Received: 23 September 2021 | Accepted: 18 August 2022

DOI: 10.1111/jocn.16541

Journal of Clinical Nursing WILEY

ORIGINAL ARTICLE

The other COVID-19 survivors: Timing, duration, and health impact of post-acute sequelae of SARS-CoV-2 infection

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Abstract

Aims and Objectives: To determine the frequency, timing, and duration of post-acute sequelae of SARS-CoV-2 infection (PASC) and their impact on health and function.

Background: Post-acute sequelae of SARS-CoV-2 infection is an emerging major public health problem that is poorly understood and has no current treatment or cure. PASC is a new syndrome that has yet to be fully clinically characterised.

Design: Descriptive cross-sectional survey (n = 5163) was conducted from online COVID-19 survivor support groups who reported symptoms for more than 21 days following SARS-CoV-2 infection.

Methods: Participants reported background demographics and the date and method of their covid diagnosis, as well as all symptoms experienced since onset of covid in terms of the symptom start date, duration, and Likert scales measuring three symptom-specific health impacts: pain and discomfort, work impairment, and social impairment. Descriptive statistics and measures of central tendencies were computed for participant demographics and symptom data.

Results: Participants reported experiencing a mean of 21 symptoms (range 1–93); fatigue (79.0%), headache (55.3%), shortness of breath (55.3%) and difficulty concentrating (53.6%) were the most common. Symptoms often remitted and relapsed for extended periods of time (duration M = 112 days), longest lasting symptoms included the inability to exercise (M = 106.5 days), fatigue (M = 101.7 days) and difficulty concentrating, associated with memory impairment (M = 101.1 days). Participants

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reported extreme pressure at the base of the head, syncope, sharp or sudden chest pain, and "brain pressure" among the most distressing and impacting daily life.

Conclusions: Post-acute sequelae of SARS-CoV-2 infection can be characterised by a wide range of symptoms, many of which cause moderate-to-severe distress and can hinder survivors' overall well-being.

Relevance to Clinical Practice: This study advances our understanding of the symptoms of PASC and their health impacts.

KEYWORDS
chronic disease, COVID-19, symptom, symptom burden

1 | INTRODUCTION

As of August 2021, SARS-CoV-2 has infected more than 214 million worldwide (Johns Hopkins University of Medicine, 2021). It is estimated that 10%–30% of persons who survive COVID-19—including those with asymptomatic, mild and moderate infection—have persistent symptoms and do not fully recover or return to pre-morbid functioning (Fernández-de-las-Peñas et al., 2021; Mahase, 2020). The medical community only recently recognised post-infectious persistent symptoms with a protracted recovery period as a new syndrome. Originally called long-COVID or "long-haul," the NIH recently re-named the condition as post-acute sequelae of SARS-CoV-2 infection (PASC). PASC has no effective treatment or cure, and the long-term consequences and symptom duration of PASC remain unknown. More than a year into the COVID-19 pandemic, survivors report persistent symptoms that have often remitted and relapsed. While it is too early to determine if PASC will eventually resolve or become a chronic condition, it is critical to characterise sequelae of this new syndrome.

Reports from PASC survivors may provide clues to inform treatment and management. Unfortunately, there are few arge studies that go beyond identification of symptoms (Carfi et al., 2020). Studies that use electronic health records likely provide accurate information about symptoms and their temporal order but are limited by completeness of all symptoms (Huang et al., 2021). Reports suggest that PASC survivors often do not disclose all symptoms to providers for fear of dismissal by clinicians and embarrassment (Fahmy, 2020). Further, it is well documented that during clinical visits to providers, patients in general tend to focus on the most bothersome symptoms (Li et al., 2019). These studies allude to the variability and complexity of symptom presentations of PASC. Comprehensive accounts, as reported by survivors of PASC, of detailed symptom onset, type, quality and duration are urgently needed to better understand PASC sequalae, its management, and strategies to improve function and quality of life. In this study, we report the patients' (n = 5163) account of number and temporal order of PASC symptoms, including median onset and duration of symptoms, and perceived distress and impact on their lives.

What does this paper contribute to the wider global clinical community?

- This study advances clinical understanding of post-acute sequelae of SARS-CoV-2 infection (PASC) symptoms and their impact on human life.
- This study enables nurses to better assist patients in recovery by identifying the range of PASC symptoms nurses can address through symptom management education and therapeutic communication.
- This study identifies the most distressing PASC symptoms, helping clinicians to prioritise symptoms to be targeted immediately to improve quality of life for PASC patients.

2 | METHODS

2.1 | Study sample

Institutional Review Board approval was obtained from Indiana University, and electronic informed consent was obtained from subjects prior to data collection. Data were collected from August 2020 to February 2021 from a convenience sample COVID-19 survivors aged 18 or older. Participants were recruited from Survivor Corps, a Facebook community of more than 176,000 COVID-19 survivors, and other online survivor communities. Inclusion criteria were (a) age 18 or older, (b) could read and respond in English and (c) COVID-19 symptoms present for 21 days or longer. COVID-19-negative individuals were excluded. Participants completed an online symptom survey in REDCap.

2.2 | Symptom survey

Symptoms were identified through content analysis of unstructured data, derived from publicly available health narrative data (unprompted

posts on Facebook where COVID-19 survivors described their symptoms). Symptoms listed in the survey were the patients' own words (e.g. "brain pressure" and "changes in hormones"). We opted to do this for two reasons. First, we wanted to ensure that survivors would recognise symptoms. Second, we were cautious to not improperly medicalize survivor symptoms without first validating that the medical terminology represented the symptom experience of survivors. Additionally, the survey asked about past medical history and their experiences seeking treatment for PASC.

For each symptom, a 5-point Likert scale (from "Not at all" to "Very much") was used to assess the degree to which each symptom caused pain and discomfort, work impairment and social relationship impact. The survey collected onset (date it started), duration (how many days), intensity (Likert scale) and burden (e.g. impact on life, Likert scale) of symptoms. It also captured whether symptoms were intermittent and whether they had resolved.

2.3 | Data analysis

All survey data were manually reviewed for completeness and cleaned using a codebook before statistical analysis. The final dataset for analysis consisted of 5163 participants. Descriptive statistics and measures of central tendencies were computed for the following: percentage of participants who reported each symptom, the median time to symptom onset, median symptom duration was calculated for each symptom instead of averages due to the presence of several large outliers, and the percentage of participants reporting that a symptom was ongoing. The percentage of participants who reported any symptom as intermittent was calculated for each symptom. To assess the impact of each symptom on pain and discomfort, work impairment and social relationships, the average score from the 5-point Likert scale was determined. The tidyverse R package was used to visualise the relationship between symptom discomfort and duration, the distribution of the number of symptoms reported by each participant, and to create a table containing all symptom metrics calculated for this study (Wickham et al., 2019). We used the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines for reporting observational studies to report results (see checklist in Appendix S1; Von Elm et al., 2007).

3 | RESULTS

3.1 | Survey demographics

The overall response rate for completing the survey was 54%. Participants were predominantly White (81.3%), female (85.7%), never hospitalised for COVID-19 (89.3%) and had RT-PCR confirmed SARS-CoV-2 infection or were clinician diagnosed (77.1%). See Table 1 for more detail.

3.2 | Prevalence, onset and duration of symptoms

Participants reported a total of 101 symptoms. Not all participants had all symptoms. The mean number of symptoms experienced by any given participant was 21 with a range of 1–93 (Figure S1). The most common symptoms experienced included: fatigue, headache, shortness of breath, difficulty concentrating, inability to exercise, cough, change in sense of taste, diarrhoea, and muscle or body aches. The prevalence of symptoms is reported in Figure 1. Median onset and duration of PASC symptoms are reported in Figure 2. Visualisation of the symptom experience presented in Figure 2 illustrates the sequence and timing of symptoms suggesting a progression in symptomatology among individuals with PASC. For example, "flu-like" symptoms (fatigue, fever/chills, headache, exercise intolerance, sleeping more than usual, sore throat, cough and upper respiratory congestion) were commonly associated with early or initial onset. A few days later, symptoms involving the neurological ("brain pressure," difficulty concentrating, and anxiety), gastrointestinal (changes in sense of taste and smell, nausea, vomiting, diarrhoea), and musculoskeletal systems (myalgias described as "lower back pain," "upper back pain" and "neck muscle pain"), manifested. Much later in the course of the PASC symptom experience, symptoms associated with disturbances to the microvasculature, such as "Covid toes," and integumentary, gynaecological and endocrine systems, resulted in reports of dry and peeling skin, changes in menstrual cycles, neuropathies, rashes, swelling of extremities, weight gain and hair loss.

Symptom duration ranged from lasting from 2 weeks after symptom onset to over 100 days, with changing symptoms being a prominent, long-lasting feature (Figure 2). For many symptoms, the onset and duration appeared to reflect an evolution of symptoms dominated by certain body systems. For example, early symptoms (arrhythmia to burning calves) with the same median symptom onset appeared to be heavily dominated by neurological and cardiovascular manifestations with some indicators of a strong immune response (enlarged and painful lymph nodes). This is then followed by symptoms suggestive of microvascular consequences (Covid toes) of infection, as well as changed in endocrine (thyroid) function. At the time of the survey, 98.0% of the respondents answered "Yes" to a question asking whether at least one of their symptoms was unresolved, and 97.8% answered "Yes" that at least one of their symptoms was intermittent, meaning it would temporarily remit and then later relapse. Collectively, these data illustrate a pattern of evolving symptoms experienced by persons with PASC.

3.3 | Impact of symptoms on participants with PASC

Subjects reported the time of diagnosis and mapped the onset and duration of symptoms. The calculations of average time to symptom onset; symptom duration; percentage of respondents who reported the symptom as intermittent or ongoing; and the average symptom impact in terms of pain and discomfort, work impairment and social

TABLE 1 Participant demographics

Characteristic	Participants ($n = 5163$), No. (%)
Race and ethnicity	
White	4198 (81.3)
Hispanic or Latinx	330 (6.4)
Multiracial	159 (3.1)
Asian/Pacific Islander	114 (2.2)
Black	111 (2.2)
Hispanic or Latinx, White	89 (1.7)
Black	41 (0.8)
American Indian	35 (0.7)
Hispanic or Latinx, Multiracial	27 (0.5)
Other	22 (0.4)
Middle Eastern	19 (0.4)
Hispanic or Latinx, American Indian	7 (0.1)
Hispanic or Latinx, Black	6 (0.1)
Hispanic or Latinx, Other	3 (0.1)
Hispanic or Latinx, Asian/Pacific Islander	2 (0.0)
Gender	
Female	4422 (85.7)
Male	714 (13.8)
Non-binary/non-conforming	15 (0.3)
Unknown	10 (0.2)
Transgender	2 (0.0)
Age	
18–24	118 (2.2)
25–34	593 (11.5)
35–44	1298 (25.1)
45–54	1560 (30.2)
55–64	1122 (21.7)
65–74	428 (8.3)
75–84	40 (0.8)
85+	4 (0.1)
COVID-19 diagnosis	
Positive COVID-19 test	2644 (51.2)
Diagnosis from doctor	1337 (25.9)
Self-diagnosed based on symptoms	918 (17.8)
Other	264 (5.1)
Hospitalised	
No	4918 (83.9)
Yes	876 (15.5)
NA	38 (0.6)

Note: Table showing distribution of participants based on race and ethnicity, gender, age, mode of determining SARS-CoV-2 infection, and hospitalisation status.

relationship are recorded in Table 2. Variables included percentage reporting a symptom; pain and discomfort of the symptom (e.g. distress); ability to work or socialise; symptom duration; percentage reporting ongoing symptoms; and percentage reporting symptoms as intermittent. Potential morbidity, especially inability to work, was assessed through symptom severity, duration and perceived impact on ability to work (Figure 3). Symptoms perceived to have the most impact on ability to work included fatigue, personality change, a sensation of "brain pressure," inability to sleep, inability to exercise, difficulty concentrating, memory problems, confusion, shortness of breath and the relapsing/remitting nature of symptoms.

4 | CONCLUSIONS

Our study findings provide a rather comprehensive patient reported list of symptoms that was generated by their narrative report, and then further validated in a larger population. On average, subjects reported 21 symptoms with the average time from initial diagnosis being 20.88 days. When symptoms were mapped for their average time of onset and duration, visualisation of these data from a large group of survivors showed a relatively predictable pattern of onset and duration, resembling a gradually increasing progression of symptoms over time. This indicates that there may be a pattern of progression of symptoms of PASC, beginning with flu-like symptoms and progressing onwards through other major body systems. Additionally, almost all subjects who completed the survey reported persistent symptoms at 21 or more days. These findings warrant additional discussion, investigation and context within the current knowledge of PASC.

Our data suggest that the patient with PASC has a heavy symptom burden (average of 21 symptoms) and that the symptom experience is more long-lasting than is currently captured by most research studies (Stavem et al., 2021; Tenforde et al., 2020). The study's ability to detect a larger number of symptoms can be attributed to including a list of potential COVID-19 symptoms based on initial open-ended research of the range of COVID-19 sequelae conducted in July of 2020 and expanded through feedback on the survey design from Survivor Corps (Lambert & Survivor Corps, 2020). The high number of reported symptoms included in this study should assist nurses in remaining cognizant of patient complaints, and to maintain understanding that PASC can manifest in a wide array of nonspecific complaints that can cause debilitating impacts on an individual's daily life.

Similar to other work, we found that PASC was present in both hospitalised and non-hospitalised survivors (Carfi et al., 2020). The majority of participants in our study were not hospitalised. Approximately 77% of participants reported clinician diagnosis or confirmed RT-PCR for SARS-CoV-2, with 5% reporting "other" and 18% self-diagnosing. Those without confirmed diagnosis may have attributed SARS-CoV-2 infection to a confirmed antibody test that was available early in the pandemic or through the presence of COVID-specific symptoms such as loss of sense of smell. While there may be an inclination for researchers to exclude participants who do not have a positive RT-PCR or antibody test, capturing the experiences of the earliest long haulers (before validated tests had become available) is essential for

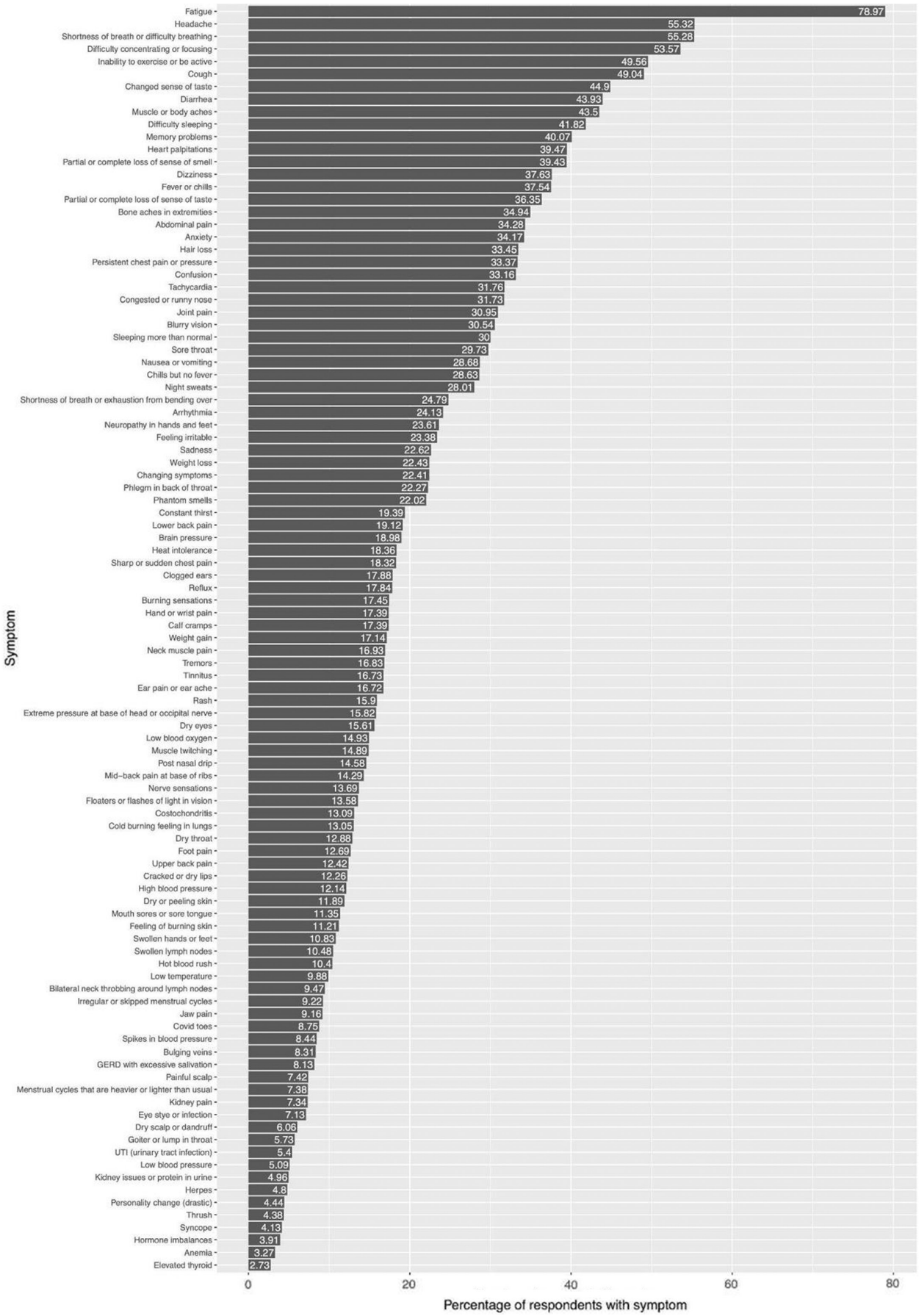

FIGURE 1 Percentage of respondents reporting each COVID-19 symptom. Graph showing percentage of participants (*x*-axis) who experienced a given symptom (*y*-axis).

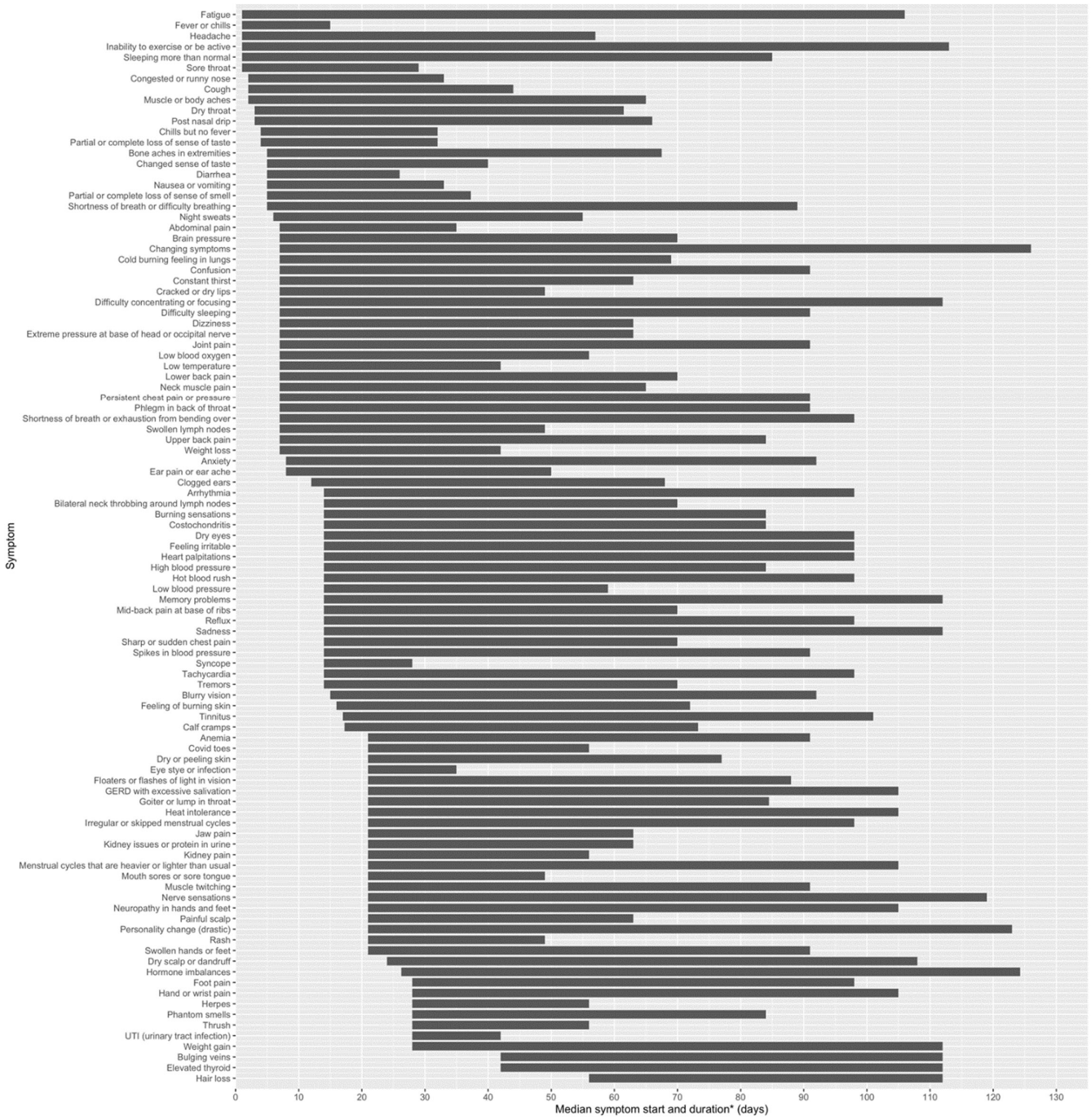

FIGURE 2 Median symptom onset and duration. Graph plotting the median time of symptom onset (in days after initial infection date) with median symptom duration. *Duration measures length of time the symptom was present and does not indicate resolution of the symptom. Participants noted these symptoms were ongoing at the time they completed the survey.

understanding the trajectory of PASC. Therefore, information obtained from PCR-positive cohorts likely lags around 3–6 months behind persons who were infected early in the pandemic.

Post-acute sequelae of SARS-CoV-2 infection impacted participants who are in the middle years of life represented 77% of our participants (n = 3980), aged 35–64. The number of women who participated in this study exceeded men. It not clear if the difference in gender reflects differences in prevalence or willingness to engage in research. Other studies also suggest that PASC occurs more frequently in women with an age distribution similar to this study, and future research should aim to validate the demographics most at risk for PASC (Sigfrid et al., 2021; Torjesen, 2021).

Participants reported multiple symptoms that when visualised by average onset and duration of specific symptoms appeared to cluster together. This observation is consistent with other reports, including of hospitalised individuals (Carfi et al., 2020). The temporal nature of these symptoms may provide clues into underlying pathogenesis, which is currently unclear. Others describe PASC symptoms, which

TABLE 2 COVID-19 symptoms and their health impacts

Symptom	Number of patients reporting symptom	Percentage of patients reporting symptom (%)	Median start date (days)	Median duration (days)	Average pain/discomfort of symptom (1–5)	Average work impairment of symptom (1–5)	Average social impairment of symptom (1–5)	Percentage afflicted reporting symptom as ongoing (%)	Percentage afflicted reporting symptom as intermittent (%)
Fatigue	4077	78.97	1	105	3.77	3.79	3.68	83.25	53.74
Headache	2856	55.32	1	56	4.15	3.22	3.07	65.90	76.68
Shortness of breath or difficulty breathing	2854	55.28	5	84	4.04	3.40	3.26	72.04	66.40
Difficulty concentrating or focusing	2766	53.57	7	105	3.14	3.66	3.18	83.41	69.99
Inability to exercise or be active	2559	49.56	1	112	3.84	3.48	3.60	84.25	32.00
Cough	2532	49.04	2	42	3.48	2.46	2.39	52.41	57.23
Changed sense of taste	2318	44.90	5	35	2.50	1.32	1.63	53.71	31.58
Diarrhoea	2268	43.93	5	21	3.50	2.49	2.39	44.22	63.62
Muscle or body aches	2246	43.50	2	63	4.05	3.12	2.98	64.07	61.62
Difficulty sleeping	2159	41.82	7	84	3.59	3.35	3.16	80.45	50.58
Memory problems	2069	40.07	14	98	3.00	3.55	3.10	86.52	63.80
Heart palpitations	2038	39.47	14	84	3.51	2.90	2.74	76.55	84.69
Partial or complete loss of sense of smell	2036	39.43	5	32.25	2.50	1.47	1.71	48.33	22.94
Dizziness	1943	37.63	7	56	3.53	3.14	2.92	68.76	82.86
Fever or chills	1938	37.54	1	14	3.68	2.60	2.47	27.19	57.28
Partial or complete loss of sense of taste	1877	36.35	4	28	2.46	1.44	1.71	45.07	24.08
Bone aches in extremities	1804	34.94	5	62.5	4.12	2.97	2.88	73.61	69.90
Abdominal pain	1770	34.28	7	28	3.77	2.47	2.56	61.07	80.51
Anxiety	1764	34.17	8	84	3.60	3.15	3.39	88.72	83.84
Hair loss	1727	33.45	56	56	2.34	1.40	1.74	76.03	15.98
Persistent chest pain or pressure	1723	33.37	7	84	4.12	3.30	3.15	66.69	67.38
Confusion	1712	33.16	7	84	3.38	3.65	3.33	78.62	77.10
Tachycardia	1640	31.76	14	84	3.62	3.09	2.94	70.49	76.77
Congested or runny nose	1638	31.73	2	31	2.86	1.89	1.83	57.39	53.79
Joint pain	1598	30.95	7	84	4.06	3.15	3.04	76.47	62.08
Blurry vision	1577	30.54	15	77	2.98	2.69	2.21	79.71	71.85
Sleeping more than normal	1549	30.00	1	84	2.63	3.25	3.16	68.82	38.80

(Continues)

TABLE 2 (Continued)

Symptom	Number of patients reporting symptom	Percentage of patients reporting symptom (%)	Median start date (days)	Median duration (days)	Average pain/discomfort of symptom (1–5)	Average work impairment of symptom (1–5)	Average social impairment of symptom (1–5)	Percentage afflicted reporting symptom as ongoing (%)	Percentage afflicted reporting symptom as intermittent (%)
Sore throat	1535	29.73	1	28	3.28	2.09	2.02	43.06	52.44
Nausea or vomiting	1481	28.68	5	28	3.88	2.84	2.77	45.78	70.02
Chills but no fever	1478	28.63	4	28	3.30	2.24	2.19	42.69	77.13
Night sweats	1446	28.01	6	49	3.29	1.93	1.88	49.03	69.16
Shortness of breath or exhaustion from bending over	1280	24.79	7	91	3.80	3.37	3.15	76.17	55.55
Arrhythmia	1246	24.13	14	84	3.53	2.84	2.77	79.86	87.72
Neuropathy in hands and feet	1219	23.61	21	84	3.71	3.04	2.86	79.66	68.33
Feeling irritable	1207	23.38	14	84	3.06	2.85	3.36	79.45	77.96
Sadness	1168	22.62	14	98	3.44	3.04	3.48	79.54	69.26
Weight loss	1158	22.43	7	35	1.91	1.55	1.53	36.01	18.05
Changing symptoms	1157	22.41	7	119	3.93	3.61	3.61	83.49	82.45
Phlegm in back of throat	1150	22.27	7	84	2.86	1.90	1.85	71.83	54.87
Phantom smells	1137	22.02	28	56	2.14	1.43	1.54	64.82	81.71
Constant thirst	1001	19.39	7	56	2.63	1.74	1.66	67.43	43.96
Lower back pain	987	19.12	7	63	4.10	3.17	2.99	65.96	63.32
Brain pressure	980	18.98	7	63	4.22	3.56	3.42	73.16	78.27
Heat intolerance	948	18.36	21	84	3.70	2.83	3.03	83.23	51.58
Sharp or sudden chest pain	946	18.32	14	56	4.25	3.15	2.95	59.83	79.49
Clogged ears	923	17.88	12	56	3.12	2.19	2.17	70.21	63.06
Reflux	921	17.84	14	84	3.56	2.23	2.23	73.07	72.42
Burning sensations	901	17.45	14	70	3.71	2.64	2.58	70.26	81.69
Calf cramps	898	17.39	17.25	56	3.69	2.37	2.28	71.38	84.97
Hand or wrist pain	898	17.39	28	77	3.78	3.05	2.47	77.17	67.37
Weight gain	885	17.14	28	84	2.72	1.81	2.11	82.94	15.14
Neck muscle pain	874	16.93	7	58	4.00	3.07	2.85	66.48	58.81
Tremors	869	16.83	14	56	3.35	3.05	2.75	66.28	76.18
Tinnitus	864	16.73	17	84	3.01	2.13	2.08	75.35	60.19
Ear pain or ear ache	863	16.72	8	42	3.51	2.35	2.23	58.98	69.06
Rash	821	15.90	21	28	2.91	1.84	1.87	46.41	46.04

TABLE 2 (Continued)

Symptom	Number of patients reporting symptom	Percentage of patients reporting symptom (%)	Median start date (days)	Median duration (days)	Average pain/discomfort of symptom (1–5)	Average work impairment of symptom (1–5)	Average social impairment of symptom (1–5)	Percentage afflicted reporting symptom as ongoing (%)	Percentage afflicted reporting symptom as intermittent (%)
Extreme pressure at base of head or occipital nerve	817	15.82	7	56	4.36	3.51	3.32	66.10	71.73
Dry eyes	806	15.61	14	84	3.16	2.32	1.99	74.81	54.59
Low blood oxygen	771	14.93	7	49	3.61	3.30	3.18	54.22	58.75
Muscle twitching	769	14.89	21	70	2.92	2.32	2.21	68.14	79.32
Post nasal drip	753	14.58	3	63	2.77	1.80	1.75	67.60	53.25
Mid-back pain at base of ribs	738	14.29	14	56	4.05	3.09	2.91	63.01	63.96
Nerve sensations	707	13.69	21	98	3.72	2.89	2.81	76.38	74.82
Floaters or flashes of light in vision	701	13.58	21	67	2.67	2.38	2.06	74.04	72.18
Costochondritis	676	13.09	14	70	4.11	3.10	2.93	67.01	60.06
Cold burning feeling in lungs	674	13.05	7	62	3.93	3.13	3.07	64.39	70.62
Dry throat	665	12.88	3	58.5	3.26	2.24	2.14	68.42	58.80
Foot pain	655	12.69	28	70	3.80	2.72	2.62	80.61	68.09
Upper back pain	641	12.42	7	77	4.03	3.17	3.02	69.11	62.25
Cracked or dry lips	633	12.26	7	42	2.60	1.46	1.46	60.98	36.02
High blood pressure	627	12.14	14	70	2.89	2.55	2.41	68.58	55.34
Dry or peeling skin	614	11.89	21	56	2.42	1.56	1.55	66.61	29.97
Mouth sores or sore tongue	586	11.35	21	28	3.30	1.84	1.85	46.93	47.10
Feeling of burning skin	579	11.21	16	56	3.69	2.59	2.49	60.28	72.54
Swollen hands or feet	559	10.83	21	70	3.35	2.62	2.40	73.35	63.69
Swollen lymph nodes	541	10.48	7	42	3.12	2.07	1.98	52.87	43.81
Hot blood rush	537	10.40	14	84	3.34	2.38	2.36	70.02	80.63
Low temperature	510	9.88	7	35	2.39	1.82	1.87	53.33	68.63
Bilateral neck throbbing around lymph nodes	489	9.47	14	56	3.66	2.58	2.54	68.92	74.03
Irregular or skipped menstrual cycles	476	9.22	21	77	2.50	1.79	1.84	66.39	42.44
Jaw pain	473	9.16	21	42	3.63	2.30	2.20	58.14	67.23
Covid toes	452	8.75	21	35	3.00	1.96	1.85	50.00	44.91
Spikes in blood pressure	436	8.44	14	77	3.25	2.98	2.76	63.53	74.77

(Continues)

TABLE 2 (Continued)

Symptom	Number of patients reporting symptom	Percentage of patients reporting symptom (%)	Median start date (days)	Median duration (days)	Average pain/discomfort of symptom (1–5)	Average work impairment of symptom (1–5)	Average social impairment of symptom (1–5)	Percentage afflicted reporting symptom as ongoing (%)	Percentage afflicted reporting symptom as intermittent (%)
Bulging veins	429	8.31	42	70	2.36	1.84	1.75	73.43	62.00
GERD with excessive salivation	420	8.13	21	84	3.80	2.68	2.70	77.38	65.48
Painful scalp	383	7.42	21	42	3.35	2.04	2.02	54.57	57.96
Menstrual cycles that are heavier or lighter than usual	381	7.38	21	84	3.09	2.22	2.24	69.55	44.88
Kidney pain	379	7.34	21	35	3.86	2.74	2.60	49.34	67.28
Eye stye or infection	368	7.13	21	14	3.28	2.12	1.93	33.70	32.61
Dry scalp or dandruff	313	6.06	24	84	2.64	1.56	1.71	79.23	28.75
Goitre or lump in throat	296	5.73	21	63.5	3.57	2.45	2.37	65.54	50.68
UTI (urinary tract infection)	279	5.40	28	14	3.87	2.75	2.74	31.54	38.71
Low blood pressure	263	5.09	14	45	3.21	2.92	2.77	61.22	59.70
Kidney issues or protein in urine	256	4.96	21	42	3.28	2.58	2.51	58.59	37.89
Herpes	248	4.80	28	28	3.60	2.71	2.68	52.82	50.40
Personality change (drastic)	229	4.44	21	102	3.78	3.69	3.98	68.12	48.91
Thrush	226	4.38	28	28	3.00	1.95	2.05	33.63	30.09
Syncope	213	4.13	14	14	4.27	3.29	3.15	38.03	62.44
Hormone imbalances	202	3.91	26.25	98	3.42	2.82	2.88	68.32	45.54
Anaemia	169	3.27	21	70	3.00	3.01	2.90	73.96	23.67
Elevated thyroid	141	2.73	42	70	3.02	2.67	2.52	68.79	17.73

Note: Health impact variables include: percentage of participants reporting symptoms, pain and discomfort (e.g. level of distress), ability to work, social impairment, symptom duration, percentage reporting symptoms as ongoing, and percentage reporting symptoms as intermittent.

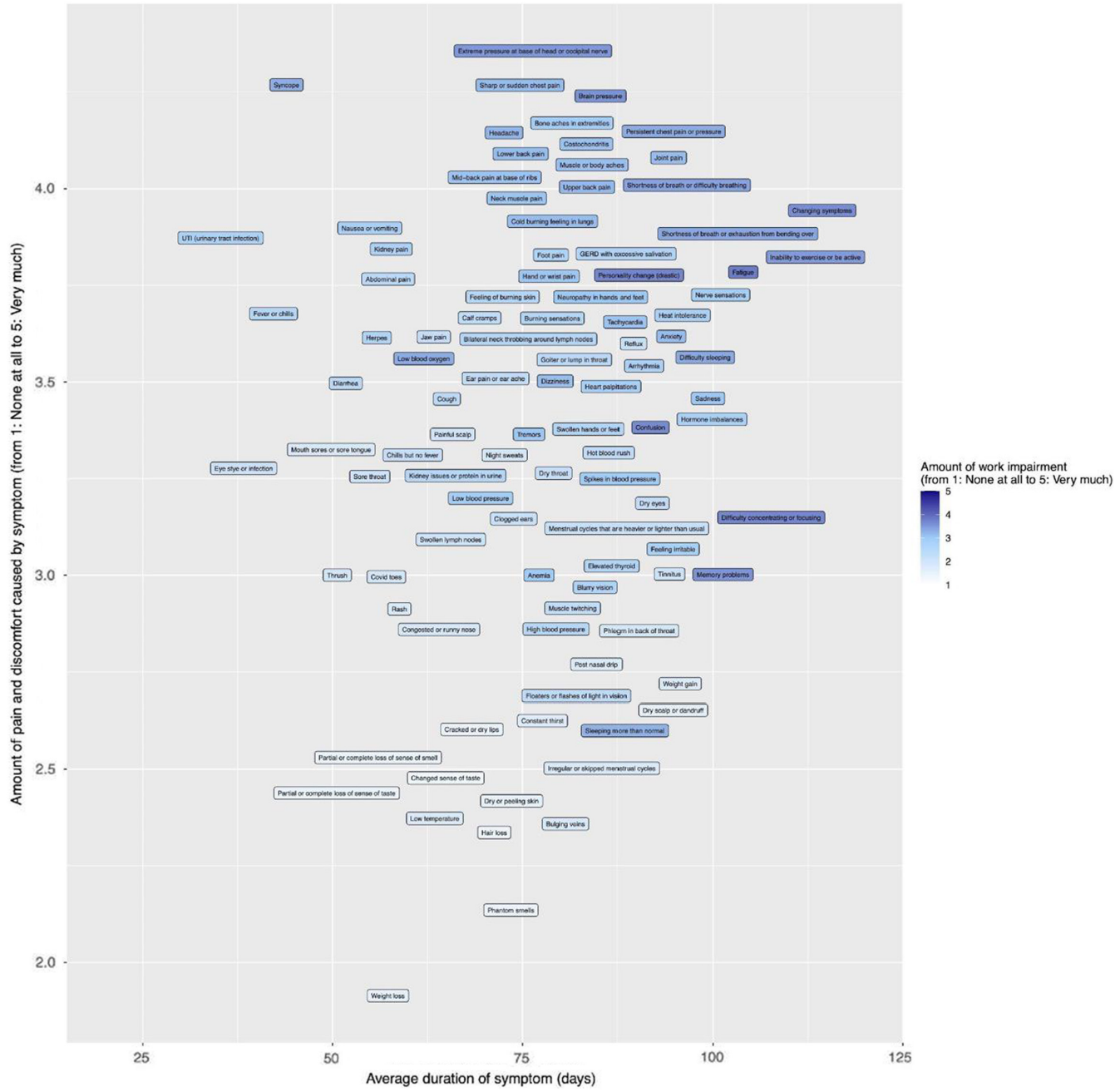

FIGURE 3 Impact of level of distress and duration of symptoms on ability to work among PASC survivors. Graph showing the effect of duration of symptoms (*x*-axis) and level of distress (*y*-axis) on ability to work. Darker shades indicate greater impact on ability to work.

may indicate an evolving process guided by endothelial dysfunction, immune-mediated inflammation, oxidative stress and hormonal imbalance (Leung et al., 2020; Theoharides & Conti, 2020). However, a causal relationship has not been established. These findings align with Huang et al. (2021)'s study of medically documented symptoms from an EHR data set that took a conservative approach with documenting symptom type (only new symptoms at 0–11 days) and establishing the temporal order of symptoms (starting 60 days after a positive SARS-CoV-2 PCR test). We also report the same symptoms as Huang et al. (2021) in which they identified five symptom clusters among non-hospitalised PASC survivors, and the dominant symptoms in those clusters all represented in the top quartile of symptoms reported here. While additional work is needed to validate symptom clusters by time, our findings are consistent with initial evidence of symptom clustering in other work using other datasets and point to consistent pattern of findings. Of note is the changing nature of symptoms, which appears to be a particularly distressing feature among PASC survivors.

Finally, PASC appears to exert variable degrees of impact on individuals such as their ability to work, but mechanistic insight is lacking. Most studies to date have focused on hospitalised patients; however, in our study most participants were never

hospitalised, suggesting that PASC has profound effects, independent of COVID-19 severity. Factors that were reported to have the most impact on participants' ability to work after developing PASC included the relapsing and remitting nature of symptoms, the long duration of many symptoms reported as unresolved, as well as fatigue and symptoms associated with altered cognition or memory impairment. Overall, reported symptoms varied with regards to duration and for their degree of distress, suggesting that a symptom of PASC can cause severe health impact for some and milder impact for others, making PASC an experience that is unique to the individual. Considering the great number and severity of health impacts caused by PASC, future research with PASC patients should endeavour to collect qualitative data characterising the lasting impact on ability to work, maintain social relationships, mental health, as well as basic everyday functioning. Future research could advance the science by examining cluster specific symptoms based on expected timing of onset and grouping symptom clusters by demographics.

The strengths of this study include development of a comprehensive tool for unstructured patient data, beginning with confirmation that these symptoms represented PASC, among the 5163 individuals who have and are continuing to experience symptoms up to a year after SARS-CoV-2 infection (PASC survivors). Participants were able to describe their symptoms and health impact caused by these symptoms in detail, which provides additional richness and insight into symptom sequelae.

There are several limitations of this study, but within the context to what little is known about PASC, we hope this work will be foundation for larger scale studies that rely less on patient recall for data collection. Additional limitations are patient recall of illness and varying times from time of initial diagnosis in which patients completed the survey. Sampling was by convenience, non-probability. It is difficult to determine if study participants were representative of PASC as it occurs in the general population or if these data are representative of survivors most engaged in advocacy and support. Further, generalizability of the findings is limited based on demographics; the sample population was predominantly white, female and non-hospitalised.

5 | RELEVANCE TO CLINICAL PRACTICE

The post-acute sequelae of SARS-CoV-2 (PASC) infection has emerged as a major public health problem. PASC is poorly understood. However, it is clear that PASC does not discriminate and can affect those who were never hospitalised for severe illness. This study provides data on a national sample of 5163 individuals who have and continue to experience symptoms up to a year after SARS-CoV-2 infection. This study advances clinical understanding of PASC symptoms and their impact on human life. Because nurses are experts in symptom management and there is no cure or treatment for PASC, nurse clinicians and researchers play a critical role in helping patients to recover through symptom management and therapeutic communication. Nurses are able to assist patients in managing symptoms using established strategies; nurse scientist can help patients more quickly move towards recovery by leveraging our self-management intervention evidence base and retooling or repurposing our already packaged symptom management interventions for PASC patients (Pinto et al., 2021). Additionally, nurses may assist patients in recovery by helping them manage illness-related health impacts through education and therapeutic communication, including validation of the patient's PASC symptom experience (Pinto et al., 2021). This is of particular importance for patients with this new disease; knowledge is limited and patients have experienced medical gaslighting and trauma when they have sought care for PASC (Pinto et al., 2021). Validating these unpleasant and often traumatising experiences with providers can help restore patient trust and prevent re-traumatization, ultimately increasing better outcomes for PASC patients and increasing the potential for their reengagement with the larger healthcare system (Pinto et al., 2021). In summary, the most distressing symptoms could be addressed by nursing practice and science, and thereby can be targeted immediately for treatment to improve functioning, chance of recovery and quality of life for PASC patients.

ACKNOWLEDGEMENTS

Thank you to Survivor Corps for mobilising many thousands of COVID-19 survivors to participate in research to find a cure for COVID-19, and for being the epicentre of hope for so many. We would like to express our deep gratitude to the thousands of long haulers who spent many hours taking this survey while suffering from the impacts of PASC. The answers we need to cure PASC will come from listening and learning from those who suffer from the disease. We would also like to thank the Precision Health Initiative at Indiana University for their support on this project.

FUNDING INFORMATION

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Lambert, N.; Survivor Corps, El-Azab, S. A., Ramrakhiani, N. S., Barisano, A., Yu, L., Taylor, K., Esperança, Á., Mendiola, C., Downs, C. A., Abrahim, H. L., Hughes, T., Rahmani, A. M., Borelli, J. L., Chakraborty, R., & Pinto, M. D. (2022). The other COVID-19 survivors: Timing, duration, and health impact of post-acute sequelae of SARS-CoV-2 infection. *Journal of Clinical Nursing*, *00*, 1–13. https://doi.org/10.1111/jocn.16541