Illness perceptions in long-COVID: A cross-sectional analysis in adults

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Abstract: Symptoms may persist after an acute COVID-19 infection, a phenomenon termed long-COVID. Increasing attention is now directed toward these long-term effects, as many seem to be affected. So far, long-COVID was primarily discussed from a medical perspective, leaving psychological factors on health-related outcomes understudied. Thus, the present study contributes to the current literature by examining Leventhal’s common-sense model of self-regulation, investigating patients’ cognitive and emotional illness perceptions and their association with different health-related outcomes in the context of long-COVID. We examined 246 long-COVID patients (89.0% female, M_age = 45.29 ± 12.12 years), assessing illness perceptions, fatigue, depressive symptoms, anxiety, and quality of life in a cross-sectional survey study. Linear regression analyses were applied to model the unique effects of the illness perception dimension on health-related outcomes. More than half of the sample had elevated levels of depressive symptoms, anxiety, and fatigue. Illness perception dimensions explained between 28% and 37% of the variance across the analyzed health-related outcomes. More symptoms, higher perceived consequences, and higher emotional representation were related to worse health-related outcomes. In general, long-COVID was poorly understood (i.e., low coherence) and perceived as difficult to control (i.e., personal & treatment control). Health professionals involved in counseling should pay close attention to both cognitive and emotional illness perceptions to address possible ways of coping with long-COVID.

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As of February 12th, 2022, globally, more than 400 million cases of SARS-COV-2 infection (COVID-19) have been recorded. While some patients are asymptomatic or show only mild symptoms, others have developed an aggressive and life-threatening condition that has claimed more than 5 million lives (Dong et al., 2020). Since a large proportion of individuals infected recover within a few weeks, an emerging aspect of COVID-19 is its long-term effects.

Long-COVID is a novel syndrome broadly defined by persistent symptoms following the acute phase of COVID-19. So far, there is no single agreed definition for long-COVID (or post-acute COVID-19); however, the WHO suggests that long-COVID “occurs in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis” (WHO, 2021). Research on long-COVID is accumulating while it appears to be common, persistent,
and disabling, causing a range of physiological, cognitive, and mental disabilities across gender, age, and acute disease severity (Nalbandian et al., 2021; Sykes et al., 2021; Townsend et al., 2020). Recently a meta-analysis of 41 studies, including approx. 1.7 million adult individuals surviving acute COVID-19 infection (hospitalized, non-hospitalized, and general population), estimated the prevalence of long-COVID to be 43%, with female adults having a higher prevalence than male adults (Chen et al., 2022). Prevalence estimates at 30, 60, 90, and 120 days after acute COVID-19 infection were 37%, 25%, 32%, and 49%, respectively. Furthermore, individuals hospitalized during acute COVID-19 had a higher prevalence of long-COVID than non-hospitalized individuals. Thus, care and disease management for many COVID-19 patients do not conclude after acute infection but continue in the outpatient setting. Numerous studies have reported a wide array of persistent symptoms in long-COVID, including fatigue, shortness of breath (i.e., dyspnea), anosmia, cognitive dysfunction, sleep difficulties, headache, cough, and mental health problems (e.g., Cha & Baek, 2021); all generally impacting everyday functioning.

The characteristics of symptoms led some researchers to suggest a connection to a debilitating but also underresearched chronic medical condition: chronic fatigue syndrome (Komaroff & Bateman, 2020). Chronic fatigue syndrome (CFS) is characterized by prolonged, debilitating, and unexplained fatigue, alongside other symptoms including cognitive, sleep, and musculoskeletal problems (Fukuda et al., 1994). Post-infectious chronic fatigue is not new as it has been associated with other (epidemic) infectious outbreaks throughout the twentieth century: e.g., Epstein–Barr Virus, Dengue virus, MERS, and SARS-CoV-1 (Poenaru et al., 2021). Recently, a systematic review has shown that the prevalence of fatigue within the first 6 months of recovery was 42% for self-reported fatigue, and patients in the post-acute stage of COVID-19 were 3.7 times more at risk for onset of fatigue compared to healthy controls (Rao et al., 2022). Research also identified a relationship between CFS and depression, although it remains unclear whether one precedes the onset of the other (Cope et al., 1994). Given the novelty of long-COVID and its unclear and heterogeneous trajectories and lack of treatment, a better understanding of how patients respond to the symptoms and how the subjective conception of the illness relates to different health outcomes is vital.

A common way of conceptualizing and measuring patients’ beliefs about their health condition is by assessing their illness perceptions. Illness perceptions originate from Leventhal’s common-sense model of self-regulation (CSM; Leventhal et al., 1984). According to the theory, subjective perceptions are determined by a specific health threat that shapes both coping strategies and health behaviors that patients adopt. Within the CSM, several dimensions of subjective perceptions of illness are usually distinguished: identity (symptoms ascribed to the illness), duration (perceived illness duration, i.e., acute vs. chronic; also known as timeline), consequences (the impact on personal life), cyclical symptomatology (symptoms are perceived as cyclical/phasic or permanent), personal control (how much the own behavior can influence the illness), treatment control (how much treatment can influence the illness), coherence (how well the illness is understood), and emotional representations (the emotional impact of the illness).

Research has shown that illness perceptions predict health outcomes in a wide range of conditions, including diabetes, cardiac diseases, neurological conditions, cancer, and also in patients affected by medically unexplained symptoms and syndromes (i.e., chronic fatigue; McAndrew et al., 2019). Hagger et al. (2017) found that patients’ illness perceptions, directly and indirectly, impacted different health outcomes. Protective perceptions (i.e., perceived control, coherence) seem related to better illness-related and functional outcomes. Subjective threat-related perceptions (i.e., consequences, identity, duration, emotional representation) had adverse indirect effects on health outcomes through greater use of dysfunctional coping strategies (i.e., denial).

Understanding how illness perceptions and health outcomes in long-COVID are related is vital because affected patients’ illness perceptions might play a key role in their disease adjustment. Given that subjective theories of diseases have a key impact on people’s disease management,
knowing long-COVID-related illness perceptions and their impact on different health outcomes would potentially enable better supporting patients in their coping efforts and psychosocial adjustment.

Thus, the present study aims to a) describe long-COVID patients’ illness perceptions, and b) examine the associations of illness perceptions with symptoms of fatigue, psychological distress (i.e., depressive symptoms & anxiety), and health-related quality of life. In general, we hypothesize that illness perceptions are directly associated with health outcomes, as shown in previous studies (e.g., Hagger et al., 2017). Specifically, we hypothesize that greater severity of consequences (H1), more symptoms (identity; H2), longer duration (H3) & cyclical symptomatology (H4), and higher emotional representations (H5) are related to worse health outcomes (i.e., fatigue, depressive symptoms, anxiety, health-related quality of life). Perceiving higher control (i.e., personal & treatment; H6 and H7, respectively) and higher coherence (H8) is assumed to be related to more favorable health outcomes. Hypotheses were pre-registered after data collection was completed but prior to data analyses (see OSF).

1. Method

1.1. Participants and study design
Recruitment for this cross-sectional correlational study took place between June 2021 and October 2021 via online platforms, such as a long-Covid self-help website, long-COVID support groups on Facebook, and messages on Twitter or LinkedIn. To be eligible for the study, participants had to be at least 18 years of age, ≥12 weeks past COVID-19 infection, currently experiencing persistent symptoms (long-COVID), and sign the informed consent form. The Ethics Committee of the Faculty of Arts and Social Sciences at the University of Zurich, Switzerland reviewed and approved the study (reference number: 21.4.3).

The sample comprised \( n = 246 \) long-COVID patients, with the vast majority being female (89.0%), \( M_{\text{age}} = 45.29 \pm 12.12 \) years (range = 20–83). Two-thirds of the sample were married or in a romantic relationship (65.4%), and 52.4% had children. Most participants had a higher education (54.9%) and were currently employed (82.1%). Slightly more than half of the participants stated that they had no pre-existing conditions (54.1%), whereas 19.5% had two or more chronic conditions prior to COVID-19. On average, the COVID-19 infection was 39.41 weeks ± 17.32 (range = 14–80) before study participation, with 21.5% reporting mild symptoms, 59.3% moderate, and 19.1% severe symptoms. Twenty-nine participants (11.8%) were hospitalized due to COVID-19, whereas only three participants (1.2%) were transferred to the intensive care unit. Two-thirds of the sample indicated having received a vaccination since the COVID-19 acute infection.

1.2. Measures
Illness perceptions were measured with the Illness Perception Questionnaire-Revised (IPQ-R; Glattacker et al., 2009; Moss-Morris et al., 2002). Following the recommendation of Broadbent et al. (2006) to adapt the IPQ to specific illnesses, the word “illness” was replaced with “long-COVID” in all items. Each dimension of illness perception was measured with three items and answered on a 6-point Likert scale ranging from 0 “not at all” to 5 “completely true” (21 items). We included the following dimensions: duration (Cronbach’s \( \alpha = .62 \); e.g., My long-COVID symptoms will last for a long time), consequences (\( \alpha = .67 \); e.g., Long-Covid has a big impact on my life), personal control (\( \alpha = .68 \); e.g., I have the power to control my long-Covid), treatment control (\( \alpha = .66 \); e.g., I can prevent or control the burdensome symptoms through treatments), coherence (\( \alpha = .71 \); e.g., Long-Covid is a mystery to me), cyclical (\( \alpha = .67 \); e.g., My long-Covid symptoms have a phased course, where it is sometimes better, sometimes worse), and emotional representations (\( \alpha = .75 \); e.g., It worries me when I think about my long-COVID). The identity dimension (i.e., subjective illness label) consisted of 37 commonly experienced symptoms reported in long-Covid literature. In addition, participants could specify up to 3 further symptoms in an open format. On a yes/no response format, participants indicated whether they currently experienced and attributed the symptom to their long-COVID
condition. The identity dimension represents the sum of symptoms participants attributed to their long-COVID disease. In addition, participants indicated on a 6-point Likert scale (0 “not at all” to 5 “extremely”) how burdening the respective symptom is for them. The illness perception dimension “cause” was not assessed in the survey as at the time the study was conducted, it was generally recognized that long-COVID is a sequel of the acute COVID-19 infection. Higher scores on the different illness perception dimensions indicate stronger perceptions that long-COVID involves many complaints (i.e., identity), has a long duration (i.e., duration), phasic symptomatology (i.e., cyclical), severely affects the personal life (i.e., consequences), can be controlled by own behavior (i.e., personal control) or medical treatment (i.e., treatment control), elicits negative emotions (i.e., emotional representation), and is understandable (i.e., coherence). Descriptive statistics of the illness perception dimensions, including inter-correlations of study variables, are presented in Table 1.

Fatigue was measured with the Checklist Individual Strength (CIS20; Vercoulen et al., 1994), including 20 items answered on a 6-point Likert scale (0 “not at all true” to 5 “completely true”). All items were first summed (α = .91) and then converted into a percentage in relation to the highest possible score, thus ranging from 0 “no fatigue” to 100 “extreme fatigue”.

Anxiety and depressive symptoms were measured with the Hospital Anxiety and Depression Scale (HADS; Herrmann-Lingen et al., 2011), including 14 items answered on a Likert scale ranging from 0 to 3. A sum score of the seven items (possible range = 0–21) measuring the subscale Anxiety was calculated (α = .81, observed range = 0–19). Depression was also calculated by summing the corresponding seven items (α = .81, observed range = 1–21). Higher scores indicate higher anxiety and more depressive symptoms.

Health-related quality of life was measured with the standardized 12-item Short Form Survey (SF-12; Ware et al., 1996). Two scales were calculated following the official coding scheme: the Physical Component Scale (PCS) and the Mental Component Scale (MCS). The resulting scores were normalized (M = 50 ± 10) against population reference scores; thus, scores above and below 50 are above and below the average, respectively.

1.3. Data analysis
A prior power analysis was performed with G*Power (Faul et al., 2007) for sample size estimation based on published effect sizes in chronic fatigue and depression (i.e., McAndrew et al., 2019). The average variance explained by illness perceptions was reported to be between $R^2 = .30$ to .40, which can be considered high using Cohen’s (1988) criteria.Conservatively, we specified power = .90, effect size ($f^2$) = .20 and alpha = .05. The sample size needed with this effect size was $n = 104$, allowing up to six potential control variables to adjust the model. Power analysis is also presented at OSF.

Statistical analyses were conducted with SPSS 27 (IBM Corp, 2020) and (R Core Team, 2018). First, bivariate associations between study variables were examined using Pearson correlation analyses. Second, following York (2018), we explored potential control variables (i.e., age, gender, number of pre-existing conditions, time since COVID-19, and subjective severity of COVID-19) to adjust our main analyses (presented in Table S1 and S2 in the online supplement). Third, the effects of the illness perception dimensions on different health-related outcomes (i.e., fatigue, anxiety, depressive symptoms, physical quality of life, and mental quality of life) were analyzed by separated multiple linear regression analyses, adjusted for control variables if needed. Additional sensitivity analyses were conducted for the identity dimension by excluding symptoms that overlap with the respective outcome variable (Table S3 in the online supplement).

2. Results

2.1. Descriptive and correlational analyses
On average, participants reported $M = 15.04 ± 5.57$ long-COVID symptoms (range = 3–32). The vast majority of participants experienced fatigue (94%) and difficulties concentration (83%; brain fog; Ellul
| Table 1. Descriptives and inter-correlations of study variables |
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| | M (SD) | abs. range | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Duration | 3.13 (0.95) | 0.67–5.00 | | | | | | | | | | | |
| 2 | | | | | | | | | | | | | |
| Personal control | 3.53 (0.98) | 0.00–5.00 | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| Treatment control | 2.89 (1.22) | 0.00–5.00 | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| Coherence | 1.89 (1.17) | 0.00–5.00 | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| Control | 3.59 (0.96) | 0.00–5.00 | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| Emotional rep. | 3.40 (1.09) | 0.00–5.00 | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| Identity | 15.06 (5.94) | 3.00–32.00 | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| Fatigue | 35.65 (2.53) | 21.18–51.67 | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| Depression symptoms | 8.45 (3.97) | 1.00–21.00 | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| Anxiety | 7.83 (1.98) | 0.00–19.00 | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| PCA | 27.89 (9.55) | 18.12–64.80 | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| MCA | 35.75 (9.96) | 9.55–59.93 | | | | | | | | | | | |

**Note.** Presented values refer to Pearson correlation coefficients \( r \) with the corresponding 95% confidence interval [lower, upper], abs. range = observed range, Emotional rep. = emotional representation; PCS = physical component scale (SF-12), MCS = mental component scale (SF-12). * \( p < .05 \), ** \( p < .01 \)**
et al., 2020). Fatigue was also the symptom perceived as most burdensome (M = 4.34 ± 0.80), followed by difficulties concentration (M M = 4.14 ± 0.85), attention deficits (M = 4.10 ± 0.84), and memory loss (M = 4.02 ± 1.00). Physical symptoms such as headaches (61%), shortness of breath (59%), or joint pain (58%) were mentioned less frequently, and were also described as less burdensome (M = 3.75 ± 0.94, M = 3.67 ± 0.95, M = 3.62 ± 1.15, respectively). Figure S1 (presented in the online supplement) shows all reported symptoms, including the corresponding average burden.

The inter-correlations of the illness perception dimension are presented in Table 1. The perception that long-COVID is a long-standing condition (i.e., duration) was positively associated with perceived consequences (r(246) = .25, p < .001), the number of attributed symptoms (r(246) = .19, p < .001), the emotional impact (r(246) = .36, p < .001), and phased-symptomatic (r(246) = .13, p < .001). In contrast, perceived duration was associated with weaker beliefs that long-COVID symptoms can be controlled, both on a personal level (r(246) = −.33, p < .001) and from treatment (r(246) = −.28, p < .001). In general, indicated by the lower mean values, participants viewed long-COVID as poorly controllable, and the condition did not make sense to them (i.e., coherence). Especially in participants reporting phased-symptomatic, illness coherence was poor (r(246) = −.34, p < .001). In the following, the results of the linear regressions are presented consecutively, while the results are summarised in Table 2.

2.2. Fatigue
On average, moderately high levels of fatigue (M = 56.65 ± 12.35) were observed but the sample was quite heterogeneous as the scores ranged from 15.83 to 81.67. Fatigue was not significantly related to age, gender, number of pre-existing conditions, time since COVID-19, or subjective severity of COVID-19. In total, illness perceptions explained 37% of the variance in fatigue (F8, 236 = 18.54, p < .001). As hypothesized (H1, H2, H4), fatigue levels were higher when participants experienced more consequences in personal life (β = 0.26, p < .001), had more long-COVID symptoms (i.e., identity; β = 0.34, p < .001), and phasic symptomatology (i.e., cyclical; β = 0.18, p = .002). In accordance with the H6, perceiving higher treatment control (β = −0.15, p = .011), but not personal control (β = 0.02, p = .750) was associated with lower fatigue levels. Against the hypotheses, perceived duration (i.e., acute vs. chronic), coherence (i.e., understanding of long-COVID), and emotional representations (i.e., emotional impact) were not associated with fatigue levels. The pattern of results did not change, when symptoms of fatigue were excluded in the identity dimension (see Table S3 in the online supplement).

2.3. Anxiety and depressive symptoms
The literature on the applied measurement (i.e., HADS) suggests that individuals scoring ≥ 8 in one of the two subscales should consult psychiatric evaluation (Wu et al., 2021). In light of this, we observed high average levels of anxiety (M = 7.83 ± 3.98, observed range = 0–19) and depressive symptoms (M = 8.45 ± 3.97, observed range = 1–21) in this sample. Anxiety and depressive symptoms were not significantly related to age, gender, number of pre-existing conditions, time since the COVID-19, or subjective severity of COVID-19. In total, illness perceptions explained 36% of the variance in depressive symptoms (F8, 236 = 18.10, p < .001), and 34% of the variance in anxiety (F8, 236 = 16.39, p < .001).

As hypothesized (H2, H5), anxiety levels were higher in individuals with higher emotional representation (β = 0.38, p < .001) and more long-COVID symptoms (β = 0.35, p < .001). Individuals with a higher perception of personal control (H6), but not treatment control showed less anxiety (β = −0.13, p = .049). Against the hypotheses, duration, consequences in personal life, coherence, and cyclical symptomatology were not associated with anxiety levels.

Long-COVID patients reported more depressive symptoms when they experienced more severe consequences in their personal life (β = 0.34, p < .001; H1), more long-COVID symptoms (β = 0.22, p < .001; H2), and higher emotional representations (β = 0.15, p = .018; H5). The perception of higher treatment control (β = −0.14, p = .019; H7), but not personal control (β = −0.06, p = .379, H6)
Table 2. Results of the linear regression analyses with illness perception dimensions as predictors of different health outcomes

|                | Fatigue | Depressive symptoms | Anxiety | PCS       | MCS       |
|----------------|---------|---------------------|---------|-----------|-----------|
|                | $R^2 = .37$ | $R^2 = .36$ | $R^2 = .34$ | $R^2 = .29$ | $R^2 = .28$ |
| **b**          | 1.66    | 0.04                | 0.04    | 0.07      | 0.16      |
| [95% CI]       | [−1.43, 1.56] | [−0.31, 0.66] | [−0.07, 0.16] | [−0.49, 0.49] | [−0.12, 0.12] |
| **β**          | 1.62    | 0.07                | 0.29    | 0.28      | 0.06      |
| [95% CI]       | [−0.14, 1.57] | [−0.63, 0.24] | [−0.18, 0.07] | [−0.49, 0.49] | [−0.12, 0.12] |
| **R**          | .37     | .36                 | .34     | .30       | .36       |
| **R**          | .37     | .36                 | .34     | .30       | .36       |
| [95% CI]       | [−0.09, 0.21] | [−0.89, 0.01] | [−0.25, 0.01] | [−0.48, 0.23] | [−0.33, −0.08] |
| Intercept      | 25.80   | 1.15                | 0.14    | 0.10      | 0.08      |
| [95% CI]       | [1.01, 1.01] | [0.23, 0.45] | [0.08, 0.24] | [−0.53, −0.11] | [−0.28, −0.04] |
| **b**          | 0.22    | 0.22                | 0.35    | 0.19      | 0.16      |
| [95% CI]       | [0.08, 0.12] | [0.11, 0.33] | [0.17, 0.33] | [−0.31, −0.06] | [−0.28, −0.04] |
| **β**          | 0.32    | 0.32                | 0.32    | 0.32      | 0.32      |
| [95% CI]       | [0.17, 0.46] | [0.24, 0.46] | [0.24, 0.46] | [−0.31, −0.06] | [−0.28, −0.04] |

Note. PCS = physical component scale (SF-12), MCS = mental component scale (SF-12). $R^2$ = adjusted $R^2$ referring to explained variance in the outcome; $b$ = unstandardized regression coefficient, $\beta$ = standardized regression coefficient, [95% CI] = confidence interval. Model PCS was adjusted for the number of pre-existing conditions ($b = −0.60, \beta = −0.07, p = .211)$. $^* p < .05, ^{**} p < .01$
was associated with fewer depressive symptoms. Against the hypotheses, duration, coherence, and cyclical symptomatology were not associated with depressive symptoms. The pattern of results in depressive symptoms and anxiety did not change, when outcome-specific symptoms were excluded in the identity dimension (see Table S3 in the online supplement).

2.4. Health-related quality of life

On average, our sample showed significantly lower health-related quality of life compared to a general public population in both subdimension of the SF-12 (norm M = 50 ± 10). In the physical component scale (PCS), we observed an average of M = 37.89 ± 9.55, and scores ranged from 18.12 to 64.80. In the mental component scale (MCS), we observed an average score of M = 35.75 ± 9.95 and a range from 9.55 to 59.93. Overall, 58.5% (PCS) and 67.1% (MCS) of the participants scored lower than the population norm (50 ± 10) in terms of health-related quality of life. On a bivariate level, PCS was negatively related to the number of pre-existing conditions (r_{246} = -.13, p = .037) but not significantly related to age, gender, time since COVID-19, or subjective severity of COVID-19. Hence, we adjusted the regression model analyzing PCS with the number of pre-existing conditions. In total, illness perceptions explained 29% of the variance in PCS (F_{9, 235} = 11.84, p < .001).

In accordance with our hypotheses, the perception that long-COVID will last for a long time (β = −0.14, p = .028; H3), more perceived consequences (β = −0.36, p < .001; H1), cyclical symptomatology (β = −0.24, p < .001; H4), and more symptoms (β = −0.19, p < .001; H2) were negatively associated with PCS. Contrary to our hypothesis, higher emotional representations were positively associated with PCS (β = 0.28, p < .001). Noteworthy, on a bivariate level, this association was not significant (r_{246} = .02, p = .752), which might point towards a suppression effect. Contrary to the hypotheses, personal & treatment control, and coherence were not associated to PCS. The number of pre-existing conditions was also not significantly contributing to the model.

MCS was not significantly related to age, gender, number of pre-existing conditions, time since COVID-19, or subjective severity of COVID-19. In total, illness perceptions explained 28% of the variance in MCS (F_{8, 236} = 13.02, p < .001). Long-COVID patients who perceived more severe consequences in their personal life (β = −.20, p < .001, H1), had higher emotional representations (β = −0.30, p < .001, H5), and attributed more symptoms to long-COVID (β = −0.16, p = .008, H2) showed lower MCS levels. Perceived duration, cyclical symptomatology, personal & treatment control, and coherence were not significantly contributing to the explained variance in MCS. The pattern of results in PCS and MCS did not change, when outcome-specific symptoms were excluded in the identity dimension (see Table S3 in the online supplement).

3. Discussion

The primary objective of the current study was to shed light on the long-COVID disease from a psychological perspective. To do so, we investigated illness perceptions—the cognitive representations of diseases—of affected individuals and their associations with different physical and psychological health outcomes. Without question, the sample analyzed in this study was heavily burdened by diverse symptoms. About 50% of the sample reported elevated levels of depressive symptoms and anxiety, suggesting the need for further psychological evaluation. Average fatigue levels were not as profound as described in CFS literature (Vercoulen et al., 1994), but 60% of the sample reached levels described as at-risk for work disability (Bültmann et al., 2000). In light of these high prevelances, it is not surprising that the reported average health-related quality of life was also considerably lower than in the general population. While the scientific evidence for effective rehabilitation measures in long-COVID is accumulating (e.g., Rodrigues et al., 2022), patients’ perceptions of the disease should not be neglected. The identification of patients’ illness perceptions provides an opportunity to intervene with the aim of improving disease adjustment and treatment.
Participants in this study reported between 3–32 long-COVID symptoms ($M = 15.04 \pm 5.57$), and as hypothesized, a higher symptom burden (i.e., identity) was consistently related to worse health outcomes: higher levels of fatigue, more depressive symptoms and anxiety, and less physical and mental health-related quality of life. Additional sensitivity analyses revealed that the associations of identity with the respective health-related outcome did not change when symptoms that show a large overlap with the outcome were exluded (i.e., the symptoms “fatigue”, “attention deficit”, “brain fog”, “memory loss” were excluded in the model analysing Fatigue; see online supplement). Nevertheless, the high number of reported symptoms also calls for a critical reflection. Recruitment for this study was mainly conducted in social network groups (e.g., self-help support groups on Facebook), potentially introducing a selection bias. In these groups, long-COVID patients actively shared information about their symptoms and discussed treatment recommendations. Research has shown that seeing another person reporting symptoms can influence the own awareness by increasing the expectations of a similar response (Vägtle et al., 2013). In addition, external sources can induce negative expectations, e.g., explicit warnings about specific symptoms or increased general awareness about possible symptoms (Petrie & Rief, 2019). Such negative expectations can also increase the reporting of adverse outcomes (Kirsch, 1985), which might have been the case in our study. Future studies might want to investigate a possible nocebo effect in symptom reporting by comparing active social media users and non-active social media users in long-COVID.

Participants who perceived long-COVID to be associated with severe consequences for their personal lives had more depressive symptoms, increased fatigue, and lower quality of life. These results replicate previous findings showing that negative views of the consequences relate to more significant emotional distress (Hagger & Orbell, 2021). Together with the high symptom burden, and the general notion that long-COVID is poorly controllable, affected individuals might end up in a downward spiral. Such belief profiles were found to be related to the application of maladaptive coping strategies (e.g., avoidance, denial), leading to not actively seeking help for a condition but potentially retreating to a state of learned helplessness (Hagger & Orbell, 2003). General practitioners, but also the social environment of affected individuals, should listen to these beliefs and offer support, reassurance, and recommendations for evidence-based treatment.

Current results also align with published literature showing that greater concern or worry (i.e., emotional representation) about diseases is related to worse psychological health outcomes (i.e., depressive symptoms, anxiety; e.g., Dempster et al., 2015). While it is important to keep in mind that causality cannot be directly inferred due to the correlational nature of this study, the current findings might emphasize a central role of emotional representations for disease adjustment in long-COVID. Those who expressed greater emotional representation (i.e., worry) perceived long-COVID to be less controllable (personal and treatment control), and they also indicated less understanding of the condition. In contrast, greater worrying was related to more perceived consequences in the personal life, more (cyclical) symptomatology, and the expectation that the condition will persist for a long time. Given the high prevalence of depressive symptoms and anxiety, professional counseling might help patients find strategies to cope with the illness and its impact on daily life. However, many participants in the present study reported in an open question at the end of the questionnaire that they felt rather stigmatized and not taken seriously by medical staff when being referred to see a psychotherapist, as the following quotes indicate: “For me it can't be a psychological problem, I had no reason to be suddenly catapulted out of life like that” (male, 29 years); “Professionals don't take me seriously [...] my symptoms are not due to suppressed psychological problems” (female, 33 years). Thus, general practitioners need to carefully explain the role of psychologists as facilitators for disease management (e.g., structuring treatment options and illness adjustment) while at the same time avoiding making patients feel that their condition is without a physiological base.

Individuals who indicated higher controllability of their symptoms had fewer psychological complaints, but not consistently. While depressive symptoms were lower in individuals with higher treatment control (but not personal control), anxiety was lower in individuals with higher personal control (but not treatment control). The latter is not surprising since lack of personal controllability
is a key symptom of anxiety disorders, particularly of generalized anxiety disorders (American Psychiatric Association, 2013). Regarding the relationship between treatment control and depressive symptoms, participants complained that there were no effective treatments for their condition, leaving many feeling helpless and hopeless. These diverging aspects of controllability in anxiety and depression replicate previous findings in heart failure patients (Morgan et al., 2014) and are also partly in line with meta-analytic evidence (Hagger & Orbell, 2003).

Studies have shown that a chronic perception of disease duration is usually negatively related to adaptive illness outcomes (i.e., psychological well-being, physical functioning) but positively related to unwanted psychological outcomes (e.g., distress; Hagger et al., 2017; Hagger & Orbell, 2003). In the regression models, this hypothesized negative association was only found for PCS. However, bivariate associations emerged as expected: a chronic perception of illness duration was positively associated with fatigue, depressive symptoms, and anxiety but negatively associated with PCS and MCS. Thus, after adjusting for the other illness dimensions, the perceived duration of long-COVID was no longer uniquely contributing to explaining variance in these outcomes (except for PCS), indicating that in this specific context, chronic perception of illness duration’s effects were too much overlapping with the other illness perception effects.

By the nature of the applied method, our survey study has its limitations. Most importantly, no causal inferences can be drawn due to the cross-sectional design. Cross-sectional studies are nevertheless important, especially in new, under-researched areas, as is the case in the context of examining psychological aspects of long-COVID. However, future research should investigate the development of illness perceptions across time, including individual trajectories thereof alongside individual trajectories of reported and diagnosed symptoms, by applying longitudinal research methods. Second, all measures were self-reported, potentially introducing biases, such as social desirability. For measuring subjective illness perception, self-reports are commonly used and well suited (alternatively, illness perception can be operationalized through drawings, see, Broadbent et al., 2019). However, future studies should strive to acquire objective health outcomes (e.g., medical/psychiatric assessments, sedentary behavior measured by accelerometry). Related to the measurement of illness perceptions, the applied IPQ-R measurement reached rather low internal consistency estimates in some dimensions (i.e., duration, consequences, treatment control). This is most likely because each dimension was measured with only three items. Thus, a version with more items would be beneficial in terms of internal consistency. At the same time, it would increase participants’ burden for completing the questionnaire. Particularly in the population of severely burdened persons with long-Covid, we prioritized a shorter, less burdensome measurement over internal consistency. Third, although women (compared to men) seem more likely to develop long-COVID symptoms (Chen et al., 2022), the current sample is disproportionately composed of 89% women. The vast majority of the sample was recruited through social media channels where mainly women contributed. This gender imbalance limits the generalizability of the current results. Future studies should consider other recruitment avenues, such as collaborating with GPs, rehabilitation clinics or psychologists. Finally, although direct associations between illness perception and health outcomes are commonly and successfully investigated, according to the common-sense model of self-regulation (Leventhal et al., 1984), illness perceptions shape coping strategies to respond to and manage health threats. Therefore, the role of coping strategies should be considered in future studies.

Despite these limitations, our study was one of the first to examine patients’ subjective perceptions of long-COVID and health-related outcomes, as suggested in previous studies (Kingstone et al., 2020). Overall, the present study’s findings show that long-COVID impacts affected individuals physically and psychologically, with profound consequences for their daily lives. Furthermore, findings show the importance of cognitive and emotional illness perceptions, explaining a large amount of variance in different health outcomes. In particular, perceiving severe consequences for personal life and excessive worrying are significantly associated with worse health-related outcomes. Finally, most participants stated that long-COVID was a mystery to them, and many felt uninformed and powerless. Physicians involved in counseling should pay
attention to both cognitive and emotional illness perception to detect maladaptive thoughts associated with long-COVID, address negative emotions, and provide patients with a realistic perspective on treatment options.

3.1. Data sharing

Data supporting the current analyses is deposited on OSF and available upon reasonable request from the first author.

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