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A clinical survey evaluating the most common factors influencing a parental decision of vaccine refusal, and whether a correlation exists between vaccine refusal and the degree of trust in pediatricians.

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Introduction:

The practice of vaccine delay and refusal has recently held the attention of the medical community, most notably due to outbreaks of vaccine preventable diseases. It is a loaded subject both for parents/guardians and pediatricians; to the point of pediatricians being more likely to dismiss families who refuse vaccinations for their children.¹ Within the field of pediatrics, this is a topic that poses a threat to the physician-patient relationship. Studies have shown an increase in vaccine refusals in the last decade; therefore, further examination of the reasons behind this decision remains key in better understanding what drives this decision when made by some parents and guardians. This survey will attempt to cite the most common reasons for this decision directly from parents/guardians, as well as to examine if there is any significant difference between the degree of trust in pediatricians amongst parents/guardians who refuse or delay vaccines when compared to non-refusing parents/guardians. The ultimate goal of such a survey will be to better understand the “why” behind parental vaccine delay and refusal. Ultimately, it is unquestioned that both sides want the best for the child and patient; the hope of this survey is to better understand the gap between the two sides.

Background Literature:

Recent outbreaks of vaccine-preventable disease in the United States have drawn attention to the phenomenon of vaccine delay and refusals.² An epidemiological study from 2016 reported that of 1416 reported measles cases, more than half (56.8%) had no reported measles vaccination. Similarly, five of the largest state-wide epidemics for pertussis outbreaks had significant proportions of unvaccinated or under-vaccinated individuals, ranging from 24-45%. Stratification of these individuals revealed that 59-93% were intentionally unvaccinated.²

It can be safely presumed that the primary reason parents refuse vaccinations is an innate desire to protect their children.³ However, it becomes critical to examine the external and internal influencing factors in parents who decide that not giving a vaccine is a form of protection for their child. There are a multitude of external sources that are available to the public such as recalls of vaccines, scientific publications regarding the true or falsified dangers of vaccines, and non-scientific sources such as anecdotal evidence of naturopaths, homeopaths, chiropractors, celebrities and lay-persons. All of these can create an anti-vaccination sentiment

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which may influence parents and guardians.³ Kajetonowicz et al. describe a concerning yet probable scenario in which “scientific data often will lose with pseudoscientific, false or anecdotal data that have higher sensational and emotional impact on parents.” Equally likely to contribute is the mere fact that we have entered a point in history in which the effective use of vaccines as public health measures have virtually removed vaccine-preventable diseases from the public eye; and a whole generation of parents who have never seen a child with measles or mumps do not feel the importance or see the benefit of these vaccines, nor the threat that exists when vaccines are no longer part of a child’s medical care.

Looking at the objective findings of studies in the last decade, there is a significant increase in the number of parents who have refused vaccinations for their children. In a national American Academy of Pediatrics (AAP) Periodic Survey¹, it was found that between 2006 and 2013, the proportion of pediatricians reporting vaccine refusals increased from 74.5% to 87.0%. This survey also found that pediatricians increasingly believe the most common reason parents refuse vaccinations is because they are deemed as unnecessary (63.4% vs 73.1% between 2006 and 2013). Perhaps the most notable finding was that in 2006, 6.1% of pediatricians reported “always” dismissing families for continued vaccine refusal, whereas by 2013, this proportion had increased to 11.7%. Of the pediatricians who had dismissed families, “lack of trust” was cited as the reason by the vast majority of physicians (87.4% in 2006, and 79.9% in 2013). A separate article similarly cited the two most common reasons for dismissals of families as 1) parental refusal suggests such lack of trust in the physicians' recommendations that it undermines the basis for a meaningful physician-patient-parent relationship; and 2) unimmunized children present an unacceptable risk to other children in the physicians' waiting rooms.⁴ The AAP survey’s findings did report that in 2006 and 2013, 31.9% and 34.4% of parents eventually changed their minds after educational efforts, with an average of 16 weeks between refusal and acceptance. Nonetheless, 9.2% of pediatricians did report that educational efforts never convinced any vaccine-refusing parent to give permission, resulting in an average of 2.6 (SD 11.6) patient dismissals in a period of one year in pediatricians, with a mean patient age of 11 months (SD 36.4).

These studies discussed multiple important points, 1) vaccine delay and refusals are a persistent phenomenon, 2) there are significant and negative epidemiological consequences to these decisions, 3) pediatrician—patient/parent relationships are negatively affected to the extent of patient dismissals, and 4) there are a subset of those who initially refuse vaccine who change their minds with educational efforts.

Study Methods:

Participants included parents/guardians of pediatric patients from two Academic General Pediatrics clinics, where a total of 76 participants were surveyed for this study. Inclusion for the target group was parents who had delayed or refused vaccines. Inclusion in the control group was open to everyone else, i.e. parents who have not delayed or refused vaccinations. Pediatric patients themselves were not involved in completing the surveys. The survey's intent was explained to potential participants as purely educational for pediatricians, with no consequence to the medical care of their child. Furthermore, the anonymity and optional nature of the survey were emphasized. No personal information was included or requested on the surveys in order to protect patient privacy. Participants were asked to fill out the surveys while in private waiting rooms, without the presence of a study researcher, unless requested otherwise.

The electronic medical record system, EPIC, was used to screen appropriate candidates for survey distribution. With EPIC, patients were selected who had not immunized or had delayed immunizations using the diagnosis codes "unimmunized" or "delayed vaccine". These parents were used as potential recipients of the survey over the span of approximately six months. The initial goal was to survey at least 30 patients in the target group. However, the final number in the target group was 9, compared to 66 in the control group. The subjects were primarily patients of two faculty members. They were offered the survey and consent (in paper) inside a private exam room in the clinic. As it was found that more participants were required in the target group, the survey was also offered to patients whose primary pediatrician was someone other than the original two faculty members. These other pediatricians agreed to participate (colleagues of faculty members) before the consent & survey were offered to their patients by study researchers.

Analysis consisted of averages of numerical scales, standard deviations, standard error of means, and confidence intervals in both groups (target and control). Differences between target and control groups were examined for the three scaled questions ("trust in pediatrician", "willingness to discuss", and "consider change"). This analysis was accomplished by using an online two-tailed t-test calculator for the comparison of means.⁵ An "n-1" Chi-squared test (same online calculator) was also calculated to determine if significant differences existed between the proportions calculated in the sources of information and the cited reasons for vaccine decisions. Secondly, the proportion of most common sources for decision making as well as most common reasons for decision were calculated. Microsoft Excel was used to electronically record the data, to calculate scaled responses in both groups, and to calculate the proportions of sources/reasons between the

groups. Data tables were constructed for graphic presentation of the data using Microsoft Excel and Word software.

The three scaled questions are included in the appendix under image 1. They are scaled from 0-10, with 10 being the highest value in agreement with the question. Participants were also asked to describe their vaccine decision status as either accept, delay, refuse, or unsure. Due to the small sample size, the three latter groups were combined as the sub-group of “non-accept.”

Results:

A total of 76 participants were included in the analysis. The distribution included 66 participants in the “accept” group, 2 in the “refusal” group, 5 in the “delay” group, and 3 in the “undecided” group. When combined there were a total of 9 in the “non-accept” group (1 participant selected both undecided and delay). The mean score of “trust in pediatrician” was 9.38 for participants accepting vaccinations for their children, with a 95% CI of 9.09-9.67. In comparison, the “non-accept” group had a mean score of 7.13, with a 95% CI of 4.89-9.36. Using a two-tailed t-test, this was considered a statistically significant difference ($p < 0.001$). The mean score on “willingness to discuss with pediatrician” was 9.6 in participants accepting vaccinations for their children, with a 95% CI of 9.36-9.84. In comparison, the “non-accept” group had a mean score of 7.89, with a 95% CI 5.44-10.00. This was a significant difference ($p < 0.005$). The mean score on “consider a change in decision” was 8.6 in participants accepting vaccinations for their children, with a 95% CI of 8.1-9.1. In comparison, the “non-accept” group had a mean score of 5.0, with a 95% CI of 2.97-7.03. This also was a significant difference ($p < 0.0001$) (Tables 1-2 & 2.1-2.3).

Amongst the vaccine “accept” group, the most common source for decision making in regard to vaccine status included books (42%) followed by internet (websites/forums), personal reflection, and other healthcare providers (37.9%, 34.8%, and 30.3%, respectfully). In the overall “non-accept” group, the most common sources included internet (66.7%), followed by personal reflection, relatives/friends, and books (all 55.6%).

In terms of reasons for vaccination status, the leading reason listed amongst the “accept” group was “make my child sick” at 18.2%, followed by “hurt immune system” at 13.6%. In the overall “non-accept” group, these were also the top two reasons cited, with “hurt immune system” at 66.7% and “make my child sick” at 55.6%. There was a larger proportion of participants listing “other” as an explanation in the “non-accept” group compared with the “accept” group (22.2% vs 7.6%) (Tables 3 & 4).

The baseline demographics of the two groups are shown in Table 5. Caucasian was the most commonly selected race for both two groups, however the proportion choosing Caucasian was nearly double in the “non-accept” group (66.7% vs 37.8%); albeit in a much smaller sample size (66 vs 9). English was the most commonly selected primary language in both groups. The “non-accept” group had the highest proportion of participants selecting “Medicaid/Medi-Cal/Medicare” insurance (66.7%), while the accept group’s most common selection for insurance was “Employer” (47%). The largest income subgroup amongst the “accept” group was “>\$100,000” (37.8%), while in the “non-accept” group, 5 of 9 participants preferred not to answer this question (55.6%).

Status	Trust (mean)	SD	Willing to Discuss (mean)	SD	Consider Change (mean)	SD
Accept	9.38	1.21	9.6	0.98	8.6	2.06
Non-Accept	7.125	3.23	7.89	3.76	5	3.12
Delay	8	2.74	10	0	7.2	2.28
Refuse	4.5	4.95	1.5	2.12	2	1.41
Undecided	6.5	2.12	9.33	1.15	3.33	1.53

Table 1. Mean values (0-10) and standard deviations (SD) for groups on three scaled questions of survey. Overall non-accept includes delay, refuse and undecided sub-groups.

Status	Trust (SEM)	Trust (95% CI)	Willing to Discuss (SEM)	Willing to Discuss (95% CI)	Consider change (SEM)	Consider change (95% CI)
Accept	0.148	9.09-9.67	0.12	9.36-9.84	0.253	8.1-9.1
Non-Accept	1.14	4.89-9.36	1.25	5.44-10.34	1.04	2.97-7.03
Delay	1.22	5.61-10.39	0	10	1.02	5.2-9.2
Refuse	3.5	<0 - >10	1.5	-1.44-4.44	1	0.04-3.96
Undecided	1.5	3.56-9.44	0.667	8.02-10.64	0.882	1.6-5.06

Table 2. Standard error of the mean and 95% confidence intervals for groups on three scaled questions of survey. Overall non-accept includes delay, refuse and undecided sub-groups. SEM: standard error of the mean. CI: $1.96 \times (SEM) \pm \text{mean}$, (95% confidence interval; $p < 0.05$)

Trust: Difference from Accept Group	δ	t-statistic	Significance level
Overall Non-Accept	2.255	-4.057	P<0.0005
Delay	1.38	-2.209	P<0.05
Refuse	4.88	-5.049	p<0.0001
Undecided	2.88	-3.913	P<0.0005

Table 2.1: Difference in scaled responses from the accept group on question 1 (trust). δ : difference.

Willing-Discuss: Difference from Accept Group	δ	<i>t</i>-statistic	<i>Significance level</i>
Overall Non-Accept	1.71	-3.103	P<0.005
Delay	0.4	0.907	p=0.3678
Refuse	8.1	-11.21	p<0.0001
Undecided	0.27	-0.464	p=0.6441

Table 2.2: Difference in scaled responses from the accept group on question 2 (willing to discuss). δ : difference.

Consider-Change: Difference from Accept Group	δ	<i>t</i>-statistic	<i>Significance level</i>
Overall Non-Accept	3.6	-4.603	p<0.0001
Delay	1.4	-1.456	p=0.15
Refuse	6.6	-4.456	p<0.0001
Undecided	5.2	-4.363	p<0.0001

Table 2.3: Difference in scaled responses from the accept group on question 3 (consider change). δ : difference.

Status	Books	Other healthcare	Internet (Websites & forums)	Newspaper & magazines	Relatives & friends	Television	Personal reflection	Other
Accept (n=66)	28 (42%)	20 (30.3%)	25 (37.9%)	11 (16.7%)	18 (27.3%)	2 (3%)	23 (34.8%)	12 (18%)
Non-Accept (n=9)	5 (55.6%)	4 (44.4%)	6 (66.7%)	4 (44.4%)	5 (55.6%)	1 (11.1%)	5 (55.6%)	3 (33.3%)
Delay (n=5)	3 (60%)	1 (20%)	3 (60%)	2 (40%)	3 (60%)	1 (20%)	3 (60%)	1 (20%)
Refuse (n=2)	1 (50%)	0	1 (50%)	0	0	0	0	1 (50%)
Undecided (n=3)	2 (66.7%)	3 (100%)	2 (66.7%)	2 (66.7%)	3 (100%)	0	3 (100%)	1 (33.3%)

Table 3: Proportion of participants selecting different sources for their decision making in regard to vaccine status.

Status	Painful	Make my child sick	Hurt immune system	Not helpful /useful	Other
Accept (n=66)	6 (9%)	12 (18.2%)	9 (13.6%)	3 (4.5%)	5 (7.6%)
Non-Accept (n=9)	0	5 (55.6%)	6 (66.7%)	2 (22.2%)	2 (22.2%)
Delay (n=5)	0	3 (60%)	3 (60%)	0	2 (40%)
Refuse (n=2)	0	1 (50%)	1 (50%)	1 (50%)	0
Undecided (n=3)	0	1 (33.3%)	3 (100%)	1 (33.3%)	0

Table 4: Proportion of participants selecting different reasons for their decision making in regard to vaccine status.

Baseline Demographics		
Race	Accept (n=66)	Non-Accept (n=9)
African-American/Black	6 (9.1%)	-
Asian/Pacific Islander	6 (9.1%)	-
Caucasian	25 (37.8%)	6 (66.7%)
Latino	12 (18.2%)	1 (11.1%)
Native American	1 (1.5%)	-
Other	1 (1.5%)	-
Two or more races	8 (12.1%)	1 (11.1%)
Not answered	6 (9.1%)	1 (11.1%)
Primary Language	Accept (n=66)	Non-Accept (n=9)
English	53 (80.3%)	7 (77.8%)
Spanish	6 (9.1%)	1 (11.1%)
Other	8 (12.1%)	4 (44.4%)
Insurance	Accept (n=66)	Non-Accept (n=9)
Employer	31 (47.0%)	1 (11.1%)
Medicaid/Medi-Cal/Medicare	16 (24.2%)	6 (66.7%)
Other	14 (42.4%)	3 (33.3%)
Home	Accept (n=66)	Non-Accept (n=9)
Rent	31 (47.0%)	8 (88.9%)
Buy	23 (34.8%)	1 (11.1%)
Income	Accept (n=66)	Non-Accept (n=9)
<\$25K	2 (3.0%)	1 (11.1%)
\$25K-under \$50K	9 (13.6%)	-
\$50K-under \$100K	16 (24.2%)	2 (22.2%)
≥100K	25 (37.8%)	1 (11.1%)

Table 5. Baseline demographic data of accept and non-accept subgroups.

Discussion:

There has been a significant increase in the number of parents/guardians who have refused or delayed vaccinations for their children in the past decade. Previous studies have noted the added implications of increased outbreaks of vaccine preventable illnesses, as well as increased number of dismissals by pediatricians of vaccine-refusing families. These are negative outcomes associated with this decision regarding childhood vaccinations. Ultimately, the role of the pediatrician is to maintain and uphold the well-being of a child, and the best path to reaching this goal is with the aid of a child's parents or guardians. Trying to better understand the decision-making process behind vaccination determinations by parents/guardians can potentially be very beneficial to a pediatrician who faces this discussion with parents on a daily basis. The goal

of this study was to see if there is a significant difference between vaccine accepting and non-accepting families when it comes to the sources they use to make their decisions, as well as if there is a difference in trust, willingness to hold a discussion, or to consider a change in their decision on this subject matter.

There was similarity between the two groups in terms of the most common sources of decision making, however there was a difference in the “most” cited source between the two groups— “books” was highest in the accepting group, while the “internet” was referenced most frequently in the non-accepting group. Nonetheless, it is important to note that the “internet” was the second highest source cited in the accepting group, and “books” was also a top-three cited source in the non-accepting group. A chi-squared test found no significant differences between these proportions for the two groups, i.e. books in accepting vs non-accepting subgroups (books: $p = 0.44$, internet: $p = 0.10$). Given the incredible degree of heterogeneity in these sources, there are sources in books and on the internet that may favor any number of different positions on this subject matter. This result does not demonstrate a significant difference in sources cited for decision making regarding vaccinations.

The mean score of “trust in pediatrician” was 9.38 in parents accepting vaccinations for their children. This can be compared with an overall “non-accept” value of 7.125. These values were found to be statistically significantly different ($\delta: 2.255$, $p < 0.0005$). Furthermore, in spite of a small sample size of 2, the “refusal” group had significant differences from the “accept” group on all three questions of the survey (see tables 2.1-2.3). Although there appears to be a detected difference, the small sample size of the “non-accept” group limits generalization to a larger population. The 95% confidence interval for the former group is 9.09-9.67, while that of the latter group is less than 0 to greater than 10; in other words, the small sample size does not allow us to significantly or meaningfully determine where the true population interval of this subgroup lies. However, we can say that there was a difference in responses between the “accept” and “non-accept” groups when it comes to comparing the participants of this study. There is a similar pattern for the other two questions (“willingness to discuss”, and “consider change”). There were statistically significant differences between the two means (i.e. “accept” and “non-accept”), however the latter group had much larger standard deviations, standard errors of the mean, and wider confidence intervals, secondary to the much smaller sample size. This results in a similar inability to generalize to the general population.

“Make my child sick” was cited by 18.2% of the “accept” group and 55.6% of the “non-accept” group. This was found to be a significant difference between the two groups (37.4% difference, $p=0.01$). The most common reason cited by the “non-accept” group was “hurt immune system” at 66.7% vs 13.6% of the “accept” group (53.1% difference, $p < 0.001$). There was also a near-significant difference between the groups

in selecting “not helpful/useful” (17.7% difference, $p < 0.05$). In summary, there were no detectable/significant differences in the proportions of participants selecting for different sources in their decision making. There were, however, a significant difference in the reasons for vaccine decisions, i.e. the “non-accept” group selected “hurt immune system” and “make my child sick” at significantly higher rates than the “accept” group.

Of note, when looking at the magnitudes of difference from the accept group’s mean (tables 2.1-2.3), on all three questions, the “refuse” group had the largest difference, δ . Particularly noticeable is the statistically significant δ of 8.1 between refusal and accepting subgroups on the question of “willingness to discuss” ($n=2$). In contrast, the “delay” and “undecided” groups had magnitudes of δ 0.4 and 0.27, respectively. This may indicate an important finding regarding the mental calculation a pediatrician may be able to make when planning discussions with parents who fall under these different sub-groups of “non-accept”. Given that the refusal group’s “consider change” scores have a δ of 6.6 from the accept group, it may be in the best interest of a pediatrician and such parents/guardians to limit the amount of time discussing the reasons vaccinations are recommended by the medical community. There may be the possibility that spending too much time on a polarizing topic with a provider in whom their degree of trust and willingness to discuss with is not very high may ultimately lead to a worsened parent-physician relationship. This may have even more detriment to a child if there is a complete discontinuation of care with that provider. This is in contrast to the “undecided” and “delay” groups which have much smaller magnitudes of δ in both the “willingness to discuss” as well as the “consider change” scores. When placed in the clinic setting of a busy general pediatrician, it becomes valuable to know where to spend the most time on educational efforts—what may be ultimately helpful for some parents/guardians, may be detrimental for others.

Due to the very small sample size of participants marking a refusal of vaccines ($n=2$), a significant correlation cannot be drawn from the current data attained, i.e. whether meaningful differences exist for this specific subgroup of the “non-accept” group. This was one of the primary outcomes for this study and it cannot be determined, which is the largest limitation of this study. The small sample size in the target group of vaccine “delay” and “refusal” makes it difficult to generalize to a larger population from this data. Nonetheless, statistically significant differences were found (all three scaled survey questions and the reasons for decision making) which would have been consistent with the hypotheses prior to the start of the study. This in and of itself gives confidence in the design of the survey, and perhaps may give an indication that if a larger sample could be attained with such a data set, better generalizations can be made to the population as a whole. If larger samples show the same statistical differences achieved on these findings, with significant

standard errors of the mean, then a more confident conclusion can be made in terms of where the sample of the study rests among the whole population.

Slight modifications to the design may be necessary to improve this study. The distribution of surveys was successful in that participants were given the option to participate and anonymity while completing the survey in private. Gathering vaccine-accepting participants was successful due to the larger representation of such parents/guardians in the population. However, being able to effectively identify participants in the “non-accept” group is where improvement is required. Solutions could include expanding the duration of the study to continue slowly increasing the sample size, or to offer more surveys to this subgroup—i.e. mailing out surveys to all patients who meet the criteria of “delay” or “unimmunized”. By asking such participants to return their completed surveys with no identifiable information on the surveys themselves, anonymity and privacy of protected information can also be maintained. It is the hope of the authors that with increased sample size, the significant differences found on this initial survey can be generalized to the larger population.

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Appendix

Image 1. Three scaled questions.

How much do you trust your pediatrician's recommendation for vaccinations?										
0	1	2	3	4	5	6	7	8	9	10
No			Little				Some			Complete
Trust			Trust				Trust			Trust
How willing are you to discuss vaccinations with your child's pediatrician?										
0	1	2	3	4	5	6	7	8	9	10
Very			Somewhat				Somewhat			Very
Unwilling			Unwilling				Willing			Willing
If your pediatrician provided you with vaccine information they trust, how likely are you to consider changing your beliefs about vaccinations?										
0	1	2	3	4	5	6	7	8	9	10
Very			Somewhat				Somewhat			Very
Unlikely			Unlikely				Likely			Likely