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Short report: Vaccine attitudes in the age of COVID-19 for a population of children with mitochondrial disease☆,☆☆

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ABSTRACT

Background: Children with developmental disabilities are vulnerable to morbidity associated with COVID-19.
Aims: To understand attitudes toward routine childhood vaccinations versus the COVID-19 vaccine in a population of families affected by mitochondrial disease (MtD), a form of developmental disability.
Methods and procedures: An online survey was administered via several advocacy groups for children with MtD.
Outcomes and result: Eighty-six percent of families reported being up to date with the childhood vaccine schedule and seventy percent reported that their affected child receives the annual flu shot. However, only fifty percent reported that the benefits of the COVID-19 vaccine outweighed the risk for their affected child. One quarter of families expressed concern that their child may become sick or deteriorate after the COVID-19 vaccine. In comparison to other routine childhood vaccines, families expressed less confidence in the COVID-19 vaccine.

Conclusions and implications: Families affected by this population of developmental disabilities are more comfortable with the vaccines included in the routine childhood immunization schedule than with the newly introduced COVID-19 vaccine, even despite this group’s vulnerability.

What this paper adds?

A survey of parents/caregivers revealed that these families are more hesitant to receive the COVID-19 vaccine than other routine childhood vaccinations and this may be associated with fear of deterioration as a result of the vaccine.

1. Introduction

During the COVID-19 pandemic, children with complex medical conditions, including those with developmental disabilities, have
been identified as a vulnerable population, with increased risk for severe manifestations when infected with the SARS-COV-2 virus (CDC, 2021; Tinker et al., 2021). One such group of children with complex neurodevelopmental disabilities is those with mitochondrial disease (MtD), a genetic, multisystemic disease caused by dysfunction of mitochondrial metabolism. Children with MtD have a broad spectrum of neurologic manifestations including varying degrees of intellectual impairment, autism and cerebral palsy, representing a diverse population of developmental disability. Some children with MtD may also experience metabolic decompensation and neurologic deterioration triggered by stressors such as infection.

The introduction of a vaccine against COVID-19 for adults in late 2020 and for children in 2021/2022, represented a major milestone of the pandemic, preventing hospitalization and death, particularly for vulnerable populations. However, in developed countries (e.g. the United States), there are high rates of hesitancy toward vaccination which have been an impediment to herd immunity (SteelFisher, Blendon, & Caporello, 2021). While childhood vaccination is an integral part of pediatric primary care and critical for protecting child health, hesitancy during the COVID-19 pandemic has posed a unique challenge for healthcare providers. For those counseling the families of vulnerable patients with developmental disabilities, understanding their attitudes toward vaccination may provide valuable insights for clinical care. In this study, we aimed to measure attitudes toward routine childhood vaccinations versus the COVID-19 vaccine in a population of families affected by MtD, a heterogenous form of developmental disability with potential vulnerability to infection.

2. Methods

A questionnaire was designed by an expert panel at our institution including specialists in neurodevelopmental disabilities, genetics, infectious disease and sociology. Questions were based on prior surveys from this group as well as publicly available vaccine questionnaires from Pew Research and the National Foundation for Infectious Disease (Gordon-Lipkin et al., 2022). We deployed the questionnaire via a cloud-based platform through MtD patient advocacy groups, including, the United Mitochondrial Disease Foundation (UMDF), People Against Leigh Syndrome, and the North American Mitochondrial Disease Consortium. All groups serve communities primarily in the United States. The largest of these groups (UMDF) represents approximately ten percent of families affected by MtD in the United States (Gordon-Lipkin et al., 2022; Schaefer et al., 2019). Each group distributed an invitation to participate via their email listserv and social media, which included a link to a cloud-based survey. The survey was open from January to March 2021.

Participants were required to be a parent/caregiver of a child (<18 years of age) with MtD and be greater than 18 years old themselves (for consent purposes). We focused on parents of children with MtD because this population routinely consents to scheduled childhood immunizations as part of standard pediatric preventative care and allowed us to compare attitudes toward the novel COVID-19 vaccine versus other vaccines. The survey was completed anonymously and was available in English. Attitude statements required responses on a three-point Likert scale. We report descriptive statistics (means, percents, standard deviations) and Pearson’s Chi-square tests of contingency tables.

The study was approved by the institutional review board and granted human subjects exemption by the Office of Human Subjects Research.

3. Results

We received 106 responses from parents/caregivers to children with MtD. Respondents were primarily female (89%) with a mean...
age of 42 years (SD = 7 years). They responded on behalf of their children with MtD who were 51% female and an average age of 11 years old (SD = 6 years). 86% reported that their child with MtD was up to date with childhood vaccinations. 70% reported that their child with MtD routinely receives the annual flu shot. 52% reported that they intend to vaccinate their child with MtD against COVID-19. Attitudes toward the COVID19 vaccine in comparison to attitudes toward other routine childhood vaccinations are illustrated in Fig. 1. Notably, only fifty percent reported that the benefits of the COVID-19 vaccine outweighed the risk for their affected child. One quarter of families expressed concern that their child may become sick or deteriorate after the COVID-19 vaccine. In comparison to other routine childhood vaccines, families expressed less confidence in the COVID-19 vaccine.

The apparent group differences between COVID-19 and the other vaccines in these figures was evaluated using Pearson Chi-square tests of the underlying contingency tables. Both were statistically significant with χ² = 24.571 (p < 0.05, on 14 d.f.) for the left pane and χ² = 67.189 (p < 0.001, on 14 d.f.) for the right pane. Examination of the standardized residuals of this test demonstrated that all of these differences can be attributed to COVID-19 vaccine attitudes in comparison to other vaccines rather than other differences among all vaccine attitudes together. The result suggests that hesitancy surrounding the COVID-19 vaccine in this population may be due to the novelty of the vaccine rather than hesitancy towards vaccines in general.

A power-analysis for the Chi-square test of contingency tables was conducted to evaluate the power of the primary statistical test reported in this paper. The power of the test for a sample size of 106 on 14 degrees of freedom to detect a medium effect size at alpha = 0.05 is b = 0.943560. The null hypothesis under this test assumes the statistic is distributed χ²(14) and the alternative assumes the statistic is distributed Noncentral χ²(14, 26.500000). The critical value of this test is: χ² = 23.684791. This is adequate evidence that the test is appropriately powered at the alpha = 0.05 level as reported in the body of the manuscript.

4. Discussion

Children with complex medical needs have previously been identified as a group that may have higher rates of vaccine hesitancy. A 2020 study showed that children with Down Syndrome have low immunization rates in comparison to typical children (Langkamp et al., 2020). In our study, only half of families intended to vaccinate their child with MtD against COVID-19, similar to surveys of the general population from the same period (Phan et al., 2022; Tyson et al., 2020). This finding has been echoed in other studies. While hesitancy rates were lower in Asia, adolescents with ADHD had rates similar to that of the general population (25%) (Tsai et al., 2021; Xu et al., 2021). In contrast, one study from Israel reported adolescents and adults with autism spectrum disorder were more likely to be vaccinated against COVID-19 than their typical peers (Weinstein et al., 2021).

Vaccine hesitancy in this community was more prevalent toward the COVID-19 vaccine than toward other routine childhood vaccinations. While other studies have reported an association between receipt of the annual flu vaccine and COVID-19 vaccine compliance, our population demonstrated a dichotomy of high flu shot compliance but also high COVID-19 vaccine hesitancy (Gordon-Lipkin et al., 2022; Phan et al., 2022). Only half of families felt that the benefits of the vaccine outweigh the risks and many families expressed concern that their child will deteriorate as a result of vaccination.

Given these attitudes, our study also highlights how data and messaging are needed about vaccine safety in special patient populations such as those with MtD and other neurodevelopmental disabilities. For example, excluding children with developmental disabilities from clinical trials may later lead to increased hesitancy to vaccinate these children who are most at-risk for the severe consequences of infection.

We acknowledge that while some of the attitudes in this community may generalize to broader groups, it is possible that these attitudes are specific to this cohort. Notably, while specific developmental disabilities may be individually rare, medical complexity and neurodevelopmental disability affect millions of children in the United States and around the world (Schaefer et al., 2019; Zablotsky et al., 2019). Further, the attitudes of the parents/caregivers of children with MtD may differ from the attitudes of the patients themselves and age of consent in the United States may range from 12 years to 18 years, depending on the city/state of residence (Morgan et al., 2021). We also acknowledge that this online questionnaire may be biased toward communities that are English-speaking and have internet access which may exclude some culturally diverse and low income groups. However, the value of understanding vaccine hesitancy in a highly at-risk population outweighs the potential lack of generalizability from these sample limitations. Future extensions of this research may explore attitudes of adults with MtD and other neurodevelopmental disabilities and how vaccine attitudes evolve over time as more data become available on safety and efficacy in special populations.

5. Conclusion

In conclusion, parents of children with MtD are more comfortable with the vaccines included in the routine childhood immunization schedule than with the newly introduced COVID-19 vaccine, even despite this group’s vulnerability. Clinicians may need to spend additional time counseling families of children with medical complexity about this vaccine, specifically addressing concerns about clinical deterioration as a result of the vaccine.

Conflicts of Interest

The authors have no conflicts of interest to disclose.
Data availability

Data will be made available on request.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.ridd.2022.104346.

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