CLINICAL RESEARCH STUDY

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# A Cross-Sectional Study of Symptom Prevalence, Frequency, Severity, and Impact of Long COVID in Scotland: Part II

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## ABSTRACT

**BACKGROUND:** There has been some effort to map the prevalence, frequency, and severity of symptoms of long COVID at local and national levels. However, what is frequently absent from such accounts is details of the impact the disease and its symptoms have had on those living with the condition. In this article, we present details of the impact on work, caring, and mental health gathered using a cross-sectional survey.

**METHODS:** Data were collected using an online survey that was available from April 21, 2022, to August 5, 2022. Included participants had either self-diagnosed or confirmed long COVID, were living in Scotland, and were aged ≥18 years. Hospitalization during initial COVID-19 infection was an exclusion criterion. Participants were asked to report on the impact of their illness on everyday activities such as working, studying, or caring. They also completed an assessment of their current mood.

**RESULTS:** People with long COVID were often severely impacted in their ability to work and study. Severe impact on work and study were predicted by more severe and more frequent fatigue, more severe pain, and more severe cognitive impairment. Respondents' ability to care for child dependents was also associated with more severe and more frequent fatigue, and more severe cognitive impairments. More severe pain associated with greater impact on adult care. Negative mood correlated most strongly with frequency and severity of neurological symptoms, including lack of attention, loss of smell, impaired sense of smell, loss of taste, impaired sense of taste, and loss of appetite.

**CONCLUSIONS:** Long COVID has a significant impact on ability to work, study, and care for dependents. The severity of this impact is associated with specific symptom burden, including fatigue, pain, and cognitive impairment.

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**KEYWORDS:** Long COVID; Post-acute infection syndrome; Post-acute sequelae of SARS-CoV-2 infection; Survey; Symptoms

## INTRODUCTION

Symptoms which develop or continue to occur weeks or months after initial acute infection with SARS-CoV-2, and which continue, without explanation, for over 12 weeks may be attributed to long COVID.[1] Within McLaughlin et al, (part 1) the prevalence, frequency, and severity of symptoms of long COVID within a national setting was established. Supporting previous reviews,[2] symptoms of fatigue and cognitive impairments were highly prevalent, alongside the

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specific fatigue-related symptom, post-exertional malaise. Bouts of post-exertional malaise were reported to be frequent and severe. Although fatigue, problems with activities of daily living, and general pain were reported to occur the most frequently, sleep difficulties, problems with activities of daily living, and nausea were reported as the most severe.

The picture of symptom experience within the population surveyed is well detailed within (Mclaughlin et al). However, what is not clear is the impact of these experiences on the lives of those with long COVID. The Office for National Statistics has estimated that approximately 172,000 people are living in Scotland with long COVID,[3] and therefore it is important to consider the potential impact on the ability to contribute to the paid and unpaid Scottish labor market, and educational development. Long COVID will continue to place significant health[4] and economic[5] burdens on society if its true nature is not fully taken into account. As such, understanding the form and scale of this impact in Scotland is vital to plan for, and mitigate, impacts on the wider economy.

**CLINICAL SIGNIFICANCE**

- The severity of the impact of long COVID on work and study were predicted by more severe fatigue, pain, and cognitive impairment.
- The impact of long COVID on the ability to care for child dependents was associated with more severe fatigue and cognitive impairments.
- More severe pain associated with the impact on the ability to care for adult dependents.
- Negative mood scores correlated most closely with frequency and severity of neurological symptoms.

Evidence for the impacts of long COVID on life in people in Scotland will shape future decision-making at the levels of government, research, and healthcare for the management and care of those suffering from the condition, and provide additional advocacy for the Scottish long COVID community. Therefore, it is imperative the effect of the condition on individuals and families is fully understood to inform policymakers when considering long COVID. As such, the aim of this study was to understand the impact of long COVID on people living with the condition in Scotland, and the impact of the condition on essential activities. Additionally, we aimed to elucidate the effect symptom prevalence, frequency, and severity exerts on factors such as work, study, and caring duties.

## METHODS

Data presented within this article were collected as part of the survey presented in McLaughlin et al, (part 1). See part 1 for details on the study design, participant demographics and study population, study outcomes, symptom number and prevalence, symptom frequency and severity, duration and improvement rating of long COVID, and individual ratings of negative mood.

### Impact of Long COVID on Work, Study, and Caring Duties

Participants were asked a series of questions regarding the impact of long COVID on their ability to work, study, and care for dependents. They were asked whether they were employed, students, or providing care prior to COVID infection, and if they had to change work hours or roles as a result of their persistent symptoms. A further question was asked to determine the severity of the impact of long COVID on the ability to work, study, or perform caring duties.

### Individual Ratings of Negative Mood

Respondents were asked to rate how angry, sad, worn out, uneasy, unable to concentrate, annoyed, anxious, helpless, and forgetful they currently feel on a scale of 1-100. From this, an overall negative mood score was determined by combining scores from each domain.[6]

### Statistical Analysis

The data were analyzed using Jamovi version 2.3.12 (Jamovi Project, https://www.jamovi.org) and GraphPad Prism version 9 (GraphPad Software, Boston, Mass, www.graphpad.com). Shapiro-Wilks tests were performed to determine normality of data distribution. All data were normally distributed. T-Tests and analyses of variance (ANOVAs) were performed to determine between-group differences for sex (grouped as males or females), vaccination status (grouped as vaccinated or unvaccinated), age difference between those reporting impact vs no impact (for work, study, and caring). Correlation coefficients were determined using Spearman's Rho, Mann Whitney U, and Krustal Wallis tests to determine associations of long COVID symptoms with impact of long COVID on work, study, and caring duties, and negative mood scores. Chi-squared analyses were performed for additional tests to determine associations between vaccination status on the impact of long COVID on work, study, and caring duties. All statistical tests where $P \leq .05$ have been reported. Additionally, tests where $P > .05$ have been reported, only where this information is pertinent. Data are presented as mean ± standard deviation.

## RESULTS

The survey was completed by 253 respondents (77.2% female, 21.1% male, 0.4% non-binary, 1.3% prefer not to say). Over half (55.9%) of respondents confirmed that they had been tested for COVID-19 at the time of initial infection. Participant demographics can be found within McLaughlin et al part 1; Table 1.).

### Impact of Long COVID on Daily Activities, Work, and Study

Of the respondents, 4.3% reported mild, 13.0% noticeable, 41.9% highly debilitating, 15.4% severe, and 41.9% very

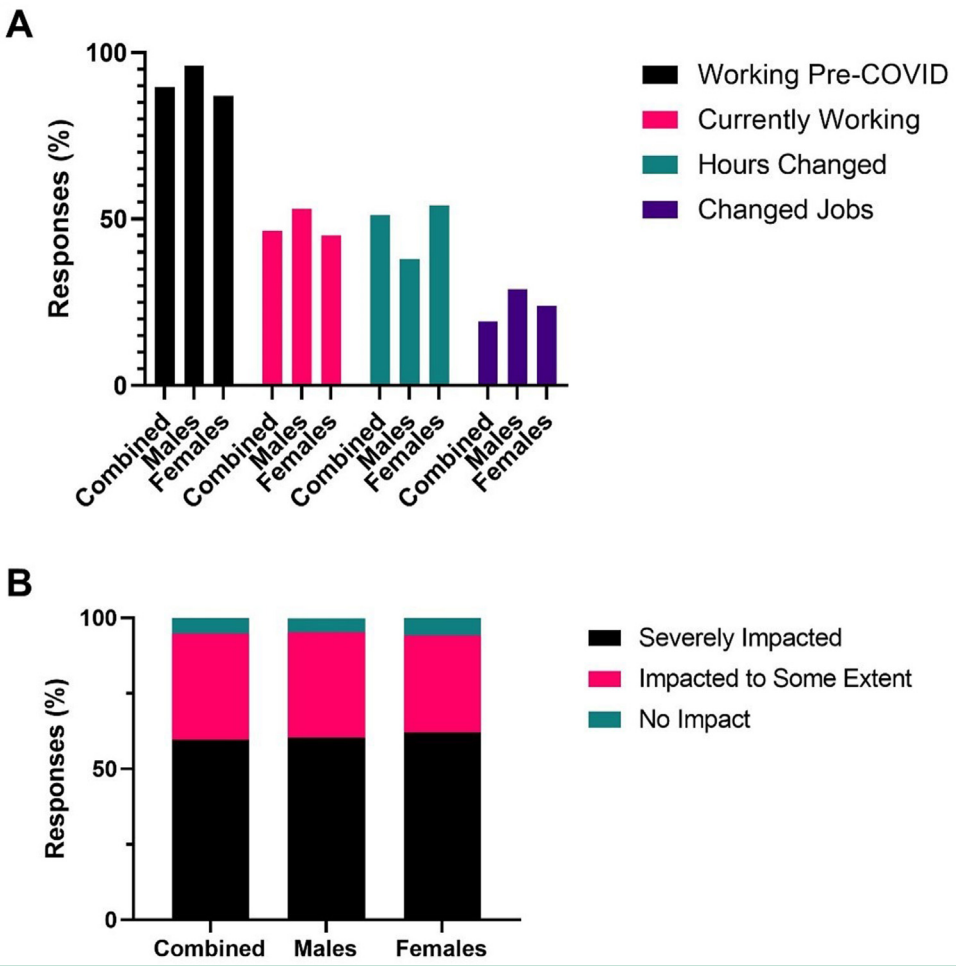


**Figure 1** (**A**) Changes to work from pre- to post-COVID and (**B**) severity of the impact of long COVID on the ability to work.

severe impact of persistent symptoms of long COVID on day-to-day activities.

Of the respondents, 89.7% were working prior to COVID-19 infection. Only 46.4% were working at the time of survey completion, 51.2% had changed working hours, and 19.2% had changed jobs or job roles. 59.7% said that long COVID had severely impacted their ability to work, 35.1% had been impacted to some extent, and 5.2% reported no impact on their ability to work. The level of these responses was similar between males and females, according to chi-squared results ($P$ = .58; Figure 1). Chi-squared analyses showed no significant association of vaccination status on the impact of long COVID on work (chi-squared value = 13.7, $P$ = 0.19). Analysis of variance revealed that there were no between-group differences for age between those who responded that long COVID had no effect, some effect, or a severe effect on the ability to work (all $P > 0.1$).

Of all the respondents, 7.7% reported being a student prior to COVID-19, with only 23.1% of these respondents still studying at the time of survey completion. In terms of impact on the ability to study, 53.1% reported that their ability to study was severely impacted by long COVID, 15.4% reported that their ability to study was impacted to some extent, and 33.3% reported no impact (Figure 2). There was no effect of age on the impact of long COVID on the ability to study as determined by 1-way ANOVA (all $P > 0.2$).

Using data collected in relation to symptoms experiences (as presented in McLaughlin et al, part 1) multiple regressions were carried out to establish if any of the 36 symptoms outlined[2] could predict the impact of long COVID on work and study. Two multiple regressions were performed with impact on work and impact on study as outcome variables. Severe impact on work was predicted by more severe and more frequent fatigue ($P < .0001$ for both), by more severe pain ($P$ = .0002), and by more severe cognitive impairment ($P$ = .0002). The same variables were significant predictors of greater impact on ability to study, that is, severity and frequency of fatigue ($P$ = .016 and .009 respectively), severity of pain ($P$ = .042) and severity of cognitive impairment ($P$ = .009).

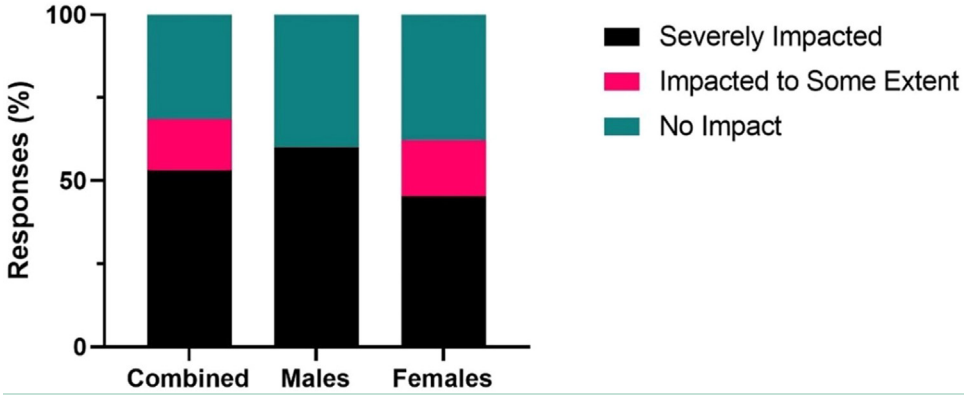


**Figure 2** Severity of the impact of long COVID on the ability to study in males, females, and combined.

## Impact of Long COVID on Caring Duties

Of the respondents, 16.7% said long COVID had made no impact on their ability to care for children, 63% had been impacted to some extent, and 20.4% had been severely impacted (Figure 3A).

Results from multiple regression analyses show that those with more severe and more frequent fatigue also reported a greater impact on childcare ($P$ = .029 and .019 for frequency and severity, respectively). Those reporting more severe cognitive impairments and mental health also reported more severe difficulties with childcare ($P$ < .0001). Chi-squared analyses showed no significant association between vaccination status on the impact of long COVID on childcare ($P$ = .73). Independent t-tests revealed that those who reported some- to severe- impact on childcare were younger than those who reported long COVID having no impact on childcare duties ($P$ = .017).

Of those caring for adult dependents, 43.2% reported that long COVID had no impact on their ability to care for adult dependents, 37.8% reported being impacted to some extent, and 18.9% reported being severely impacted (Figure 3B). Spearman's Rho correlations showed that more severe pain positively associated with greater impact on adult care ($P$ = .0008). Independent t-test revealed that those reporting no impact of long COVID on adult caring duties were significantly younger than those reporting some and severe impact ($P$ < .0001).

## Long COVID and Mood

Negative mood scores were collated based on 10 negative mood items (Ingram et al, 2020). Feeling worn-out was the most highly scored negative mood, with an average score of 75.21 ± 24.34 (Figure 4). The average cumulative negative mood rating was 423 ± 212 (range: 200-900).

Neurological symptoms as detailed in part 1 clustered around mood disturbances with significant Spearman's Rho correlations, based on symptom frequency, for lack of attention (Spearman's Rho = 0.41, $P$ < .001), cognitive impairment (Spearman's Rho = 0.17, $P$ = .022), loss of smell (Spearman's Rho = 0.36, $P$ = .008), impaired sense of smell (Spearman's Rho = 0.27, $P$ = .02), loss of taste (Spearman's Rho = 0.37, $P$ = .02), impaired sense of taste

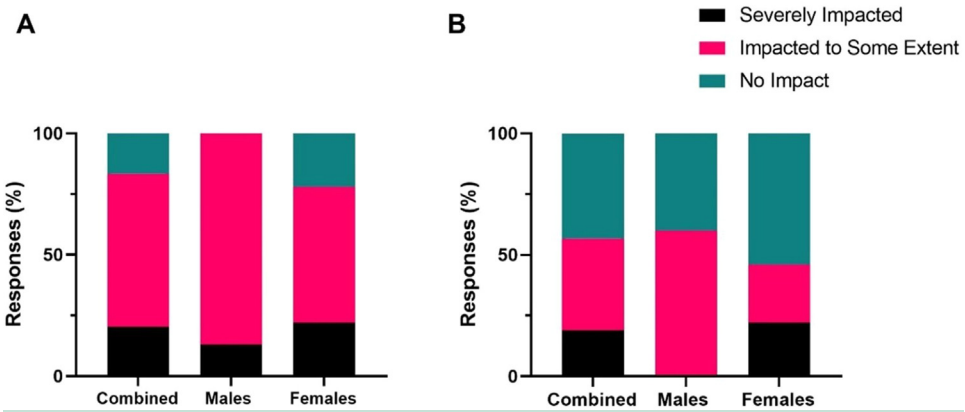


**Figure 3** Severity of the impact of long COVID on the ability to perform (**A**) child and (**B**) adult caring duties in males, females, and combined.

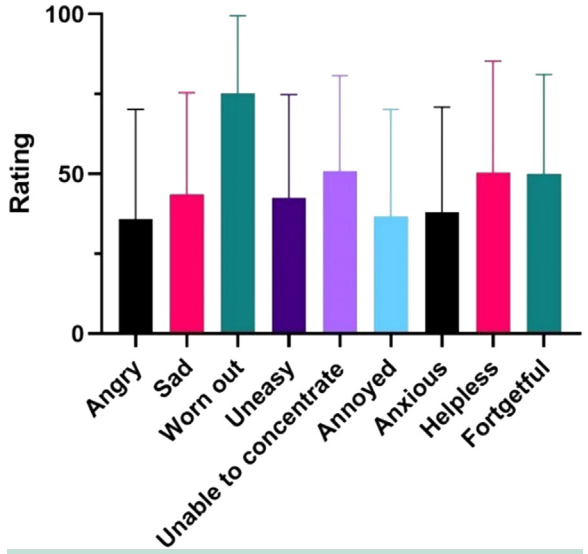


**Figure 4** Average rating for each negative mood domain. Data are displayed as mean ± standard deviation.

(Spearman's Rho = 0.38, $P$ = .02), loss of appetite (Spearman's Rho = 0.27, $P$ = .02), and eye irritation (Spearman's Rho = 0.26, $P$ = .006).

Neurological symptoms also clustered around mood disturbances based on symptom severity, with significant Spearman's Rho correlations for lack of attention (Spearman's Rho = 0.20, $P$ = .016), loss of smell (Spearman's Rho = 0.41, $P$ = .002), impaired sense of smell (Spearman's Rho = 0.23, $P$ = .045), loss of taste (Spearman's Rho = 0.39, $P$ = .01), impaired sense of taste (Spearman's Rho = 0.36, $P$ = .004), and loss of appetite (Spearman's Rho = 0.37, $P$ = .001).

One-way ANOVAs revealed that mood scores were similar between groups for the impact of long COVID on childcare (no impact: 316.3 ± 173.2, impacted to some extent: 407.6 ± 188.7, severely impacted: 330.8 ± 241.3, all $P$ > .1), adult care (no impact: 331.8 ± 248.6, impacted to some extent: 425.8 ± 239.4, severely impacted: 333.8 ± 253.6, all $P$ > .6), work (no impact: 433.1 ± 168.3, impacted to some extent: 397.7 ± 202.7, severely impacted: 440.7 ± 220.9, all $P$ > .3) and study (no impact: 336.4 ± 249.6, impacted to some extent: 495.3 ± 159.8, severely impacted: 371.0 ± 253.2, all $P$ > .3).

Furthermore, independent t-tests revealed no significant between-group differences for overall mood score for sex (grouped as males or females) or vaccination status (grouped as vaccinated or unvaccinated), with $P$ = .88 and .14, respectively.

## DISCUSSION

### Impact of Long COVID on Work and Study

More than half of those surveyed have changed their working hours, and nearly 60% indicated that their work had been severely impacted by long COVID, indicating a potentially concerning trend of long COVID impacts on employment. As of 2022, across the whole of the United Kingdom, it was found that the working-age population is at the greatest risk of developing long COVID from initial infection and that an estimated 80,000 individuals have left employment due to long COVID, further exacerbating the UK labor shortage.[7] It is, therefore, necessary to fully grasp the impact of long COVID on the ability to maintain employment within the Scottish population to quantify the degree of financial and rehabilitative support available for those affected and mitigate the effects of this impact in both short- and long-term economic forecasts.

In addition to this, over half the student population included in this study reported that their long COVID symptoms severely impacted their ability to participate in their studies. There is very limited evidence for the impact of long COVID on students in higher education. Participation in social events within universities, a common foundation of the university experience, has been found to correlate with a higher incidence of COVID-19 infection,[8] and therefore students in higher education are potentially at greater risk of developing long COVID than the general population. Nevertheless, there remains a gap in the research to understand the impact of long COVID on students in higher education and the support required of universities to facilitate the maintenance of studies in the presence of debilitating symptoms.

### Impact of Long COVID on Caring Duties

The age of those reporting severe impacts of long COVID on childcare was significantly lower than those who reported no impact. The questionnaire given to participants did not request the age of the children under the participants' care, but it is likely that younger participants with children also had younger children, and thus with greater dependency on care duties. However, no information was collected regarding the age demographics of the participants' child dependents. Conversely, with regard to adult caring duties, age was found to be positively correlated with long COVID symptoms having a severe impact on care duties. Adult carers were older than those with child dependents (43.79 ± 6.02 years vs 52.13 ± 9.32 years, $P$ < .0001), and as such may have a reduced capacity for strenuous care responsibilities in conjunction with long COVID symptoms compared with younger adult carers as age progressed.

Another important finding from the current study involves the impact of long COVID on caring duties for both children and adult dependents. Of those reportedly carrying out regular caring duties, 63% have been impacted to some extent, 20.4% have been severely impacted in their ability to care for children, and for those caring for adult dependents, 37.8% have been impacted to some extent, and 18.9% have been severely impacted. Another study reported long COVID had an impact on childcare in 33% of

survey respondents and affected caring for other adults in 25% of respondents.[9] This is a UK-wide study and therefore, the current findings suggest that caring duties are affected to a greater extent within the Scottish population in comparison to the UK-wide population. This may result in a higher consequential burden on childcare and healthcare sectors in Scotland in comparison to the UK.

## Long COVID and Mood

Due to the potentially multi-directional relationship between symptoms of long COVID, impact of long COVID, and mental well-being we have reported in this article both the symptoms that cluster around high negative mood scores and the differences in negative mood related to the impact of long COVID on daily activities, work and caring. Interestingly, both severity and frequency of neurological symptoms, including lack of attention, loss of smell, impaired sense of smell, loss of taste, impaired sense of taste, and loss of appetite, associated most strongly with negative mood. Previous research has found that a loss of taste and smell attributed to COVID-19 infection has strong detrimental impacts on psychological well-being and quality of life.[10] Targeting these specific neurological symptoms for treatment may be a way forward to reduce the psychological burden of long COVID and improve quality of life.

Perhaps surprisingly, average negative mood scores were similar across the different levels of impact severity (no impact, impacted to some extent, severely impacted) of long COVID on childcare, adult care, work, and study. Therefore, the complex interactions between long COVID and the impact on mood requires further investigation to identify contributing factors and subsequent consequences of negative mood.

## Limitations

One limitation of this study was the reliance of subjective self-reporting from participants to generate population data, which has greater risk of producing erroneous results than objective measures.[11] However, given the complexities, costs, and rigidity of available data associated with scaling objective measures to the cohort size obtained in this study, significant advantages are still to be gained from the cost-benefit and flexibility of self-reported questionnaires. As such, despite this limitation, this study has reported both comparative and novel data outlining the scope and symptom burden of people with long COVID in Scotland, adding to the broader body of research in this subject area.

The cross-sectional design of the current study limits our understanding of the changeability of long COVID over time.[12] A prospective longitudinal design to track symptom burden to elucidate a fuller picture of long COVID symptoms and impact would be beneficial to mitigate this limitation, and as such a remote symptom tracking study is proposed as the next research step.

The method of online questionnaire administration may have introduced demographical biases into the study, limiting access to populations less likely to have internet access, as seen in the absence of participants aged >70 years. While other studies have demonstrated that this need not be a barrier to this method of self-reporting,[13] it is unfortunate that this was the case in this study and represents an area where future efforts in demographically focused recruitment can be optimized. Nonetheless, despite the potential limitations an online questionnaire may have had for a selection of demographics, it remains an advantageous format for survey data collection due to its scalability and environmental benefits, compared with paper-based methods, and will remain the optimal method for similar studies in the future.

Based on participant demographics, the current sample of survey respondents is not entirely representative of Scotland as a whole nation, with 60.5% of respondents living in households with 2 adults—50%[14] of Scottish households consist of 2 adults. With regard to relationship status, >90% of respondents were married, which means an over-representation of the married population within Scotland as only ~50% of adults in Scotland are married.[15]

Another bias may have been introduced by presenting participants with a pre-defined list of long COVID symptoms within the questionnaire, potentially limiting the range or specificity of symptoms likely to be reported by participants. The effects of this bias were mitigated, however, by the addition of "Other" as an option, which allowed for participants to self-define a symptom not covered within the list of options. However, only 1 participant added a symptom which was not listed. Additionally, given the size of the cohort within this study (n = 253), exclusively self-defined symptoms may have introduced needlessly excessive symptom definitions based on individuals' health literacy and preferred vocabulary.

This study only included responses from non-hospitalized individuals. Although this excludes those with likely more severe initial infection, it is important to determine the characteristics and the impact of long COVID in less severely affected initial infections as these groups are often underrepresented. The majority of studies investigating long COVID have included people who had a severe acute infection, as determined by hospitalization.[16,17] However, for the vast majority of people infected with SARS-CoV-19, infections do not lead to hospitalization.[18] Long COVID still occurs in those with a less severe or mild acute infection.[19] This study now adds knowledge to the literature regarding the symptom burden experienced by those with less severe initial infection. However, it would now be of interest to determine if long COVID severity differs with initial disease severity, but we cannot compare this from this data. Furthermore, those with no lab evidence of their infection during the first wave of the pandemic when testing was not accessible are often omitted from research and are therefore underrepresented within the long COVID community.[16,17] Hence, this study includes those who did not receive a positive test at the time of infection, increasing the representation of those often omitted from long COVID research studies.

## CONCLUSION

The current findings show that long COVID often severely impacts the ability to work and study in those suffering from the condition, and, for the first time, this has been quantified at a national level within Scotland. The severity of the impact of long COVID on work and study were predicted by more severe and more frequent fatigue, more severe pain, and more severe cognitive impairment. Furthermore, the impact of long COVID on the ability to care for child dependents was also associated with more severe and more frequent fatigue, and more severe cognitive impairments. With regard to the impact on the ability to care for adult dependents, more severe pain was the only significant association identified. Considering the psychological impact of long COVID, negative mood scores correlated most closely with frequency and severity of neurological symptoms, including lack of attention, loss of smell, impaired sense of smell, loss of taste, impaired sense of taste, and loss of appetite.

Overall, this survey has highlighted the detrimental impact of long COVID on the ability to work, study, and care for dependents, and has provided evidence of the condition's association with considerable disturbances of mood. The burden of long COVID must be tackled to ensure a contributory society that is able to function optimally, supporting employment, further education, and providing care to adult and child dependents to reduce reliance on childcare and healthcare sectors. The identification of associating factors within the current study may provide therapeutic targets to reduce the overall impact of long COVID and the subsequent societal burden.

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