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Long COVID symptoms and loneliness: findings from the World Trade Center Health Registry

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Abstract

Background Symptoms of long COVID can profoundly impact affected individuals' functioning, including their ability to participate in social activities. While individuals experiencing long COVID symptoms frequently report loneliness, few studies to date have investigated whether loneliness is more common among those with symptoms compared to those without. We examined associations between long COVID symptoms and loneliness among World Trade Center Health Registry (WTCHR) enrollees.

Methods Among WTCHR enrollees who reported an acute COVID-19 infection in 2022-23 on a self-administered survey, we used modified Poisson regression to estimate multivariable-adjusted prevalence ratios (PR) and 95% confidence intervals (95% CI) for associations of self-reported long COVID symptoms (any vs. none, selected from a predefined symptom list) with loneliness. Overall loneliness was assessed with the 6-item de Jong Gierveld loneliness scale (range: 0–6); social and emotional loneliness were assessed with their respective subscales (range: 0–3). We also assessed whether level of social support prior to COVID-19 infection modified associations of long COVID symptoms with loneliness.

Results Analyses included 5,692 enrollees (mean age: 62 years); prevalence of loneliness was 61%. In fully adjusted models, enrollees who reported any long COVID symptoms had higher prevalence of loneliness compared to those without symptoms (PR = 1.19, 95% CI: 1.13, 1.25). Associations were somewhat stronger for emotional loneliness than for social loneliness (PR = 1.22, 95% CI: 1.15, 1.29 and PR = 1.12, 95% CI: 1.07, 1.18, respectively). Effect modification by social support was not observed on either the additive or multiplicative scale.

Conclusion Long COVID symptoms were associated with prevalence of loneliness in a sample of primarily older adults. As loneliness itself is associated with subsequent adverse health outcomes, addressing loneliness among people living with long COVID may help prevent further reductions in quality of life.

Keywords Long COVID, Loneliness, COVID-19 pandemic, Social support

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Introduction

Though most individuals infected with SARS-CoV-2 fully recover, some proportion will develop long COVID, a chronic condition that occurs after an acute COVID-19 infection and persists for at least three months [1, 2]. Long COVID symptoms can vary in severity, and may improve, worsen, or relapse and remit over time. Multiple organ systems may be affected by long COVID, and commonly reported symptoms include fatigue, post-exertional malaise, dizziness or lightheadedness, difficulty concentrating, problems with memory, shortness of breath, cough, and sleep problems [2]. Lifetime prevalence of long COVID among US adults has recently been estimated to be between 6 and 8% in population-based surveys [3, 4].

As a result of their symptoms, individuals with long COVID often experience negative impacts on employment, functioning, and quality of life [5–7]. Long COVID symptoms, particularly fatigue [8], may reduce individuals' capacity to participate in social activities, and data from qualitative studies show that individuals with long COVID frequently report social isolation and loneliness [9–11]. Social isolation refers to an objective lack of social interactions and limited social network [12]. Though conceptually related, social isolation is distinct from loneliness, which is distress that occurs as the result of a perceived discrepancy between desired and attained social relationships [13]. Two main types of loneliness have been identified: social loneliness, which occurs when an individual has a smaller than desired social network, and emotional loneliness, which occurs when an individual has fewer intimate relationships than desired [14]. As loneliness itself is an independent predictor of poor physical and mental health outcomes [15, 16], greater understanding of loneliness among those with long COVID may help identify individuals at risk of further reductions in health and quality of life.

In a recent analysis of individuals enrolled in a long COVID clinic, 40% reported feeling lonely some or all of the time [17]. However, loneliness is also prevalent in the general population and may have been exacerbated due to declining social participation during the COVID-19 pandemic [18]; thus, it is not currently clear whether loneliness is more common among those with long COVID compared to those without the condition. In the present study, we analyzed data from individuals enrolled in the World Trade Center Health Registry to compare the prevalence of loneliness among individuals with long COVID symptoms to those who were infected with COVID-19 but did not report long-term symptoms. As social support has been hypothesized to mitigate the association of stressful events with subsequent distress [19], we also assessed whether associations between long

COVID symptoms and loneliness differed by pre-infection social support.

Methods

Study population

The World Trade Center Health Registry (WTCHR) is a closed cohort of individuals who lived, worked, went to school, or were passersby in the vicinity of the World Trade Center disaster on September 11, 2001 (9/11), or who performed rescue and recovery work related to the disaster. As previously described in detail [20], a total of 71,426 individuals were enrolled in the WTCHR in 2003–2004 when they responded to the Wave 1 survey that queried 9/11 experiences, demographic information, and health and disease status. Since that time, four additional major wave surveys have been conducted every 3–4 years to monitor the physical and mental health consequences of World Trade Center disaster exposure, including most recently the Wave 5 survey, which was fielded between April 2020 and February 2021. The sample for the Wave 5 survey was 39,647 enrollees who had responded to at least three previous surveys (i.e. Wave 1, Wave 2, Wave 3 and/or Wave 4) or who had turned 18 years old after the Wave 1 survey. Of eligible enrollees, 28,356 completed the Wave 5 survey. Following the Wave 5 survey, two in-depth surveys were developed to assess the health and experiences of enrollees during the COVID-19 pandemic. Between March 2021 and August 2021, enrollees included in the Wave 5 survey sample were invited to respond to the COVID-19 baseline survey; of 36,831 eligible enrollees, 22,301 responded. Enrollees who responded to the baseline COVID-19 survey and who had not died or withdrawn ($N = 22,282$), were subsequently invited to respond to the COVID-19 follow-up survey between December 2022 and September 2023; of those, 17,442 enrollees completed the COVID-19 follow-up survey. The Wave 5 survey and both COVID-19 surveys were self-administered using web or mailed paper forms. Informed consent was obtained verbally from all WTCHR enrollees at the time of their enrollment survey (Wave 1), which was administered by computer-assisted telephone interview. The WTCHR protocol was approved by the US Centers for Disease Control and Prevention (CDC) and the New York City Department of Health and Mental Hygiene (DOHMH) institutional review boards.

Our analytic sample comprised enrollees who were 18 years or older at 9/11 ($N = 68,041$); who responded to Wave 5, COVID-19 baseline, and COVID-19 follow-up surveys ($N = 16,402$); who self-reported a COVID-19 infection ($N = 9,440$) and who reported a date of COVID-19 infection of March 2020 or later on either their COVID-19 baseline or COVID-19 follow-up survey ($N = 8,818$; see Appendix for eligibility flowchart). To

reduce potential misclassification, we used data from the earlier of the two surveys where an enrollee reported a valid infection date. To ensure that time-varying covariates were not affected by COVID-19 infection, we also restricted to enrollees whose reported date of first COVID-19 infection was later than their Wave 5 survey date ($N=7,648$). The definition of long COVID requires that symptoms be present at least 3 months after acute COVID-19 infection; therefore, we also restricted to enrollees who reported a date of first infection >12 weeks prior to their COVID-19 follow-up survey date ($N=6,499$). As only month and year of first infection were collected, we conservatively set COVID-19 infection date to the first day of the month to exclude enrollees who responded to the Wave 5 survey after their first infection. Conversely, we set infection date to the last day of the month to exclude enrollees whose first infection occurred within 12 weeks of their COVID-19 follow-up survey date. Due to survey item skip patterns, we excluded 380 enrollees who reported no acute COVID-19 symptoms, as these enrollees were not asked about long COVID symptoms. Finally, we restricted analyses to 5,692 enrollees who responded to the survey item assessing long COVID symptoms and who had complete data on loneliness. The average time between first reported COVID-19 infection and COVID-19 follow-up survey date was 418 days (SD: 232) when date of COVID-19 infection was set to the first day of the month.

Measures

COVID-19 infection

On the COVID-19 baseline survey, enrollees were asked whether they had ever been sick with an illness they thought might be COVID-19; on the follow-up survey, enrollees were asked if they had ever had COVID-19. On both surveys, enrollees who responded affirmatively were asked to report the month and year of their first infection. Information about enrollees' most recent COVID-19 infection was also queried on the COVID-19 follow-up survey. On both COVID-19 baseline and follow-up surveys, enrollees were asked about whether they had tested positive for COVID-19, the symptoms they experienced during their infection, and whether they had been hospitalized for their infection. We did not require self-report of a positive COVID-19 test, in accordance with a consensus definition of long COVID released by the National Academies of Science, Engineering and Medicine [2]. We used self-reported symptoms and hospitalization to categorize acute COVID-19 severity as severe (reported hospitalization for COVID-19), moderate (no hospitalization, reported shortness of breath as a symptom), or mild (no hospitalization or shortness of breath, reported any other symptom) [21].

Long COVID symptoms

On the COVID-19 follow-up survey, enrollees who reported ever having had COVID-19 and reported at least one COVID-19 symptom were asked whether they had experienced any of the following symptoms more than 12 weeks after their acute COVID-19 illness started: unusual tiredness or fatigue; difficulty breathing, shortness of breath or cough; altered sense of taste or smell; confusion/trouble thinking or concentrating/brain fog; muscle or joint pain; trouble sleeping; lightheadedness upon standing; anxiety or depression; other problem; or no symptoms. Enrollees who selected at least one symptom, including 'other problem' were considered to have long COVID. Enrollees who indicated ever experiencing any long COVID symptoms were additionally asked whether they were currently experiencing these symptoms (yes/no).

Loneliness

Loneliness was measured on both the COVID-19 baseline and follow-up surveys with the 6-item De Jong Gierveld Loneliness scale [14]. This scale comprises two 3-item subscales measuring social loneliness and emotional loneliness, separately. The scale includes three negatively worded statements (e.g., "I feel rejected") and three positively worded questions (e.g., "There are enough people I feel close to"). Respondents were asked to rate the level to which each statement described their feelings, with positive ("yes"), neutral ("more or less"), and negative ("no") response options. For negatively worded questions, neutral and positive responses were coded as 1 and negative responses as 0. Conversely, for positively worded questions, neutral and positive responses were coded as 0 and negative responses as 1. Responses were summed to calculate scores that ranged from 0 to 6 for overall loneliness, and 0 to 3 for both social and emotional loneliness. Overall loneliness was categorized based on total score as not lonely (0–1) or lonely (≥ 2) based on recommendation of the scale developers [22]. For each subscale, enrollees were considered socially or emotionally lonely if they had a score of ≥ 1 on the corresponding subscale.

Social support

Perceived social support was assessed on the Wave 5 survey with a 5-item version of the Medical Outcomes Study Social Support Scale [23]. Enrollees indicated how often someone was available to provide emotional support (e.g., someone to hug you, someone to have a good time with, someone to understand your problems) and tangible support (e.g., someone to take you to the doctor, someone to prepare you a meal). Response options had five levels, ranging from 'none of the time' (coded as 0) to 'all of the time' (coded as 4), resulting in total scores ranging from 0 to 20. As no validated threshold for adequate

social support exists, we created categories based on the tertiles of total scores observed in our study population. High social support was defined as a score of 20, moderate social support was defined as a score of 15–19, and low social support was defined as a score of ≤ 14 .

Other covariates

Covariates of interest included sociodemographic characteristics, health risk factors, and physical and mental health conditions. Enrollees self-reported whether they had ever been diagnosed with specific physical and mental health conditions; analyses included self-reported diagnoses of the following physical health conditions: asthma, gastroesophageal reflux disorder, cardiovascular disease, stroke, cancer, chronic obstructive pulmonary disease, hypertension, diabetes, autoimmune conditions, and sleep apnea. Mental health conditions examined were self-reported diagnosis of depression and post-traumatic stress disorder. Time-invariant characteristics (e.g., race/ethnicity, sex) were assessed at Wave 1, while time-varying characteristics were assessed at Wave 5 unless missing, in which case we carried forward values from Wave 4.

Analyses

We first conducted descriptive analyses to assess the distributions of covariates by self-reported long COVID symptoms in our study population. We also examined the proportion of enrollees who were lonely, socially lonely, and emotionally lonely by self-reported long COVID symptom status. We used modified Poisson regression [24] to estimate associations between self-reported long COVID symptoms and dichotomous measures of overall, social, and emotional loneliness, using not lonely as the referent category. As this was a cross-sectional analysis, prevalence ratios (PRs) and 95% confidence intervals (CI) for are presented instead of risk ratios. Two sets of multivariable-adjusted models were estimated. Model 1 included age category (< 50 , 50–59, 60–69, ≥ 70 years), sex (male, female), race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, non-Hispanic Asian, non-Hispanic other), annual household income ($< \$50,000$, $\$50,000$ – $< \$75,000$, $\$75,000$ – $< \$150,000$, $\geq \$150,000$), employment status (employed, not employed), educational attainment (high school graduate or less, some college, college graduate), marital status (married/living with partner, divorced or separated, widowed, never married), household size (1, 2, ≥ 3), BMI category (< 25 , 25–30, ≥ 30 kg/m²), number of self-reported diagnosed physical health conditions (0, 1, 2, ≥ 3), number of self-reported diagnosed mental health conditions (0, 1, 2), and acute COVID-19 infection severity (mild, moderate, severe). Model 2 additionally adjusted for social

support category. We hypothesized that pre-infection social support may confound the association between loneliness and long COVID through associations of low social support with post-infection loneliness [25] and indirect associations of low social support with long COVID through pre-infection loneliness [26]. An available case approach was used for missing data, and a total of 239 (4.2%) of enrollees who had missing data on any covariate were not included in fully adjusted models.

We assessed whether associations between long COVID symptoms and loneliness were modified by pre-infection social support category on the multiplicative scale using cross-product terms, and estimated associations between long COVID and loneliness stratified by social support category. Because interaction on the additive scale may be of public health interest, we used prevalence ratios to assess whether interaction between long COVID symptoms and social support category was present on the additive scale by calculating the relative excess risk due to interaction (RERI), a measure of whether the joint presence of two exposures increases risk of an outcome beyond what would be expected based on the sum of the risk associated with each exposure individually [27]. For RERI analyses, the stratum with the lowest risk should be selected as the reference category; therefore, high social support was the referent group, such that measures assessed excess risk associated with moderate and low social support [28]. RERI values of > 0 indicate a positive interaction, while values < 0 indicate a negative interaction.

Several sensitivity analyses were performed. First, to ensure that associations between long COVID and loneliness were not affected by symptoms or isolation due to a recent COVID-19 infection, we excluded enrollees who reported that their most recent COVID-19 infection occurred within 3 months of their COVID-19 follow-up survey. Second, to assess whether observed associations were attributable to mental health symptoms of long COVID, we restricted our definition of long COVID to exclude 28 enrollees who only reported anxiety or depression as symptoms. Third, we assessed whether associations differed when examining current long COVID symptoms (any v. none) as the outcome. Fourth, to assess whether associations differed when loneliness thresholds were increased, we ran models where the cut-point for overall loneliness was raised to ≥ 5 , which aligned with the scale developers' definition of severe loneliness. Similarly, severe emotional and social loneliness were defined as the maximum score of 3 on their respective subscales. All analysis were conducted using SAS version 9.4 software (Cary, NC).

Results

Differences in sociodemographic characteristics were observed by long COVID status (Table 1). For example, compared to enrollees who did not report long COVID symptoms, enrollees who reported at least one symptom were more likely to be female (39.8% v. 33.8%), have annual household incomes <\$50,000 (15.4% vs. 8.0%), and live alone (17.0% v. 14.2%). Those with long COVID were also less likely to be non-Hispanic White (74.0% vs. 84.0%), have graduated from college (53.4% v. 65.4%), be married or live with a partner (74.1% v. 80.0%) or be employed (56.0% v. 59.5%). Compared to those without long COVID symptoms, those with any symptoms were more likely to have pre-existing physical health conditions (≥ 3 conditions: 40.0% v. 24.9%) and mental health conditions (2 conditions: 15.7% v. 7.6%), have high BMI (≥ 30 kg/m²: 40.8% v. 29.0%), and were more likely to report having been hospitalized for their COVID-19 infection (7.0% v. 1.5%). Low social support was also more common among those with long COVID compared to those without (39.4% v. 26.1%). Prevalence of overall, social, and emotional loneliness were each higher among those with long COVID symptoms compared to those without (Fig. 1). Among those with long COVID symptoms, prevalence of overall loneliness was 61.2%, compared to 43.5% among those without symptoms. Social loneliness and emotional loneliness were also each higher among those with symptoms than among those without (63.7% v. 49.4% and 58.4% v. 40.9%, respectively).

Significant associations were observed between any self-reported long COVID symptoms and loneliness (Table 2). In unadjusted models, enrollees who reported any long COVID symptoms had a 41% higher prevalence of overall loneliness compared to those without long COVID symptoms (95% CI: 1.34, 1.48). Addition of covariates in Model 1 attenuated this association (PR = 1.27, 95% CI: 1.20, 1.34); estimates were also somewhat attenuated after further adjustment for social support category in Model 2 (PR = 1.19, 95% CI: 1.13, 1.25). In unadjusted and adjusted models, significant associations were also observed between long COVID symptoms and both emotional and social loneliness, though associations appeared somewhat stronger for emotional loneliness. For example, in fully adjusted models, long COVID symptoms were associated with a 22% higher prevalence of emotional loneliness (95% CI: 1.15, 1.29), and a 12% higher prevalence of social loneliness (95% CI: 1.07, 1.18).

We did not find evidence that associations between long COVID symptoms and loneliness were modified by level of pre-COVID social support on the multiplicative scale (Table 3). When stratified by social support category, associations between long COVID and loneliness appeared slightly stronger among those with high

social support than among those with low social support, though confidence intervals overlapped. For example, long COVID symptoms were associated with a 16% higher prevalence of overall loneliness (95% CI: 1.10, 1.22) among enrollees with low social support, compared to an 26% higher prevalence (95% CI: 1.07, 1.49) among those with high social support ($P_{\text{interaction}}=0.20$). In analyses of additive interactions, no evidence of interaction on the additive scale between social support and long COVID symptoms was observed (e.g., RERI = 0.13, 95% CI: -0.13, 0.37 for low social support and long COVID on overall loneliness) (Supplemental Table 1). These analyses found that low social support in the absence of long COVID was associated with over twofold higher prevalence of each type of loneliness (e.g., RR = 2.88, 95% CI: 2.57, 3.22 for association of low vs. high social support with overall loneliness).

Sensitivity analyses using a higher loneliness threshold showed stronger associations than main analyses, particularly for overall loneliness (PR = 1.51, 95% CI: 1.30, 1.75) and emotional loneliness (PR = 1.59, 95% CI: 1.30, 1.93), though associations with social loneliness also appeared stronger (PR = 1.21, 95% CI: 1.11, 1.31) (Supplemental Table 2). Results from other sensitivity analyses were similar to those from main models. For example, associations between long COVID symptoms and overall loneliness were similar when excluding enrollees with a COVID-19 infection in the past 12 weeks (PR = 1.20, 95% CI: 1.14, 1.27), when excluding enrollees who only reported mental health symptoms of long COVID (PR = 1.18, 95% CI: 1.12, 1.24), and when examining current long COVID symptoms as the outcome (PR = 1.17, 95% CI: 1.11, 1.24).

Discussion

During the COVID-19 pandemic, policy measures implemented to reduce the virus's spread led to increases in social isolation and drew additional attention to loneliness as a potential threat to public health, with the US Surgeon General declaring loneliness an epidemic in 2023.¹⁸ However, while population-level increases in loneliness during the COVID-19 appeared relatively small [29], results of our analysis suggest that individuals experiencing long COVID symptoms may experience persistent effects of the pandemic on social well-being. We found that long COVID symptoms were associated with higher prevalence of loneliness, highlighting associations of long COVID with individuals' psychosocial wellbeing, in addition to their physical and mental health. While the magnitudes of association observed in our study were modest at the individual level, given the prevalence of long COVID, our findings suggest that long COVID could contribute to a substantial burden of loneliness in the adult population. Thus, while there is concern about pandemic restrictions increasing social

Table 1 Sociodemographic characteristics, health risk factors and conditions, and social support, by self-reported long COVID symptoms (any v. none), among World Trade Center Health Registry enrollees who self-reported a COVID-19 infection*

	Did not report any long COVID symptoms		Reported ≥ 1 long COVID symptoms		$P_{\text{chi-sq}}$
	N	%	N	%	
Total (row %)	3,356	59.0%	2,336	41.0%	
Age category, years					
< 50	567	16.9%	341	14.6%	0.0060
50–59	1,029	30.7%	811	34.7%	
60–69	1,183	35.3%	801	34.3%	
≥ 70	577	17.2%	383	16.4%	
Sex					
Male	2,223	66.2%	1,406	60.2%	< 0.0001
Female	1,133	33.8%	930	39.8%	
Race/ethnicity					
Non-Hispanic White	2,820	84.0%	1,728	74.0%	< 0.0001
Non-Hispanic Black	143	4.3%	166	7.1%	
Hispanic	218	6.5%	279	11.9%	
Non-Hispanic Asian	117	3.5%	97	4.2%	
Non-Hispanic other	58	1.7%	66	2.8%	
Educational attainment					
High school graduate or less	352	10.5%	341	14.6%	< 0.0001
Some college	809	24.1%	748	32.0%	
College graduate	2,193	65.4%	1,246	53.4%	
Employment status					
Employed	1,996	59.5%	1,308	56.0%	0.0082
Not employed	1,358	40.5%	1,028	44.0%	
Annual household income					
<\$50,000	262	8.0%	354	15.4%	< 0.0001
\$50,000–<\$75,000	318	9.7%	326	14.2%	
\$75,000–<\$150,000	1,287	39.2%	952	41.5%	
$\geq$ \$150,000	1,417	43.1%	664	28.9%	
Smoking status					
Never	2,122	63.3%	1,417	60.7%	0.0024
Former	1,098	32.8%	780	33.4%	
Current	132	3.9%	136	5.8%	
Body mass index (BMI) category, kg/m ²					
< 25	973	29.2%	532	23.0%	< 0.0001
25–<30	1,392	41.8%	839	36.2%	
≥ 30	966	29.0%	945	40.8%	
Marital status					
Married/living with partner	2,684	80.0%	1,731	74.1%	< 0.0001
Divorced or separated	299	8.9%	270	11.6%	
Widowed	96	2.9%	112	4.8%	
Never married	277	8.2%	223	9.5%	
Household size					
1	477	14.2%	397	17.0%	0.0051
2	1,427	42.6%	917	39.3%	
≥ 3	1,449	43.2%	1,018	43.7%	
N, self-reported diagnosed physical health conditions					
0	833	25.1%	369	16.1%	< 0.0001
1	940	28.3%	541	23.6%	
2	719	21.7%	466	20.3%	
≥ 3	828	24.9%	919	40.0%	
N, self-reported diagnosed mental health conditions					

Table 1 (continued)

	Did not report any long COVID symptoms		Reported ≥ 1 long COVID symptoms		$P_{\text{chi-sq}}$
	N	%	N	%	
0	2,541	75.8%	1,498	64.2%	< 0.0001
1	557	16.6%	469	20.1%	
2	256	7.6%	365	15.7%	
Acute COVID-19 infection severity, COVID follow-up survey					
Mild	2,947	88.0%	1,442	61.8%	< 0.0001
Moderate	350	10.5%	730	31.3%	
Severe	50	1.5%	163	7.0%	
Social support category**					
Low	875	26.1%	919	39.4%	< 0.0001
Moderate	1,284	38.3%	831	35.7%	
High	1,192	35.6%	580	24.9%	

Due to rounding, column percentages may not sum to 100%

Due to missing data for some covariates, numbers may not sum to column total

*Unless otherwise noted, time-varying covariates are assessed at Wave 5 (2020–2021); when Wave 5 data were missing, Wave 4 (2016–2017) data were used, when available

**Based on distribution of 5-item Medical Outcome Study Social Support Scale scores in study population

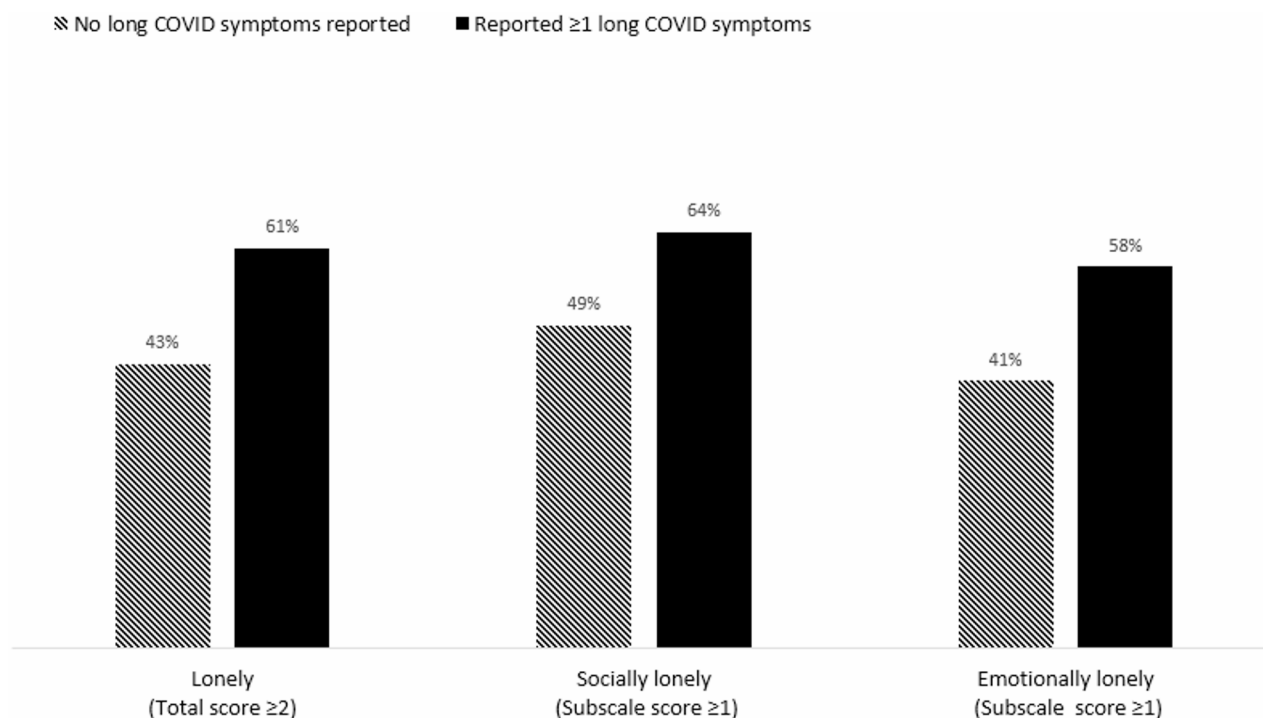


Fig. 1 Prevalence of loneliness by long COVID symptoms among World Trade Center Health Registry enrollees ($N = 5,692$). Percentage of World Trade Center Health enrollees categorized as lonely, socially lonely, or emotionally lonely by self-reported long COVID symptoms (striped: no symptoms reported; solid: any symptom reported) among enrollees who self-reported any symptomatic COVID-19 infection

isolation, such measures may play a role in a broader public health approach to mitigating loneliness during and after infectious disease outbreaks by reducing the incidence of post-acute sequelae.

Though our findings are in line with evidence from qualitative studies in which individuals with long COVID symptoms frequently reported feelings of loneliness, few studies have compared levels of loneliness among

individuals with and without long COVID symptoms. Using survey data from youths aged 11–17 years living in England, McOwat et al. reported that those with long COVID had a nearly 3-fold risk of loneliness compared to those without long COVID [30]. To our knowledge, at this time, there are no comparable studies examining this association among adult populations. However, our results are in line with previous literature demonstrating

Table 2 Prevalence ratios (PR) and 95% confidence intervals (95% CI) for associations of self-reported long COVID symptoms (any v. none) and loneliness

	Unadjusted		Model 1		Model 2	
	PR	95% CI	PR	95% CI	PR	95% CI
Overall loneliness						
Not lonely (total score < 2)	1.00	ref.	1.00	ref.	1.00	ref.
Lonely (total score ≥ 2)	1.41	1.34, 1.48	1.27	1.20, 1.34	1.19	1.13, 1.25
Social loneliness						
Not socially lonely (subscale score = 0)	1.00	ref.	1.00	ref.	1.00	ref.
Socially lonely (subscale score ≥ 1)	1.29	1.23, 1.35	1.19	1.13, 1.25	1.12	1.07, 1.18
Emotional loneliness						
Not emotionally lonely (subscale score = 0)	1.00	ref.	1.00	ref.	1.00	ref.
Emotionally lonely (subscale score ≥ 1)	1.43	1.35, 1.51	1.28	1.21, 1.36	1.22	1.15, 1.29

Model 1 is adjusted for age category, sex, race/ethnicity, educational attainment, household income category, employment status, household size, BMI category, smoking history, number of self-reported physical and mental health conditions, severity of acute COVID-19 infection

Model 2 is additionally adjusted for social support category

Table 3 Prevalence ratios (PR) and 95% confidence intervals (95% CI) for associations of self-reported long COVID symptoms (any v. none) and loneliness, stratified by social support category

	Low social supportScore: 0–14N = 1,724		Moderate social supportScore: 15–19N = 2,035		High social sup- portScore: 20N = 1,694		<i>P</i> _{interaction}
	PR	95% CI	PR	95% CI	PR	95% CI	
Overall loneliness							
Not lonely (total score < 2)	1.00	ref.	1.00	ref.	1.00	ref.	0.20
Lonely (total score ≥ 2)	1.16	1.10, 1.22	1.21	1.10, 1.33	1.26	1.07, 1.49	
Social loneliness							
Not socially lonely (subscale score = 0)	1.00	ref.	1.00	ref.	1.00	ref.	0.59
Socially lonely (subscale score ≥ 1)	1.10	1.04, 1.15	1.12	1.03, 1.23	1.17	1.01, 1.36	
Emotional loneliness							
Not emotionally lonely (subscale score = 0)	1.00	ref.	1.00	ref.	1.00	ref.	0.25
Emotionally lonely (subscale score ≥ 1)	1.18	1.10, 1.26	1.27	1.14, 1.40	1.24	1.06, 1.44	

All models are adjusted for age category, gender, race/ethnicity, educational attainment, household income category, employment status, household size, BMI category, BMI category, smoking history, number of self-reported physical and mental health conditions, and severity of acute COVID-19 infection

higher levels of loneliness among individuals living with chronic conditions and those with poorer self-rated health [31–33].

Building on this evidence, mechanisms through which long COVID symptoms may increase loneliness are numerous. First, individuals living with long COVID frequently report that their symptoms greatly interfere with their ability to participate in social activities, which may leave individuals feeling less socially connected. Exacerbations in symptoms that occur after social activities may also lead individuals with long COVID to avoid participation [34]. In addition to relationship with friends and family, long COVID may also broadly impact other sources of social interaction and connectedness. For example, long COVID is associated with unemployment, which itself is associated with loneliness [35]. In addition to decreased capacity for social interaction, individuals living with long COVID often report shifts in their social roles and sense of identity [36–39], consistent with the concept of ‘biographical disruption’ that has been noted to occur after a chronic disease diagnosis [40–42]. As

individuals adapt to new limitations caused by their condition, they may experience profound shifts in self-identity and relationships with others, leading to feelings of isolation and loneliness. Additionally, many individuals with long COVID also report feelings of stigma related to their condition, including internalized stigma, the adoption of negative beliefs about oneself that can lead to feelings of alienation and social withdrawal [43, 44]. Previous research has found associations between stigma and loneliness among those with other chronic conditions, including depression [45].

While long COVID may increase loneliness, the stress-buffering hypothesis of social support posits that high levels of social support may reduce the negative impacts of stressful events on subsequent physical and mental health [19]. However, our analysis did not find that associations between long COVID and loneliness were modified by pre-infection social support on either the additive or multiplicative scale. Several considerations should be made when interpreting this result. First, pre-infection levels of social support were assessed in this study

and may not accurately reflect social support during or after long COVID symptom onset, leading to misclassification. Additionally, social support was assessed in the context of the COVID-19 pandemic restrictions, a period when population-level shifts from in-person to digital social contact were noted [46, 47]. Individuals with long COVID may have also turned to alternative systems of social support, including online groups [36], that were not reflected in pre-baseline measures of support. Moreover, pandemic-related changes in social interaction may have had also had consequences for the nature of social support and its benefits; one previous analysis found that inverse associations between social support and depressive symptoms among older adults during the pandemic were weaker compared to associations observed in the pre-pandemic period [48]. Our results regarding pre-infection social support should not be taken to mean that social support is not beneficial for individuals with long COVID. Conversely, previous work by Luscher et al. showed that individuals with long COVID who reported higher levels of emotional support had better mental health outcomes compared to those with lower levels of support [49]. In our study population, enrollees with low social support also had a substantially higher prevalence of loneliness than those with high levels of social support, underscoring that even in the absence of effect modification, social connectedness is still an important protective factor against loneliness.

Although our study is among the first to compare the prevalence of loneliness between individuals with and without long COVID, limitations of our analysis should be noted. First, while data on covariates were collected prospectively, long COVID symptoms and loneliness were assessed cross-sectionally. Therefore, it is not possible to assess whether loneliness differed in these groups prior to onset of symptoms. We also relied on self-reported data on long COVID, based on a checklist that did not include all recognized symptoms, which may have led to misclassification of long COVID status. Similarly, data on COVID-19 infection was self-reported, and enrollees with less symptomatic acute infections may have been improperly excluded from our study population. As some evidence suggests that loneliness may be a risk factor for long COVID [26], our results may be confounded by pre-infection loneliness, leading to bias away from the null. Lastly, our analysis was conducted among a population of older, trauma-exposed adults who have high prevalence of pre-existing mental and physical health conditions, including depression [50]; these factors have been associated with higher prevalence of loneliness in previous studies [32, 51, 52]. To our knowledge, no population-based US studies have used the De Jong Gierveld scale to assess loneliness, limiting direct comparison to our study population. Using a 4-item measure,

loneliness among US adults has recently been estimated to be approximately 37% [53], suggesting that WTCRH enrollees may have a higher baseline risk than the general population using a 4-item survey. As a result, the magnitude of associations observed in this study may not be generalizable to other populations, although the underlying mechanisms may be similar across groups.

Currently, there are no currently approved treatments for the physical and neurocognitive sequelae of long COVID. A public health approach to this condition includes not only prevention of long COVID, but also mitigation of its downstream implications for health and social well-being. Our results suggest that all individuals living with long COVID may benefit from interventions to promote social connection. In qualitative studies, individuals with long COVID cite participation in online support groups as a source of information and community [54], and online communities may represent an accessible form of social interaction for individuals whose symptoms limit in-person socialization. However, the efficacy of peer support groups on reducing loneliness has not been widely examined, and some negative consequences of participation in support groups have also been cited by some individuals with long COVID [55]. Though some interventions have been effective in reducing loneliness among population subgroups [56, 57], adaptations to these interventions that prioritize flexible formats and virtual participation may be required for those experiencing activity limitations due to long COVID symptoms. More work is needed to develop and evaluate evidence-based strategies for reducing loneliness in individuals with long COVID.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12889-025-26006-8>.

Supplementary Material 1.

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Authors' contributions

All authors were involved in conceptualizing the study, developing study methodology, and interpreting results. JS performed data analyses and wrote the original draft. SP and JM reviewed and edited the manuscript. All authors read and approved the final manuscript.

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Data availability

Due to privacy restrictions, data may be made available to researchers following review of applications to the Registry. Survey instruments are publicly available at <https://www.nyc.gov/site/911health/researchers/survey-materials.page>.

Declarations

Ethics approval and consent to participate

In accordance with the Helsinki Declaration, the World Trade Center Health Registry protocol was approved by the US Centers for Disease Control and Prevention (CDC) and the New York City Department of Health and Mental Hygiene (DOHMH) institutional review boards (#02-058). Informed consent was obtained verbally from enrollees at the time of their enrollment.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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