

# **Patient experiences with SARS-CoV-2: Associations between patient experience of disease and coping profiles.**

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**Authors:** Hendrickson KW, Hopkins RO, Groat DL, Stokes SC, Schroeder FM, Butler JM, Hirshberg EL

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Writing – original draft

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Writing – original draft

Writing – review & editing

Writing – original draft

Writing – review & editing

Writing – review & editing

Project administration

Writing – review & editing

Writing – original draft

Writing – review & editing

<https://orcid.org/0000-0002-3838-2679>

Project administration

Writing – original draft

Writing – review & editing

The Oregon Clinic, Department of Pulmonary, Critical Care, and Sleep Medicine East, Portland, Oregon, United States of America

Department of Psychology and Neuroscience Center, Brigham Young University, Provo, Utah, United States of America

Intermountain Health, Center for Humanizing Critical Care, Murray, Utah, United States of America

Intermountain Health, Division of Pulmonary and Critical Care, Murray, Utah, United States of America

Intermountain Health, Strategic Research, Salt Lake City, Utah, United States of America

Department of Biomedical Informatics, University of Utah, Salt Lake City, Utah, United States of America

Division of Geriatrics, Department of Internal Medicine, University of Utah, Salt Lake City, Utah, United States of America

Informatics Decision-Enhancement and Analytic Sciences (IDEAS), Center for Innovation & Geriatrics Research, Education, and Clinical Center (GRECC), VA Salt Lake City Health Care System, Salt Lake City, UT, United States of America

Division of Pulmonology, School of Medicine, University of Utah, Salt Lake City, Utah, United States of America

University of Macerata: Universita degli Studi di Macerata, ITALY

ellie.hirshberg@mail.org

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Severe acute respiratory syndrome coronavirus 2, (SARS-CoV-2,) caused an influx of patients with acute disease characterized by a variety of symptoms termed COVID-19 disease, with some patients going on to develop post-acute COVID-19 syndrome. Individual factors like sex or coping styles are associated with a person's disease experience and quality of life. Individual differences in coping styles used to manage COVID-19 related stress correlate with physical and mental health outcomes. Our

study sought to understand the relationship between COVID-19 symptoms, severity of acute disease, and coping profiles.

An online survey to assess symptoms, functional status, and recovery in a large group of patients was nationally distributed online. The survey asked about symptoms, course of illness, and included the Brief-COPE and the adapted Social Relationship Inventory. We used descriptive and cluster analyses to characterize patterns of survey responses.

976 patients were included in the analysis. The most common symptoms reported by the patients were fatigue (72%), cough (71%), body aches/joint pain (66%), headache (62%), and fever/chills (62%). 284 participants reported PACS. We described three different coping profiles: outward, inward, and dynamic copers.

Fatigue, cough, and body aches/joint pains were the most frequently reported symptoms. PACS patients were sicker, more likely to have been hospitalized. Of the three coping profiles, outward copers were more likely to be admitted to the hospital and had the healthiest coping strategies. Dynamic copers activated several coping strategies both positive and negative; they were also younger and more likely to report PACS.

Cough, fatigue, and body aches/joint pain are common and most important to patients with acute COVID-19, while shortness of breath defined the experience for patients with PACS. Of the three coping profiles, dynamic copers were more likely to report PACS. Additional investigations into coping profiles in general, and the experience of COVID-19 and PACS is needed.

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<https://orcid.org/0000-0002-3838-2679>

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Our study protocol, IRB approval (IRB # 1051610), and patient consent preclude our ability to publicly share these data. We have appropriately presented the data in aggregate format. De-identified data

may be obtained through approval from the Intermountain Health IRB. Data requests should be directed to Valerie Aston at

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Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), the agent responsible for coronavirus disease 2019 (COVID-19), caused an influx of hospitalized patients with severe, acute disease world-wide [

PACS occurs in adults and children with probable or confirmed SARS-CoV-2 infection, which persists months to years and cannot be explained by an alternative diagnosis [

Individual experiences of disease are influenced by factors such as sex or behavior traits (coping styles) and such characteristics can be associated with a person's experience of disease [

This diversity of presentation makes it crucial to incorporate patient reports to understand the experience and lasting effects of the disease. In addition, evidence based frameworks of stress and coping demonstrate that individuals under stress assess their stressful circumstances, harness internal resources, and engage in coping strategies to deal with stress [

In collaboration with our Patient Family Advisory Council (PFAC) we designed this study. Semi-structured interviews with concept elicitation were used to prompt symptoms experienced before, during, and after hospitalization as well as specific details of the COVID-19 experience, including what occurred during an average day in the hospital for hospitalized patients. Two cohorts of semi-structured interviews were completed. All semi-structured interviews were conducted 2–8 weeks after hospital discharge through a secure web platform including the participant and a member of the research team. A total of fifty-six patients who had a positive SARS-CoV-2 test and a diagnosis of COVID-19 viral illness completed the interviews. Interview exclusion criteria included prior cognitive impairment or significant mental illness impairing ability to participate in an interview, residence in a medical institution at the time of hospital admission, lack of stable domicile and/or not willing to share contact information, incarceration, and known or suspected pregnancy.

Using the semi-structured interview data from the first 26 patients, we designed a survey instrument to assess symptoms, functional status, and recovery in a larger group of patients. This interview data was used to develop a ranking activity to allow patients to identify symptoms that they experienced, their most bothersome symptoms, and symptoms most important to be free from, and ranked a subset of symptoms by the degree to which the symptoms characterized their experience of COVID-19. The online survey also included validated questionnaires; the Brief-COPE to assess coping responses [

### Online survey and study population

Study patients were recruited from national research panels. An ethnically diverse group of COVID-19 survivors, aged 18–85 from around the United States, were recruited. The participants were screened and considered eligible if they reported a positive SARS-CoV-2 PCR and a COVID-19 related healthcare utilization (outpatient primary or urgent care, no hospital, inpatient hospital stay, or emergency department visit). Demographic data included age (grouped 10-year intervals (18–65+), and education level (less than high school, high school/GED, some college, associate degree, bachelor's degree, master's degree, doctorate/professional degree). The survey was administered using the Qualtrics platform, a nationally recognized consumer experience software. The online survey can be found in the Online Data Supplement

### Ethical considerations

The Intermountain Health Institutional Review Board approved the study and all procedures (IRB number 1051610). Informed consent was obtained for all participants prior to participating in the online, semi structured interviews. For the online survey, a cover letter of explanation was included at the start of the Qualtrics survey to inform potential participants that completing the survey implied consent. All data was securely stored using the Qualtrics secure web platform and then transferred to a secure REDCap system database [

### Data and statistical analysis

Participants whose survey responses did not include answers to demographics questions, the Brief-COPE, or SRI questions were excluded from analysis. Participants that repeatedly marked the same answer for each question in the Brief-COPE section of the survey were excluded from analysis. Descriptive statistics were calculated as median (interquartile range) or count (%) as appropriate.

Cluster analysis, employing k-means clustering, was used to identify coping profiles based on patterns of responses to the strategies patients reported using to cope with COVID-19 related stress measured by the Brief-COPE, and quality of social support with person for whom they had close relationships was measured by SRI [

Chi squared test and Fisher's exact test in cases where cell counts were less than 5, were used to test for differences between groups. Prior to performing statistical tests by PACS status and coping profiles, categories for age, gender, race/ethnicity, education, and religion were condensed into fewer categories. Statistical significance was set to 0.05. Due to the exploratory nature of the analyses, we did not correct for multiple comparisons. All statistical analyses were conducted using R 4.0.3.

We recruited a total of 17,271 individuals from the Qualtrics research panels. Of those, 1194 met study inclusion criteria. There were 218 (18%) of the respondents that did not interact with the survey in a meaningful way, resulting in 976 (82%) participants that were included in the analysis

The majority of participants were ages 25 to 54 years (57%), and the most common education levels were high school/GED or some college (47%). Sixty one percent were female, 67% were non-Latino white and 16% were Black/African American with 12% Hispanic/Latino. Most (87%) respondents had health insurance. Fifty percent of participants did not require an interaction with a hospital facility, 27% visited the emergency department (ED), and 23% were admitted to the hospital (general hospital or intensive care unit [ICU])

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Self-reported demographics, n = 976.

Black/African American

Less than high school

Doctoral/Professional Degree

Hospital Inpatient (includes ICU)

The most common symptoms reported were fatigue (72%), cough (71%), body aches/joint pain (66%), headache (62%), and fever/chills (62%). The most bothersome or difficult (or most important) symptoms with the highest frequency were cough (38%), fatigue (32%), and body aches (30%). Twenty nine percent of our cohort reported experiencing PACS (which was described as long COVID on the survey)

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Self-reported symptoms.

Symptoms over entire course of COVID-19 (multiple selections)

Body aches/joint pain

Most bothersome symptoms during course of COVID-19 (up to three selections)

Body aches/joint pain

\*Participants with post-acute COVID-19 syndrome (PACS) self-identified as experiencing long COVID, they did not have to meet the current criteria for PACS definition.

The ranking activity asked participants to rank which symptom best described their COVID-19 experience. The symptom most frequently reported in the position that best describes the COVID-19 experience was shortness of breath (36%)

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Symptoms that best described the COVID-19 experience for A) entire cohort B) by post-acute COVID-19 syndrome (PACS) status.

#### Participants with PACS

Of participants with self-reported PACS, 64.4% (183/284) had a time interval between their positive COVID-19 test and when they took the survey of 90 or more days which meets the current criteria for PACS [

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#### Demographics by PACS status.

Acute COVID-19 only, n = 692

#### Hospital Inpatient (includes ICU)

The most common symptoms overall for the PACS group were similar to those reported by the entire cohort; however, symptoms of chest pain (49% compared to 32%; P<0.001), shortness of breath (57% compared to 42%; P<0.001), gastrointestinal issues (28% compared to 18%; P = 0.001), body aches/joint pains (73% compared to 63%; P = 0.006), trouble sleeping (33% compared to 26%; P = 0.04), and cognitive symptoms (46% compared to 25%; P<0.001), were reported disproportionately by respondents who reported PACS compared to those without PACS. Chest pain (24.6% compared to 13.3%; P < 0.001), GI symptoms (12.0% compared to 7.4% P = 0.03), and cognitive impairment (16.2% compared to 8.7%; P = 0.001), were reported most bothersome at higher rates by participants with PACS compared to those without PACS

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#### Symptoms by PACS status.

Acute COVID-19 n = 692

#### Symptoms over entire course of COVID-19 (multiple selections)

Body aches/joint pain

Brain fog (cognitive impairment)

Most bothersome symptoms during course of COVID-19 (up to three selections)

Body aches/joint pain

### Brain fog (cognitive impairment)

Based on the ranking activity, the symptoms best describing the participants overall COVID-19 experience were different between participants with PACS and those without PACS ( $P<0.001$ ). Participants with PACS reported shortness of breath at a higher rate and cough at a lower rate than non-PACS respondents

### Coping profiles and patterns of coping

Silhouette analysis based on misclassification rates from discriminant analysis identified three clusters as the optimal number of groups.

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Normalized average scores for brief-COPE and SRI by cluster.

Brief-COPE subscales include self-distracted (SD), active coping (AC), denial (Den), substance use (SU), emotional support (ES), instrumental support (IS), behavioral disengagement (BD), venting (Ven), positive reframing (PR), planning (Pla), humor (Hum), acceptance (Acc), religion (Rel), and self-blame (SB). Subscales for SRI include helpful (Hel), upsetting (Ups), and unpredictable (Unp).

### Coping profiles—Demographics and symptoms

Outward copers were characterized by female gender, white race, aged 55 plus, education beyond high school and very religious. Inward copers were nearly equally split between education levels. However, inward copers, also contained a higher proportion of patients reporting white race, those reporting no religiosity, and having received care outside of the hospital setting during their original illness. Dynamic copers when compared to inward and outward copers, were younger, male gender, belonged to a racial or ethnic minority, college graduates, and more likely to have visited the emergency department or be admitted to the hospital during their COVID-19 illness

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### Demographics of coping profiles.

Symptoms also differed by coping profile. In selections of symptoms experienced (multiple selections permitted), the top five most common symptoms reported across all three coping profiles, although ranked differently by the profiles, were cough, body aches/joint pain, fatigue, fever/chills, and headache. When investigating symptom reports by profile, a higher proportion of outward copers reported symptoms in each of these 5 symptom groups (70%-88%) dynamic copers reported each of these 5 symptom groups in the lowest proportion (51%-60%), and inward copers reported each of these 5 symptoms groups at intermediate levels (61%-78%).

Dynamic copers reported that chest pain was a bothersome symptom at higher rates (25%) compared to outward or inward copers ( $P<0.001$ ). A higher proportion of outward copers reported fatigue (39%) and shortness breath (27%) as bothersome compared to dynamic and inward copers. Dynamic copers reported PACS at a higher rate than either inward or outward copers (36%;  $p = 0.005$ )

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Symptoms by coping profiles.

Symptoms over entire course of COVID-19 (multiple selections)

Body aches/joint pain

Most bothersome symptoms during course of COVID-19 (up to three selections)

Body aches/joint pain

Post-acute COVID-19 syndrome

All coping profiles ranked shortness of breath as the symptom that best defined their COVID-19 experience. Dynamic copers indicated that chest pain best characterized the COVID-19 experience at a higher rate than the other two profiles. However, inward and outward copers chose cough and fatigue at higher rates when compared to dynamic copers when asked about symptoms that described their COVID-19 experience

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Symptoms that best described the COVID-19 experience by coping profiles.

This study contributes to the growing body of literature describing both acute and chronic symptoms of COVID-19 in an ethnically and racially diverse group of Americans. We uniquely centered the experience of COVID-19 around participant prioritized symptoms and explored how coping profiles related to the experience of COVID-19 disease and PACS. The most common symptoms reported by our diverse cohort were cough, fatigue, and body aches/joint pains. PACS was reported by 29% of our cohort and those who reported PACS were more likely to be bothered by chest pain and brain fog than participants without PACS. Importantly, participants with PACS were also more likely to report being hospitalized (including ICU) or visiting the emergency department than those who did not report PACS.

The most common symptoms overall for the PACS group were like those reported by the entire cohort; however, symptoms of gastrointestinal issues, trouble sleeping, and cognitive symptoms were all more likely to be reported by individuals with PACS than those without PACS. Interestingly, patients with PACS ranked fatigue as a bothersome symptom less frequently than those who reported acute COVID-19 recovery (i.e., those who did not report PACS). This is in contrast to other reports of non-hospitalized patients with PACS who reported anosmia, fatigue, and shortness of breath as persistent symptoms [

We also found three distinct coping profiles (inward, outward, and dynamic) based on the Brief-COPE and the SRI and explored how coping profiles related to the COVID-19 experience. Symptom patterns were relatively similar across coping profiles with all profiles reporting the same top 5 symptom groups within the coping profile. Chest pain was disproportionately to be reported most bothersome by dynamic copers compared to the other two profi

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## Citation

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