0.5)	3.0 (0.6)	0.720	2.9 (0.5)	2.8 (0.6)	0.343
Affordability of care	2.8 (0.6)	3.1 (0.7)	2.7 (0.6)	0.065	3.0 (0.6)	2.6 (0.7)	0.126
Encountered information provoking fear about vaccine-autism link - n (%)	32 (65.3)	5 (27.8)	22 (91.7)	<0.001 [†]	18 (54.5)	13 (92.9)	0.017*

SD: standard deviation, ASD: Autism Spectrum Disorder, CARS: Childhood Autism Rating Scale, DAS: Differential Ability Scales, PCP: Primary Care Provider.

*p<0.05, [†]p<0.01.

^a Response options for parents' education-level included, "graduate/professional training", "college graduate", "some college", "high school / general equivalence degree", "some high school", "junior high school", and "less than 7 years of education". Data were dichotomized at the mean (1 = some college or greater, 0 = no college attendance). Given that 50% of respondents reported that father's education level was "not applicable", mother's educational attainment was used for analysis.

^b Response options for household income included, "Less than \$10,000", "\$10,000 - \$24,999", "\$25,000 - \$49,999", "\$50,000 - \$100,000", and "Greater than \$100,000". Data were dichotomized (1= \$25,000 or greater, 0 = Less than \$25,000) at the mean and to closely correspond with the US Federal Poverty Level for a four person household (US Department of Health and Human Services, 2013).

Table 2. Description and internal consistency of subscales within the Parent Satisfaction with Care Scale

Scale	Items	Example Item	Coefficient α
Physician's informativeness	5	The doctor thoroughly explains everything to me.	0.87
Physician's interpersonal sensitivity	4	The doctor shows a genuine interest in my child's well-being.	0.81
Physician/caregiver partnership building	4	The doctor asks for my thoughts about autism.	0.80
Physician's Competence	3	The doctor's office has everything needed to provide complete medical care to a child with autism.	0.79
Accessibility of care	4	I can make doctors' appointments at a time that is convenient for my schedule.	0.51
Affordability of care	3	I have to pay for more of my child's medical care than I can afford.	0.71

The modified questionnaire contained six subscales examining parents' 1) perceived safety and efficacy of childhood vaccines, 2) perceived benefits of childhood vaccination, 3) trust in health institutions such as healthcare providers, the government, and pharmaceutical companies, 4) communication with the child's PCP about vaccination, 5) sense of responsibility to vaccinate their child for his/her welfare and the benefit to society and 6) desire for autonomy in making childhood vaccination decisions. Responses were arranged on a 4-point Likert scale ranging from strongly agree to strongly disagree. Table 3 provides items and coefficient alphas. Likert scale items on both the Parent Satisfaction with Care and Vaccine Attitude Questionnaires were recoded for analysis such that higher values indicated attitudes more positively associated with the subscale construct.

Caregivers were also queried about their exposure to information about links between vaccines and

autism. Parents were asked the following three questions: 1) "Have you encountered information on/from [source] about links between vaccines and autism?"; 2) "Was the information useful?"; and 3) "Did the information increase your fears regarding vaccines and autism?" These questions were asked for six different sources (see figure 1). From these data, a binary variable was created in which caregivers with an affirmative response on the third question for any source were assigned a 1 and their counterparts were assigned a 0.

Three items on the Vaccine Attitude Questionnaire served as the outcome measures for analysis. Responses to the following three questions were dichotomized (1=strongly agree/agree; 0=strongly disagree/disagree): "Vaccines contributed to the cause of my child's autism," "I would recommend to others not to vaccinate their children," and "If there were no penalties for doing so, I would refuse to vaccinate my children."

Table 3. Description and internal consistency of subscales within the Vaccine Attitude Questionnaire

Question	n (%) ^a	Coefficient α^b
<i>Vaccine safety and efficacy</i>		
		0.85
Childhood vaccines are safe (n=47)	18 (38.3)	
Childhood vaccines are very effective in preventing disease. (n=47)	42 (89.4)	
More research is needed to fully investigate the effects of childhood vaccines. (n=47) ^c	47 (100.0)	
Possible complications of vaccination can be very serious for children. (n=47) ^c	45 (95.7)	
Scientific evidence has shown that vaccines do not cause autism. (n=47)	14 (29.8)	
My child getting autism from vaccines is a major concern for me. (n=49) ^c	35 (71.4)	
<i>Consequences of non-vaccination</i>		
		0.83
The diseases childhood vaccines prevent are serious. (n=48)	44 (91.7)	
Without vaccines, my child would be at risk for getting the diseases they prevent. (n=48)	42 (87.5)	
People who do not vaccinate their children put others at risk. (n=47)	34 (72.3)	
More kids should be vaccinated so that outbreaks do not occur. (n=48)	32 (66.7)	
<i>Trust in health institutions involved with vaccination</i>		
		0.80
I trust the opinion of my healthcare provider regarding safety of vaccines. (n=47)	28 (59.6)	
I trust the companies producing my child's vaccines. (n=47)	22 (46.8)	
The government would stop childhood vaccination programs if they were dangerous to children. (n=49)	22 (44.9)	
The government is too defensive about childhood vaccines. (n=48) ^c	35 (47.9)	
<i>Communication about vaccination with healthcare provider</i>		
		--- ^a
I discuss my concerns about vaccination openly with my child's healthcare provider. (n=47)	37 (78.7)	
My concerns about vaccination are taken seriously by my child's healthcare provider. (n=47)	33 (70.2)	
<i>Desired autonomy in vaccination decision</i>		
		--- ^a
Parents should make decisions regarding their child's vaccination rather than healthcare providers or the government. (n=49)	35 (71.4)	
Vaccines should not be required to attend school. (n=49)	11 (22.4)	
<i>Sense of parental/societal responsibility to vaccinate</i>		
		--- ^a
I have a responsibility to vaccinate my children for the protection of all children. (n=49)	41 (83.7)	
As a caregiver, I have a responsibility to vaccinate my child for his/her welfare. (n=49)	45 (91.8)	

^aNumber and percent who indicated that they agreed or strongly agreed with the statement.

^bCoefficient alpha not computed for scales comprised of fewer than three items.

^cItems were reverse coded for computation of subscale score and coefficient alpha.

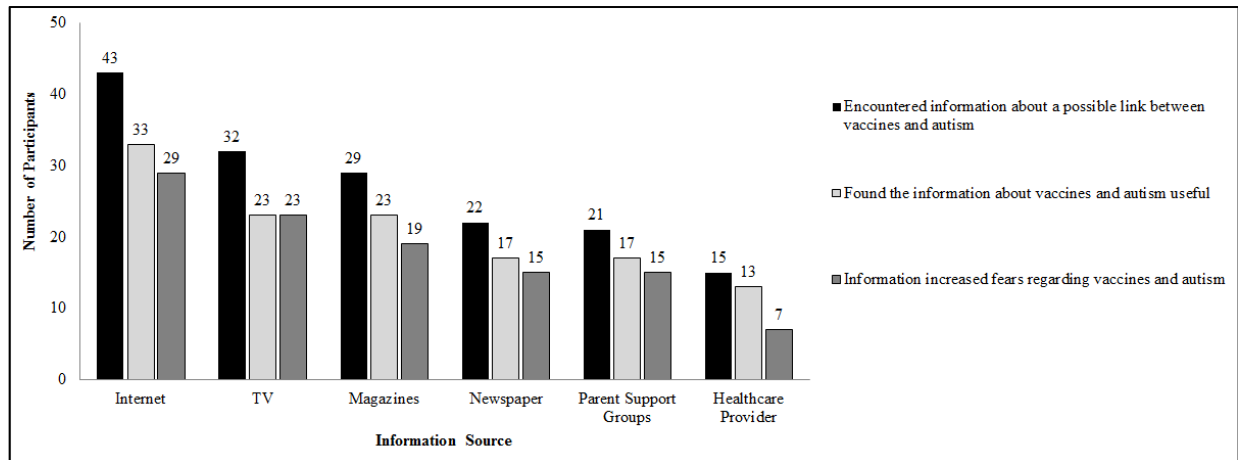


Figure 1. Caregivers' exposure to information regarding a link between vaccines and autism.

Subscale scores were computed as an average of item ratings. Bivariate associations between the outcome variables and continuous and categorical correlates were assessed through a series of independent samples t-tests and chi-square tests, respectively.

Our findings

Demographic characteristics of the sample are described in table 1. The majority of the sample was white (68%), 50% reported a family income of greater than \$25,000, and 54% of mothers had attended some college. The majority (86%) of children were male. The average age of children was 5.82 (range: 3 to 9); 22% were under the age of 5 years. Most children (70%) had at least one sibling.

Table 3 describes participants' attitudes toward childhood vaccination. Of note, only 38% believed that childhood vaccines were safe, 30% believed that scientific evidence had shown that vaccines do not cause autism, and 71% reported that they were concerned that their child could get autism from vaccines. However, the majority (89%) did believe that vaccines were effective in preventing disease. Most (92%) believed that VPDs were serious and 88% believed that their children would be at risk for those diseases without vaccination. The majority of parents (72%) also believed that people who do not vaccinate their children put others at risk. Similarly, 84% felt that they had a responsibility to vaccinate their children "for the protection of all children".

Parents' trust in regulatory and health-related institutions involved with vaccination was relatively low. For example, only 60% trusted the opinion of their child's PCP regarding the safety of vaccines, and 47% trusted the pharmaceutical companies producing vaccines. Fewer than half (45%) believed that the government would stop vaccination programs if they were found to be dangerous to children. Despite mistrust, most parents (79%) reported that they did discuss their concerns about vaccination openly with their child's PCP and 70% reported that their concerns were taken seriously. Most parents valued their autonomy in the vaccine decision process, with 71% reporting that vaccination should be a parental decision rather than one mandated by healthcare providers or the government. Moreover, nearly one-fourth (22%) reported that vaccines should not be mandatory for school attendance.

Figure 1 describes parents' exposure to information about the vaccine-autism controversy. The most common source was the internet (reported by 88%), followed by television, magazines, newspaper, parent support groups, and healthcare providers. The majority of parents reported that the information they obtained was useful, ranging from 65% of those receiving information from healthcare providers to 77% for that from parent support groups. Except for those who acquired information from a healthcare provider, the majority of parents reported that the information increased their fears about the association between vaccines and autism. Information obtained from parent support groups provoked fear among proportionally more parents (71%) than did

television (70%), internet (67%), magazines (63%), and newspapers (60%). Of note, among those encountering information from healthcare providers, comparatively fewer (37%) reported an increased fear of the links between vaccines and autism.

Over half (56%) of the parents believed that vaccines had contributed to the cause of their child's autism, 30% reported that they would refuse to vaccinate their children if there were no penalties for doing so, and 16% reported that they would recommend others not to vaccinate their children. Most parents (71%) believed that vaccines given later in childhood were less likely to cause autism than those given to children at a younger age and 60% believed that vaccines involving doses that were weeks or months apart were less likely to cause autism than vaccines given all that once.

Bivariate analyses

Table 1 presents results from bivariate analyses. Due to the low number ($n=8$) of participants who reported that they would recommend others not to vaccinate their children, this variable was not included as an outcome in analyses.

Demographic characteristics and satisfaction with care. None of the demographic variables, including parent education level or child's autism severity, were associated with beliefs of vaccines as a cause of autism or refusal to vaccinate if no penalties existed. Of note, characteristics related to parents' perceptions of their child's PCP and accessibility/affordability of medical care were not significantly associated with parents' belief that vaccines had contributed to their child's autism or to their desire to refuse vaccination.

Belief that vaccines contributed to child's autism. Parents who believed that vaccines had contributed to the cause of their child's autism were significantly more likely to report that they had encountered media that caused them to have fear about the possible links between vaccines and autism ($p<0.001$). These parents had lower average ratings on subscales assessing perceived vaccine safety and efficacy ($p<0.001$), negative consequences of non-vaccination ($p=0.008$), trust in healthcare institutions ($p<0.001$), and sense of responsibility to vaccinate for the welfare of their child and for other children

($p=0.043$). Parents who believed vaccines had contributed to the cause of their child's autism also believed that parents should have more autonomy in childhood vaccination decisions ($p=0.036$). Child autism severity nor child cognitive ability were significantly associated with parents' belief that vaccines had contributed to their child's autism.

Desire to refuse vaccination. Parents who reported that they would refuse to vaccinate their children if there were no penalties for doing so were significantly more likely to report that they had encountered media that caused them to have fear about the possible links between vaccines and autism ($p=0.017$). These parents had a lower average ratings on subscales assessing perceived vaccine safety and efficacy ($p=0.002$), lesser trust in healthcare institutions ($p=0.043$), and believed that parents should have more autonomy in childhood vaccination decisions ($p=0.004$). Parents who reported that they would refuse to vaccinate their children if there were no penalties for doing so had children with significantly lower DAS scores; however, autism severity was not significantly associated.

Discussion

Among this sample of PCA, over half believed that vaccines had contributed to the cause of their child's autism, and over 70% reported that they were concerned that a child could get autism from vaccination. Nearly one-third reported that they would refuse to vaccinate their children if there were no penalties for doing so and nearly one in every six parents reported that they would discourage other parents from vaccinating their children. In this sample, nearly 90% believed that vaccines were effective in preventing disease and over 90% believed that the diseases vaccines prevent are serious. Moreover, nearly 88% of parents reported that, without vaccines, VPDs would pose a risk to their children. These findings are similar to those found in previous research (31). Many studies have reported that low perceived risk of VPDs and doubts about vaccine efficacy contribute to negative attitudes toward childhood vaccination (32-34), though there has been some evidence to the contrary (35).

Perceived safety of childhood vaccines was low, with fewer than 40% reporting that vaccines were safe. Parents who believed that vaccines had contributed to the cause of their child's autism and those who would refuse to vaccinate their children if there were no penalties for doing so reported significantly less confidence in vaccine safety and efficacy than did their counterparts. Distrust of health-related institutions responsible for ensuring safety was common, with fewer than half reporting that they trusted the companies producing vaccines and 45% believing that the government would stop an unsafe vaccination program. Parents who believed that vaccines had contributed to their child's autism and those who would refuse vaccination reported significantly less trust in health institutions. Previous research suggests that institutional trust and perceptions of safety are related. Parental trust in the institutions that develop and regulate vaccines may affect information-seeking behavior and how they receive, process, and react to risk communication from those sources, including material insisting upon vaccine safety (36). As such, vaccine promotion activities involving increased dissemination of information from sources perceived as having questionable credibility is likely to have a limited impact on vaccine attitudes, particularly when the material targets parents' risk:benefit calculus and fails to address underlying mistrust (36).

Of note, the majority of parents believed that alterations in the vaccine schedule would improve the safety of vaccines, specifically delaying vaccines until later in childhood and spacing the doses further apart. Similar attitudes have been identified in previous research (18) and national data suggest that delayed vaccination is not uncommon in the United States (37). These beliefs may be indicative of parents' attempt to educate themselves about vaccination and of their exposure to social discourses, advocated by vaccine-resistant groups and others, suggesting a moral imperative for parents to make empowered, informed, and educated decisions about vaccination to protect their children's health (38). Thus, in a sense, vaccine-resistant groups and public health authorities are promoting the same message: individuals should be informed and empowered to take personal responsibility for their health-related decisions. In this quest, however, individuals are exposed to various

information sources and often to 'mixed messages' (38).

While the cross-sectional design precludes ability to draw conclusions about the origins of parents' attitudes, it is notable that 65% reported encountering information from popular media sources, parent support groups, and/or healthcare providers that increased their fear about the links between vaccines and autism. Parents who were exposed to information that provoked fears related to vaccines and autism were significantly more likely to report that vaccines had contributed to the cause of their child's autism and that they would refuse to vaccinate their children in the absence of penalties. Healthcare providers were described as the least frequent source eliciting fear, and the internet was the most common source of exposure to information about the controversy over vaccines and autism. These findings are consistent with those of Woo and colleagues (11) who found that information from magazines/newspapers, healthcare providers, and the internet played important roles in parents' suspicion about links between vaccination and their child's autism.

The implications of these findings for public health practice are complex. Parental mistrust in governmental and pharmaceutical institutions undermines these institutions' ability to discredit and/or counteract information from other sources. Moreover, mistrust may motivate parents to seek information from alternative sources, and circularly, information from alternative sources may contribute to further mistrust. Future longitudinal research is needed to unpack details about the temporality and directionality of these associations. Public health authorities' engagement in an 'information war' with other sources will likely be ineffective if content explicitly or implicitly communicates that vaccine resistance is an 'irrational' and/or ignorant miscalculation of risk without addressing trust, uncertainty, parent's personalized concepts of their children's vulnerability, and the social and political contexts in which scientific evidence is produced and vaccine decisions are made (36,38,39).

With the exception of information received from healthcare providers, information about autism and vaccination encountered from other sources provoked fear in the majority of those parents exposed to it. Interestingly, proportionally more parents who

encountered information about autism and vaccines from parent support groups reported that it provoked fear than those who encountered the information from other sources. Previous research has shown that PCA perceive autism organizations to be an equally credible or more credible source of vaccine information than organizations such as the CDC, National Vaccine Information Center, and American Academy of Pediatrics (11). However, dimensions of trust and attitudes regarding credibility and authority are complex. For example, discourses of vaccine-resistant groups frame 'trusting blindly' in traditional scientific authority as symptomatic of disempowerment and entailing a substantive risk (38). Thus, vaccine promotion efforts aiming to improve public trust in traditional health-related institutions may be misguided if 'trust' is in itself seen by consumers as a risk (38). Of note, the present study did not inquire about the specific type of support groups with which parents were involved. Additional research about the types of organizations with which PCA typically affiliate, as well as informal and/or formal discourses about vaccination within these organizations is needed to more fully understand if and how parents' affiliation with these groups affects vaccination behavior. Furthermore, researchers and public health practitioners interested in working with and writing about these groups should be thoughtful in how they frame their language. Specifically, previous research cautions against the tendency to identify these groups with an anti-vaccine 'social movement', as this attribution may inherently grant more social theoretic foundation to their claims by conflating it with broader political transformations focused on individual rights and resistance to authority (40).

Studies have highlighted the important role healthcare providers play in encouraging the uptake of childhood vaccination (17,30). In fact, a literature review revealed that mistrust in healthcare systems and negative experience communicating healthcare providers about vaccination are often associated with lower vaccine uptake (6). In the present study, the vast majority of parents reported that they discussed their concerns about vaccination with their child's healthcare provider and that the provider took their concerns seriously. On average, parents had positive ratings of their healthcare providers' informativeness, sensitivity, competence, and partnership building.

Nevertheless, only 60% reported that they trusted their provider's opinion regarding vaccine safety. This percentage is slightly less than that reported in a recent nationally representative survey of parents (41). Although somewhat low, the level of trust in healthcare providers exceeded that reported for other authorities associated with vaccination (pharmaceutical companies, government, etc); thus, the patient-provider relationship may represent an opportunity for effective dialogue about childhood vaccination. Of note, however, none of the measures related to satisfaction with child's PCP or accessibility and affordability of medical care were significantly associated with vaccine attitude outcomes in this study. Given these findings and the logistical constraints faced by healthcare providers (12), immunization campaigns cannot rely solely on healthcare providers to promote vaccination, but must engage other mobilization activities and/or electronic, visual, and print media channels (41) directed at parents and support groups specifically.

Demographic and ASD-related characteristics were generally not associated with vaccine attitudes, with the exception that children of parents who reported they would refuse vaccination had lower cognitive functioning, as assessed by the DAS. Additional research is needed to investigate factors that mediate the association between childhood cognitive functioning and parents' attitudes toward childhood vaccination. For example, mediators may include differences in timing of diagnosis and appearance of symptoms of regression and/or variations in parents' information-seeking behavior according to child's level of cognitive functioning.

Most parents desired autonomy in vaccine decision-making, but the majority reported that they felt a personal obligation to vaccinate for the protection of others and the child. Parents who believed that vaccines contributed to the cause of their child's autism and those who would refuse vaccination desired significantly more decision-making autonomy than their counterparts. The former also felt significantly less responsibility to vaccinate. Interestingly, the concept of societal responsibility to vaccinate often has been ignored in vaccine promotion materials. Although the public health rationale for mitigating vaccine refusal is to maintain coverage levels necessary to achieve herd immunity,

many promotional materials focus on presenting the individual-level risks and benefits of vaccination (36). In the present study, 84% of parents believed that they had a responsibility to vaccinate their children for the protection of all children, and parents' sense of societal responsibility to vaccinate was strongly associated with their vaccine attitudes; these findings highlight a pivotal point to target in vaccine promotion. Public health communications and efforts addressing vaccine uptake among PCA should leverage and include information addressing attitudes surrounding the societal implications of individual-level vaccine uptake.

Nevertheless, the tension between individual autonomy and government regulation in immunization has a long and contentious history in the United States and will be difficult to address (42). Nationally, parents are increasingly seeking nonmedical exemptions for vaccination (43), citing religious, ideological, and/or safety concerns (44,45). As discussed above, in the public health arena, vaccine refusal is often assumed to be a matter of miscalculated risk; however, autonomy in the context of social movements involving 'alternative' concepts of health and responsibility (36), empowered decision-making (38), and tendencies toward a more personalized approach to parenting and vaccine decision-making (39) also play a role. In the coming years, these and other significant health-related issues related to vaccine refusal (46-48) will force the public health community, policy makers, and the public to confront questions surrounding boundaries of personal autonomy and societal responsibility (44).

While this study provides important preliminary insights into the vaccine attitudes of PCA, the study is not without limitations. Though they were based on measures used in previous research in other settings, the questionnaires assessing parent satisfaction with care and vaccine attitudes were self-developed for this formative study and are in need of further evaluation and integration with validated measures developed since the commencement of this study (49). Additionally, although demographic differences between survey respondents and non-respondents were not observed, the response rate (63%) does raise concerns of participation bias. The study was based on a convenience sample of parents participating in a separate autism-related study; given that the vaccine

attitudes of participating parents may differ from non-participants, the findings should be generalized with caution. The small sample size also resulted in limited statistical power to detect differences in some pairwise comparisons.

Conclusion

PCA are at the center of arguably one of the most heated debates surrounding vaccination in recent history (7,8). The present study highlights the complexity of parents' beliefs about vaccination and underscores the failure of popular narratives dichotomizing attitudes as "pro-vaccine" and "anti-vaccine" to adequately portray nuances. In this study, most parents reported serious concerns about vaccine safety, but the majority viewed vaccines as necessary and effective. Concerns about safety are likely related, in part, to issues of trust, perceived credibility, and exposure to sources of information suggesting a link between vaccines and autism. From a public health perspective, the findings clearly point to a need to reestablish parents' trust in scientific evidence suggesting no link between vaccines and autism and in government-backed immunization programs more generally. This will be an ongoing and tenuous process that should involve transparent and truthful dialogue (50), engage trusted members of the community, and acknowledge the value of parent empowerment and information-seeking.

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