



REVIEW ARTICLE

Exploring Covid-19 Vaccine Counseling Efforts of People with Autism by Medical Chart Review

Vijay Vasudevan, PhD MPH¹; E. Meryl Shychuk, MD²; Haley Moss, JD³;

Lindsay A. Thompson, MD MS⁴

¹*Autism Speaks, Princeton, New Jersey*

²*University of Florida, College of Medicine, Gainesville, Florida*

³*Haley Moss, LLC, Coral Gables, Florida*

⁴*Wake Forest University, School of Medicine, Department of Pediatrics, Winston-Salem, North Carolina.*

ABSTRACT

Objectives/Background:

Autistic individuals were at increased risk of being hospitalized from COVID-19. However, despite the COVID-19 vaccines having been shown to have reduced the risk of hospitalization and death, autistic people face numerous equity and access barriers to receiving the COVID-19 vaccines. Healthcare provider counseling is an important group to target in order to promote vaccine equity. This study explored the feasibility of conducting a medical chart review of COVID-19 vaccine counseling topics for autistic patients.

Methods:

Medical charts were coded from a random sample of 60 autistic patients from a large academic medical center, stratified by vaccination status. The authors explored whether the patient received any documented COVID-19 vaccine counseling. Of the patients who received any COVID-19 vaccine counseling, the authors categorized the counseling into one of the themes chosen *a priori*: Health, COVID-19 Vaccine Safety, Cost, and COVID-19 Misinformation.

Results:

Zero of the unvaccinated patients had any documented COVID-19 vaccine-specific counseling. Just six of the vaccinated autistic patients had received any documented COVID-19 vaccine counseling. Five of these six patients had no documented content of their vaccine counseling. The only patient who had documented the content of their COVID-19 vaccine counseling was related to the 'Health' theme.

Conclusion:

This study is the first to explore medical chart review as an opportunity to provide COVID-19 vaccine outreach for the autistic community. The pandemic offers an opportunity to improve the quality of medical charts by addressing administrative documentation and knowledge about how to provide counseling.

INTRODUCTION

Approximately 1 in 36 children and 1 in 45 adults have autism spectrum disorder (ASD).^{1,2} Yet, prior to the COVID-19 vaccines becoming available, autistic individuals were at increased risk of contracting and being hospitalized from COVID-19.^{3,4} These autistic individuals were also at increased risk of losing access to critical ongoing health services due to lock-downs, isolation, or quarantine.⁵ For example, an autistic child might have received physical, occupational, or speech therapy provided by school but were not able to receive those services if they or their school had to quarantine. The Centers for Disease Control and Prevention (CDC) identified autistic people as individuals at risk for facing equity barriers to receiving the COVID-19 vaccine.⁶

Pediatricians and other healthcare workers were identified as target populations that can build COVID-19 vaccine equity for people with ASD.^{7,8} The CDC created resources to educate healthcare providers on COVID-19 vaccine counseling for parents, patients, and patients with intellectual and developmental disabilities, including autistic patients.⁹ However, no studies have explored the documentation of these vaccine counseling sessions via a medical chart review for the autistic community. Providing COVID-19 vaccine counseling would ensure that autistic patients and caregivers can make informed medical decisions and allay any vaccine hesitancy. This manuscript aims to explore the content of COVID-19 vaccine counseling of autistic patients by conducting a medical chart review.

METHODS

This study was deemed exempt as a quality improvement study by the University of Florida's Institutional Review Board. The authors conducted a systematic review from a random selection of 60 autistic patients. The patients were identified using ICD9 and ICD10 codes (299.0 and F84.0, respectively) and randomized by an electronic random sorter before being distributed to the authors. The patients were stratified by age (5-11 years old, 12-17 years old, and 18 years old and older) and whether or not the patients were up-to-date on COVID-19 vaccination. At the time of the study, only children five years and older were eligible for a COVID-19 vaccine. Demographic variables listed in the electronic health record (HER) were also extracted, including sex, race, insurance (private, public, other), and diagnosis of COVID-19 at any time. The authors also collected co-morbid medical conditions as defined by the CDC list of medical conditions that increase the severity of COVID-19 infection (Table 1).¹⁰ These co-morbid conditions were stratified into four categories (zero, one, two, and three or more conditions).

	n (Percent)
Overweight or Obesity	22 (36.7)
Mental Health Conditions	15 (25.0)
Dementia or other Neurological Conditions	12 (20.0)
Immunocompromised	3 (5.0)
Chronic Liver Disease	1 (1.7)
Chronic Lung Disease	1 (1.7)
Diabetes (type 1 or type 2)	1 (1.7)
Heart Conditions	1 (1.7)
Sickle Cell Disease or Thalassemia	1 (1.7)
Cancer	--
Chronic Kidney Disease	--
Cystic Fibrosis	--
HIV Infection	--
Physical Inactivity	--
Smoking (current or former)	--
Solid organ or blood stem cell transplant	--
Substance use disorders	--
Tuberculosis	--

Table 1: Medical Diagnoses Identified by the CDC for increased risk of becoming very sick if COVID-19 is contracted of the sampled autistic patients (N=60)

The authors coded the records by whether the patient received any documented COVID-19 vaccine counseling. Subsequently, if the patient received any COVID-19 vaccine counseling, the authors categorized it into one of four presumed themes chosen a priori: Health, COVID-19 Vaccine Safety, Cost, and COVID-19 Misinformation.

RESULTS

Table 2 describes the EHR-based demographics of the randomly sampled autistic patients from January 1 through December 31, 2021 (N=60). The majority of autistic patients were male (75.0%), white, non-Hispanic (53.3%), and had public insurance (60.0%). Approximately half of the patients were vaccinated (51.7%) for COVID-19. Over a third of the autistic patients (38.3%) had one co-occurring condition, and 25.0% had two or more co-occurring medical conditions.

	n (Percent)
Vaccination Status	
Unvaccinated	29 (48.3%)
Incomplete dosage	5 (8.4%)
Up-to-date*	26 (43.3%)
Gender	
Male	45 (75.0%)
Female	15 (25.0%)
Child age	
5-11 years old	26 (43.3%)
12-17 years old	16 (26.7%)
18 years old or older	18 (30.0%)
Race	
White, non-Hispanic	32 (53.3%)
Black, non-Hispanic	14 (23.3%)
Hispanic	6 (10.0%)
Asian	4 (6.7%)
Other/Unknown	4 (6.7%)
Insurance	
Private or military	24 (40.0%)
Any public	36 (60.0%)
Number of Diagnoses from CDC Increased Risk List**	
0	22 (36.7%)
1	23 (38.3%)
2	11 (18.3%)
3	4 (6.7%)
Diagnosis of COVID-19 at any time	
No diagnosis of COVID-19	37 (79.3%)
Diagnosed with COVID-19	13 (21.7%)
* all patients received a Moderna or Pfizer vaccine, thus up-to-date was two doses, and a third dose was considered a booster	
**Does not include disabilities such as ASD	

Table 2: Demographics of Autistic Patients (N=60)

An in-depth chart review revealed that none of the unvaccinated autistic patients had any COVID-19 vaccine-specific counseling documented, and just six vaccinated patients (10% overall, 19.4% of those vaccinated) had documentation of receiving any COVID-19 vaccine counseling. Five of the six patients with COVID-19 counseling had a generalized statement that COVID-19 vaccine counseling was provided. The notes for these five counseling sessions did not specify the extent or content of vaccine counseling. The only patient who had documentation of the content of their counseling was categorized into the 'Health' theme as it discussed how the patient was a member of a high-risk group and how the vaccine would help reduce COVID-19 infection complications.

DISCUSSION

This study is the first to explore medical chart review as a COVID-19 vaccine outreach opportunity for the autistic community. In general, documentation of patient-provider interactions in medical charts has been poor.¹¹ The COVID-19 pandemic offers a novel opportunity to improve the quality of the documentation in medical charts by addressing barriers to documentation and improving the knowledge of the content to improve the healthcare outcomes subsequently.¹²

Administrative barriers exist to COVID-19 vaccine counseling, which includes actual documentation of the counseling with EHR and the provider's ability to counsel autistic patients or their parents/caregivers. To encourage documentation of COVID-19 vaccine counseling, the Centers for Medicare and Medicaid Services (CMS) required states to cover COVID-19 vaccine counseling for healthcare providers¹³ as part of the bundled administration fees that could be recouped. This increased reimbursement should incentivize healthcare providers to document COVID-19 vaccine counseling sessions to receive the 100% federal match. Documentation of such counseling in the EHR medical chart ensures appropriate continuity of care and provides opportunities for continued counseling on vaccine hesitation.

To maximize the CDC's recommendation that healthcare providers improve COVID-19 vaccine counseling, and drawing from the preliminary results highlighted here, the authors offered an educational webinar where continuing medical education (CME) and continuing education (CE) credits were available.¹⁴ The content of this CME/CE course included a discussion of ASD, ableism, and healthcare access; a discussion of the chart review findings and implications; and finally, how to increase COVID-19 vaccine confidence for the autistic community, especially for the pediatric population. Knowledge about vaccine hesitancy and the CME/CE course quality was measured immediately post-webinar. The participants who immediately completed the webinar exam had to score at least 80% on the knowledge to receive CME/CE credit. A total of 15 participants attended the live webinar. The CME/CE course was consistent with the recommendation that providers offer and document COVID-19 vaccine counseling.¹⁵ The authors suspect that once the COVID-19 vaccine emergency use authorization was expanded to children six months and older, there would not be an increased rate of providers seeking education on discussing COVID-19 vaccines with autistic patients. The authors' reasoning is that the average age of diagnosis is around five years of age, and many children are not identified as autistic until they are in the school system.^{1,16} Despite this educational opportunity and hopeful enhanced counseling, provider recommendation is only one step in an autistic individual receiving a COVID-19 vaccine or booster. To measure this, the field of building COVID-19 confidence could learn lessons from other vaccines that have met resistance, such as the human papillomavirus (HPV) vaccine. Multilevel approaches have shown promise and gained popularity in improving HPV vaccine uptake by assessing for medical records and confirming receipt of the HPV vaccine while intervening at the clinic, provider, parent, and patient levels.^{17,18} Future studies should explore how a multilevel intervention impacts COVID-19 vaccine uptake.

A primary limitation of this study is documentation and counseling are different; a healthcare provider might have counseled their autistic patient or caregivers but did not make any administrative notes in the EHR. A potential remedy is that healthcare providers could partner with their electronic medical record build groups and IT departments to create specific "dot phrases" detailing usual vaccine counseling and reasons for vaccine refusal. Currently, there are no EHR dot phrases to identify vaccine counseling. The COVID-19 vaccine dot phrases that do exist primarily measure if the patient received a COVID-19 vaccine and needed a reminder. There are no standardized dot phrases across EHR systems, primarily for the COVID-19 vaccine. Additionally, this study included a random sample of autistic patients from one health system. Patients from other health systems or who receive care at congregate care sites might have different vaccine counseling experiences with their healthcare providers.

This project explored COVID-19 vaccine counseling for autistic patients using medical chart review. Because autistic individuals are at increased risk of hospitalization from COVID-19, multilevel approaches must work to increase vaccination rates in this autistic population, especially as newer COVID-19 variants emerge, which might be resistant to the protective benefits of the COVID-19 vaccines.

REFERENCES

1. Maenner MJ, Warren Z, Williams AR, et al. Prevalence and characteristics of autism spectrum disorder among children aged 8 years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *MMWR*. 2023;72(2):1-14.
2. Dietz PM, Rose CE, McArthur D, Maenner M. National and state estimates of adults with autism spectrum disorder. *J Autism Dev Disord*. 2020;50(12):4258-4266.
3. Karpur A, Vasudevan V, Shih A, Frazier T. Brief report: impact of COVID-19 in individuals with autism spectrum disorders: analysis of a national private claims insurance database *J Autism Dev Disord*. 2022;52(5):2350-2356.
4. Schott W, Tao S, Shea L. COVID-19 risk: adult Medicaid beneficiaries with autism, intellectual disability, and mental health conditions. *Autism*. 2021;26(4):975-987.
5. White LC, Law JK, Daniels AM, et al. Brief Report: Impact of COVID-19 on individuals with ASD and their caregivers: a perspective from the SPARK cohort. *J Autism Dev Disord*. 2021;51(10):3766-3773.
6. Centers for Disease Control and Prevention. Barriers to equity in childhood COVID-19 vaccination. 2022; <https://www.cdc.gov/vaccines/covid-19/planning/children/equity-barriers.html>. Accessed July 7, 2022.
7. Wiggins LD, Jett H, Meunier J. Ensuring equitable COVID-19 vaccination for people with disabilities and their caregivers. *Pub Health Rep*. 2021;137(2):185-189.
8. Tinker SC, Cogswell ME, Peacock G, Ryerson AB. Important considerations for COVID-19 vaccination of children with developmental disabilities. *Pediatrics*. 2021;148(4):e2021053190.
9. Centers for Disease Control and Prevention. Vaccine recipient education. 2022; <https://www.cdc.gov/vaccines/covid-19/hcp/index.html>. Accessed August 5, 2022.
10. Centers for Disease Control and Prevention. Underlying medical conditions. 2022; <https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/underlyingconditions.html>. Accessed August 9, 2022.
11. Weiner SJ, Wang S, Kelly B, Sharma G, Schwartz A. How accurate is the medical record? A comparison of the physician's note with a concealed audio recording in unannounced standardized patient encounters. *J Am Med Inform Assoc*. 2020;27(5):770-775.
12. Mathioudakis A, Rousalova I, Gagnat AA, Saad N, Hardavella G. How to keep good clinical records. *Breathe (Sheff)*. 2016;12(4):369-373.
13. Centers for Medicare and Medicaid Services. Biden-Harris administration makes 100% federal Medicaid matching funds available for state expenditures on certain COVID-19 vaccine counseling visits for children and youth. 2021; <https://www.cms.gov/newsroom/press-releases/biden-harris-administration-makes-100-federal-medicaid-matching-funds-available-stateexpenditures>. Accessed August 8, 2022.
14. Vasudevan V, Moss H, Shychuck EM, Brosco J. Building COVID-19 vaccine confidence for the autistic community in Florida. [Webinar]. 2022; <https://srahec.org/autism-speaks/>. Accessed June 14, 2022.
15. Finney-Rutten LJ, Zhu X, Leppin AL, et al. Evidence-based strategies for clinical organizations to address COVID-19 vaccine hesitancy. *Mayo Clin Proc*. 2021;96(3):699-707.
16. Autism Speaks. Autism by the numbers: age of diagnosis. 2023; <https://nationalautismdatacenter.org/age-of-diagnosis/>. Accessed April 20, 2023.
17. Staras SAS, Richardson E, Merlo LJ, et al. A feasibility trial of parent HPV vaccine reminders and phone-based motivational interviewing. *BMC Public Health*. 2021;21(1):109.
18. Paskett ED, Krok-Schoen JL, Pennell ML, et al. Results of a multilevel intervention trial to increase human papillomavirus (HPV) vaccine uptake among adolescent girls. *Cancer Epidemiol Biomarkers Prev*. 2016;25(4):593-602.