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Willingness to obtain COVID-19 vaccination in adults with multiple sclerosis in the United States

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ABSTRACT

Background: As vaccines for the coronavirus become available, it will be important to know the rate of COVID-19 vaccine acceptability in adults with multiple sclerosis (MS), given that vaccination will be a key strategy for preventing SARS-CoV-2 infections. Using a national sample of adults with MS in the United States obtained early in the COVID-19 pandemic, the current study aimed to: (1) assess willingness to get a COVID-19 vaccine when available; (2) determine demographic, MS, and psychosocial correlates of vaccine willingness; and (3) measure where people with MS get their COVID-19 information and their perceived trustworthiness of such sources, which may influence COVID-19 vaccine willingness.

Methods: Adults with MS (N = 486) living in the United States completed a cross-sectional online survey (between 10 April 2020 and 06 May 2020) about their willingness to receive a COVID-19 vaccination once available. Participants also completed measures to describe the sample and to assess factors potentially related to vaccine willingness, including demographics, MS-specific variables, psychological measures, COVID-19 information sources, and perceived trustworthiness of their information sources.

Results: Approximately two-thirds of the participants (66.0%) reported a willingness to obtain a future COVID-19 vaccine, whereas 15.4% of the sample was unwilling. Greater willingness to receive the vaccine was associated with having a higher level of education and holding a higher perception of one's risk of catching COVID-19. Participants reported accessing COVID-19 information from many different sources. Approximately a third (31.6%) of the sample reported getting their information from healthcare providers. Healthcare providers and the National MS Society had the highest perceived trustworthiness for COVID-19 information. The perceived trustworthiness of information sources was highly associated with vaccine willingness.

Conclusion: Early in the pandemic, willingness to get a COVID-19 vaccine was not universal in this large sample or people living with MS. Vaccine willingness was associated with a few variables including education level, perceived risk for COVID-19 infection, and trust in COVID-19 information sources. These results have important implications for guiding healthcare providers and the MS community as COVID-19 vaccines become widely available.

1. Introduction

Vaccination will be a key strategy for preventing SARS-CoV-2 infections, including in people with multiple sclerosis (MS); however, people's willingness to obtain a COVID-19 vaccine is not universal. Though there are no known studies of vaccine willingness in people with MS, an online survey of adults living in the United States (U.S.: N = 2,006) revealed that 69% reported that they were willing to get a COVID-19 vaccine if one was available.[1] Willingness was associated with perceived risk of being infected with COVID-19, perceived severity

of COVID-19 infections, and perceived effectiveness of a vaccine. Demographic factors - such as gender, race, and income - have also been associated with a greater willingness to get a COVID-19 vaccine.[1-4] In prior pandemics, such as H1N1, factors such as the perceived trustworthiness of information about H1N1 also influenced vaccine willingness.[5]

The MS community has met COVID-19 with unique concerns about the intersection of the disease with the virus, including if and how disease modifying therapies may interact with vaccines.[6] It is therefore important to ascertain this unique population's perspective on

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COVID-19 vaccine willingness. Understanding the rate and drivers of vaccine willingness in the MS population will inform educational and clinical efforts as vaccines become increasingly available. Using a national sample of adults with MS in the United States obtained early in the COVID-19 pandemic, the current study aimed to: (1) assess willingness to get a COVID-19 vaccine when available; (2) determine demographic, MS, psychosocial correlates of vaccine willingness; and (3) measure where people with MS get their COVID-19 information and their perceived trustworthiness of such sources, which may influence COVID-19 vaccine willingness.

2. Methods

2.1. Study design and participants

Participants completed a cross-sectional online survey about their experiences early in the COVID-19 pandemic (between 10 April 2020 and 06 May 2020).^[7] Individuals in the present analyses (a) were ≥ 18 years old; (2) were able to read English to complete the questionnaire; (3) self-reported having an MS diagnosis; and (4) were in the U.S. after 20 Jan 2020, the date of the first COVID-19 case in the U.S. Participants were invited to complete the survey through newsletters disseminated by email by the University of Washington (UW), as well as other online sources, including social media, the UW MS Rehabilitation and Wellness Research Center website, and research recruitment registries and websites, including ParticipateinResearch.org and researchmatch.org. We specifically recruited persons with a self-reported diagnosis of MS via these recruitment sources. A survey link was also posted on the National MS Society's COVID-19 research webpage and in emails they disseminated describing COVID-19 research opportunities. The survey was completed using the REDCap (Research Electronic Data Capture) web-based data capture platform ^[8] that can be completed by any digital device with internet access; it included a human verification service (reCAPTCHA) to avoid responses from bots. Participants were not compensated for completing the survey. Further details on the sample and methodology were published in an article on psychological distress and COVID-19 risk perception.^[7] All procedures were approved by the UW Human Subjects Division.

2.2. Measures

Participants indicated their willingness to receive a COVID-19 vaccination once available using an adapted version of a measure used to assess vaccine willingness during influenza pandemics.^[9] Responses were on a 5-point scale (1 = not at all willing, 2 = a little willing, 3 = moderately willing, 4 = very willing, and 5 = extremely willing). For descriptive purposes, we categorized responses as "willing" to receive a vaccine (4 [very willing] or 5 [extremely willing]), "moderately willing" (3), and "not willing" (1 [not at all willing] or 2 [a little willing]).

To characterize the sample and examine potential correlates of vaccine willingness, we assessed demographics (age, gender, race, marital status, education level), MS disease-related factors (disease duration, course, current use of disease-modifying therapy [DMT], and disease severity as measured by the Patient Determined Disease Steps ^[10]), and psychological distress (depression: PROMIS Short Form v1.0 – Depression 6a,^[11] anxiety: PROMIS Short Form v1.0 – Anxiety 6a,^[11] and intolerance of uncertainty: Intolerance of Uncertainty Scale - Short Form ^[12]). Perceived risk for contracting, being hospitalized for, or dying from COVID-19 in the future was assessed using a 0% (no risk) to 100% (guaranteed to happen) scale. Participants rated on 5-point scales the places from which they receive their information about COVID-19 (e.g., healthcare providers, social media, where 0 = not at all to 4 = a lot) and the extent to which they trust that information source (1 = do not trust at all to 4 = totally trust).

2.3. Analysis

Descriptive statistics were calculated to characterize the sample and vaccine willingness (Aim 1). A hierarchical multiple regression was calculated to determine the association of demographics (age, race, and gender), MS disease severity (PDDS), and psychosocial factors (perceived risk of getting/dying from COVID-19, depression, anxiety, and intolerance of uncertainty) with vaccine willingness (Aim 2). Finally, Pearson bivariate correlations were used to examine the relationship of information sources and perceived trustworthiness of information sources with vaccine willingness (Aim 3). All analyses were conducted using SPSS version 25 (IBM Corp., Armonk, NY).

3. Results

Of the 3,109 respondents who completed the full survey, 522 self-reported a diagnosis of MS. After removing duplicates ($n = 7$) and individuals with insufficient complete data ($n = 29$), the resulting sample was $N = 486$. As described in the prior report,^[7] the sample was predominantly middle-aged ($M = 55.7$ years ± 12.6 years), female (81.3%), and White (90.5%). Disease duration was 16.6 ± 15.4 years, on average, and over two-thirds (65.0%) reported a relapsing-remitting disease course, with a majority (67.5%) of the sample on a disease modifying therapy. Only one participant (0.2%) reported testing positive for COVID-19 by the time of the survey. Additional participant characteristics are in [Table 1](#) and the previous report.^[7]

The mean willingness to get a COVID-19 vaccine was 3.86 (SD = 1.23; Mdn = 4). Overall, 66.0% (321/486) participants were categorized as willing, 18.5% (90/486) as moderately willing, and 15.4% (75/486) as not willing to get a COVID-19 vaccine when available (see [Table 1](#) for frequencies for each of the five response options). On average, participants' self-reported perceived risk of contracting COVID-19 was 36.3% (SD = 24.6), of being hospitalized for COVID-19 was 29.2% (SD = 25.0), and of dying from COVID-19 was 18.7% (SD = 23.4).

The overall model for the hierarchical multiple regression of potential correlates of vaccine willingness was statistically significant ($F(11, 432) = 4.16, p < 0.001$), and captured 9.6% of the variance. The only statistically significant predictors of higher vaccine willingness were having more education ($\beta = 0.20, p < 0.001$) and perceiving oneself to be at greater risk of contracting COVID-19 ($\beta = 0.18, p = 0.001$). Other demographics, including age, were not associated with vaccine willingness, nor were MS factors (course, severity) or psychological distress.

Sources and trustworthiness of information, and their associations with vaccine willingness are reported in [Table 2](#). Participants with MS reported accessing COVID-19 information from many different sources, most often by reading print or web news sites or from TV news. Only roughly a third of the sample got their information from healthcare providers, although providers, followed by the National MS Society, had the highest perceived trustworthiness for COVID-19 information. The current U.S. president and social media were the least trusted sources. The perceived trustworthiness of information sources was highly associated with vaccine willingness, whereas the information sources accessed were less related to vaccine willingness.

4. Discussion

In this convenience sample of adults with MS living in the United States during the early phase of the COVID-19 pandemic (between 10 April 2020 and 06 May 2020), approximately two-thirds of participants (66.0%) reported a willingness to receive a future COVID-19 vaccine. Greater vaccine willingness was associated with having a higher level of education and a higher perception of one's risk for COVID-19 infection. Many different sources of COVID-19 information were reportedly accessed by participants, but the sources of information were less associated with vaccine willingness than the perceived trustworthiness of the sources.

Table 1
Participant Characteristics and Vaccination Intention

Variable	Total (N = 486) n (%)
Demographics	
Age group	
18-29	12 (2.5%)
30-39	49 (10.1%)
40-49	86 (17.7%)
50-59	139 (28.6%)
60-69	131 (27.0%)
70-79	58 (11.9%)
80+	6 (1.2%)
No response	5 (1.0%)
Self-reported Gender	
Woman	395 (81.3%)
Man	84 (17.3%)
Non-binary	2 (0.4%)
Transgender	1 (0.2%)
Other/Prefer Not to Say/No answer	4 (0.8%)
Race	
White	440 (90.5%)
More than one race	20 (4.1%)
Black or African American	12 (2.5%)
American Indian/Alaska Native	2 (0.4%)
Asian	1 (0.2%)
Prefer not to say	7 (1.4%)
Other	4 (0.8%)
Education	
< 12th grade	2 (0.4%)
High school graduate or GED	23 (4.7%)
Vocational or Technical School	28 (5.8%)
Some college	95 (19.5%)
College graduate	185 (38.1%)
Graduate or professional school	153 (31.5%)
Employment	
Retired	144 (29.6%)
Employed full-time	143 (29.4%)
Unable to work	107 (22.0%)
Employed part-time	34 (7.0%)
Unemployed due to COVID-19	30 (6.2%)
Unemployed unrelated to COVID-19	20 (4.1%)
Student	4 (0.8%)
No response	4 (0.8%)
Household size	
1	119 (24.5%)
2	197 (49.5%)
3	87 (17.9%)
4	49 (10.1%)
5	12 (2.5%)
6	6 (1.2%)
7 or more	6 (1.2%)
No response	10 (2.1%)
Marital status	
Married	276 (56.8%)
Divorced	92 (18.9%)
Never married	65 (13.4%)
Widowed	20 (4.1%)
Domestic partner	20 (4.1%)
Other	10 (2.1%)
No response	3 (0.6%)
MS Characteristics	
Disease course	
Relapsing remitting	316 (65.0%)
Secondary progressive	80 (16.5%)
Primary progressive	48 (9.9%)
Clinically isolated syndrome	5 (1.0%)
Unknown or uncertain	32 (6.6%)
No response	5 (1.0%)
Disability (Patient Determined Disease Steps)	
0	94 (19.3%)
1	95 (19.5%)
2	63 (13.0%)
3	63 (13.0%)
4	62 (12.8%)
5	37 (7.6%)
6	41 (8.4%)
7	28 (5.8%)

Table 1 (continued)

Variable	Total (N = 486) n (%)
8	1 (0.2%)
No response	2 (0.4%)
COVID-19 Vaccine Willingness	
not at all willing	29 (6.0%)
a little willing	46 (9.5%)
moderately willing	90 (18.5%)
very willing	119 (24.5%)
extremely willing	202 (41.6%)

As a point of comparison, Pew Research Center conducted surveys in May, September, and November 2020 on COVID-19 vaccine willingness in the general U.S. population.[13] Comparing our data (conducted in April-May 2020) to their May survey, we observed that vaccine willingness in our sample - 66.0% - was slightly lower than what they found in the general population (72%). They also reported a steep decline in vaccine willingness over time (51%, Sept 2020), with a more recent partial recovery (60%, Nov 2020), even as the availability of efficacious, safe vaccines became more likely.[13] Whether adults with MS would have shown a similar pattern over time is unknown, given the cross-sectional design of this study. It is possible that vaccine acceptability may be lower in people with MS now, given the decline seen in the general population. Whether these rates change as the first vaccines are introduced and people begin to receive them, or as more people become infected with COVID-19, remains to be seen.

Vaccine willingness was not readily explained by demographics, psychological distress, health status, or sources of COVID-19 information. Although other studies in the general population have found demographic factors to play an important role in vaccine acceptability, [1-4,14] we only found education to be related. Psychological distress, although prevalent in this sample,[7] was also not a factor. What was related, similar to what was found in other studies,[4,13-15] was risk perception: a higher perceived risk for getting COVID-19 was associated with a higher willingness to be vaccinated. Participants' reported trust in their COVID-19 information sources was also highly associated with vaccine willingness. Trustworthiness of government officials (except the U.S. president) and of news sources (print, web, National Public Radio, and TV) were all positively correlated with vaccine willingness. These findings may reflect, in part, broader trends in the U.S. which indicate that vaccine willingness is influenced by political beliefs as well as trust in the COVID-19 vaccine development process,[2,4,13,15] although neither was assessed in our survey. The fact that the regression model only captured 9.6% of the variance in vaccine willingness indicates that other factors not assessed in this study - such as past vaccination behavior,[4] political factors,[16] and perceptions of vaccine safety, [17] could be influential and should be examined in future research.

These findings - including that the two COVID-19 information sources most highly trusted, and also highly associated with vaccine willingness, were healthcare providers and the National MS Society - have important implications for the MS community. Given that provider recommendations are a key determinant of vaccine behavior in general [18] and potentially, in COVID-19 vaccine intentions,[1] healthcare providers will play a key role in promoting vaccine uptake among vaccine eligible people with MS. MS providers are well-positioned to provide accurate education about COVID-19 disease and vaccine considerations (efficacy, safety, side effects, and possible interactions with disease-modifying therapies) specific to the MS population as well as to their individual patients. However, the fact that at the time of the survey, only 31.6% of the sample reported obtaining COVID-19 information from their providers suggests that MS providers may need to conduct vaccine education and/or outreach initiatives in order to reach all of their MS patients. People who are undecided or ambivalent (only moderately or a little willing) about obtaining a vaccine -sometimes referred to as "vaccine hesitancy" and as many as 28.0% of this sample - may represent a particularly important subgroup for providers to engage

Table 2
COVID-19 Information Sources, Perceived Trustworthiness, and Bivariate Correlates of Vaccine Willingness

Information source	% using source ^a	Trustworthiness M (SD)	Source & willingness ^b r	Trustworthiness & willingness ^c r
Reading news on news website or print	78.2%	2.40 (.65)	.150**	.218**
TV news	69.4%	2.33 (.70)	-.089	.101*
Government website	48.0%	2.58 (.83)	.019	.222**
Family and friends	41.4%	2.31 (.70)	-.039	-.014
Social media	40.8%	1.46 (.55)	.051	.009
National Public Radio	33.2%	2.64 (.93)	.188**	.317**
Healthcare provider	31.6%	3.38 (.69)	-.003	.212**
Local radio stations	18.7%	2.03 (.70)	-.014	.117*
National MS Society		3.05 (.72)		.210**
CDC		2.92 (.76)		.299**
State or local public health officials		2.75 (.77)		.272**
State government officials (e.g., governor)		2.58 (.87)		.210**
Local elected officials		2.30 (.69)		.144**
US President (Donald Trump)		1.41 (.80)		-.181**

Note. If a cell is blank, that information source was not assessed in the survey. CDC = Centers for Disease Control and Prevention.

^aReflects the proportion of participants answering “some” or “a lot” to the question about where they received COVID-19 information. Participants could endorse multiple sources, and thus percentages do not add up to 100%. ^bReflects the correlation between the information source accessed and vaccine willingness. ^cReflects the correlation between the perceived trustworthiness and vaccine willingness.

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

with to understand their concerns about vaccination and inform them about their specific risks and benefits of vaccination. The fact that the National MS Society was highly trusted is also encouraging, as they have been providing up-to-date COVID-19 information and guidance tailored to the population and communicating this information via multiple mass media channels (including social media) since the start of the pandemic, [19] effective strategies for increasing vaccine uptake in other populations.[20]

A limitation of this study is that the survey was conducted early in the pandemic when the COVID-19 vaccine was hypothetical. The extent to which the reality of vaccine availability and time has changed willingness is unknown and an area for future research. Given the paucity of vaccine willingness data in the MS population to date, this study's findings provide a starting point for understanding vaccine acceptability as well as a comparison for future vaccine studies in the MS population. Our survey was limited to one vaccine willingness question; we did not assess concerns about vaccine risks (including risks, real or perceived, related to MS and/or DMT use) or history of vaccination for other diseases, both of which have been related to COVID-19 vaccine willingness in the general population.[4] Our participants were highly educated and, at the time of the survey, had a very low rate of experience with COVID-19. The sample also did not have many participants with significant disability on the PDSS. Therefore, these findings may not be reflective of people with MS in general or at the present time.

In conclusion, as vaccines offer hope in curtailing SARS-CoV-2 infections, it is important to understand the perspectives of both the general population and subpopulations that may have unique perspectives or needs, such as people with MS. Results such as those reported here can inform efforts to effectively guide the MS community during this critical period in public health intervention. Healthcare providers and MS organizations such as the National MS Society will play critical roles in these efforts.

CRediT Author Statement

Dawn M. Ehde: Conceptualization, Methodology, Formal analysis, Writing-original draft, Writing-review and editing. Michelle K. Roberts: Conceptualization, Methodology, Investigation, Data curation, Writing-review and editing, Project administration. Tracy E. Herring: Conceptualization, Methodology, Writing-review and editing. Kevin N. Alschuler: Conceptualization, Methodology, Formal analysis, Writing-review and editing, Supervision.

Declaration of Conflicting Interests

The authors declare no conflicts of interest

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