



Research article

Capturing the emotional and social experiences of COVID-19 through journal entries: A qualitative study of COVID-19 experiences over six weeks following infection

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ABSTRACT

COVID-19's wide-ranging effects on patients' physical health are well-documented, but comparatively less research has explored the impact on patients' emotional and social experiences. We examined how patients across a multi-state health system experience the emotional and social aspects of COVID-19 during the first six weeks of recovery from infection. We leveraged the larger My COVID Diary project to capture open-ended journal data from an app-based platform available to patients who test positive for COVID-19 within the health system. Our sample was limited to participants with multiple journal entries during the first six weeks after infection, with one entry in the top 5% of all participants for word count to ensure sufficient journal content was available for analysis. We randomly selected 100 eligible participants and coded and analyzed all of their journal entries in weeks 1–6 after infection, utilizing a thematic analysis approach. Despite journal entry prompts' orientation towards physical symptoms, the majority of participants discussed emotional experiences (such as anxiety, depression, and gratitude) and social factors (such as work and family) when describing their COVID-19-related experiences. Physical, emotional, and social experiences related to COVID-19 infection and recovery were often interconnected and overlapping. These findings demonstrate that a holistic understanding of the patient experience that extends beyond physical symptoms is necessary to fully support patient care and recovery.

1. Introduction

Since February 2020, more than 103 million cases of COVID-19 have been recorded in the United States (U.S.) [1]. The acute clinical manifestations of COVID-19 and post-acute sequelae of these millions of infections have been well-studied and found to span nearly every major organ system [2,3]. While COVID-19's wide-ranging effects on patients' physical health are well-documented, less research has focused on patients' emotional and social experiences. More recent research is starting to shed light on the multiple ways that COVID-19 infection impacts not only patients' physical health but also their emotional wellbeing [4]. Studies of hospitalized

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COVID-19 patients have found that their emotional experiences range from feelings of fear, denial, and stigma to loneliness, uncertainty, and worry to acceptance, gratitude, and personal growth [5–10]. An outpatient study found that patients' psychological experiences include depression, anxiety, irritability, frustration, isolation, and worry [11].

Other research has begun to explore the far-reaching effects of COVID-19 infection on patients' daily lives, economic wellbeing, and social support networks. Disruption to patients' daily lives is a common effect of COVID-19; one study found that six weeks after symptom onset, 32% of respondents were unable to live without assistance, 64% were unable to perform their usual activities, and 90% avoided usual activities and duties [12]. Other studies have found that economic insecurity and financial hardship feature prominently as part of patients' larger worries for the future [13–16]. Support from patients' families, social networks, and medical staff can mediate their psychological experiences [5,8,9], but infection can also negatively impact patients' social roles in areas such as their daily lives, their professions, their families, their social activities, and their relationships with care providers [17]. Further, researchers have started to conceptualize how these experiences might better inform treatment provided to COVID-19 patients, with one recent study suggesting that continuity of care, from hospital to home, is necessary to address the psychological distress caused by COVID-19 [18].

Existing qualitative research on the non-physical patient experience is often limited to data collected early in the pandemic (early 2020) when anxiety associated with COVID-19's novelty was particularly high, focused on international locations (outside of the U.S.), or restricted to hospitalized patients; these studies also typically utilized a retrospective study design or were limited to small sample sizes [9,16,19–21]. Therefore, the aim of this study was to use a prospective study design that focuses on patient experiences throughout the first few years of the COVID-19 pandemic to better understand the emotional and social impacts of COVID-19 in the U.S. This understanding is potentially of special importance for nurses, clinicians, and policy makers who are developing and updating COVID-19 best practices as infection rates remain high in the U.S. [1], new variants continue to emerge [22], and previously infected patients continue to navigate post-acute sequelae [23].

1.1. Study rationale

In this study, we leveraged the ongoing My COVID Diary (MCD) research project based out of a large integrated U.S. health system that spans seven states in the western U.S. MCD uses a mobile app-based platform to provide participants with structured questionnaires and the opportunity to share open-ended journal (text) responses to prospectively monitor the patient experience of individuals infected with COVID-19. Journal entries provide a unique lens into patients' lives by supporting ongoing data collection to capture experiences over multiple timepoints and contemporaneous reflection to minimize recall bias, while also providing time for contemplation that interviews might not allow [24]. The aim of this study was to understand and describe the emotional and social experiences of individuals who contracted COVID-19 over the first six weeks of infection using journal entries written in their own words to understand participants' complex and interconnected experiences. This study contributes to our understanding of COVID-19 by further expanding knowledge of the patient experience beyond physical symptoms, and it provides insight for nurses, clinicians, and health systems to better deliver holistic patient-centered care for COVID-19 patients during both initial infection and recovery.

2. Methods

2.1. Study design

The present study utilized data gathered prospectively through the larger MCD research project, which sends participants closed-ended and open-ended questions at regular intervals through an app to track their COVID-19 symptoms and experiences over time [4,25]. This study utilized the open-ended data gathered through MCD, referred to as journal entries.

2.2. Participants & recruitment

Study participants were individuals 18 years or older who tested positive for COVID-19 via a nucleic acid amplification test at a hospital or outpatient location within the health system's seven state footprint. When a patient tests positive for COVID-19 at a facility within the health system, they are automatically invited to participate in MCD. As of October 2022, 18,462 individuals had enrolled in MCD, representing 12% of the total number of patients invited to participate, and 27% of invitees who viewed the invitation message. Our sample was limited to participants with more than one journal entry over their first six weeks of infection; a six-week period was used to capture participants' experiences with quarantine, possible hospital or ICU admission, likely recovery from acute illness, and probable re-engagement in social activities. Our sample was further limited to participants who wrote at least one entry in the 95th percentile of journal length (at least 72 words long) to ensure that adequate context was provided related to the emotional and social experiences associated with COVID-19 illness and recovery ($n = 2231$). We then randomly selected 100 participants who met these criteria and analyzed all their journal entries (regardless of length) in the first six weeks following their infection.

2.3. Data collection

The invitation to participate, consent, and all subsequent data collection occurred through the MCD app on a participant's mobile device. Data collection for MCD began in August 2020 and will continue until July 2024. Participants received journal prompts every two days for the first two weeks, weekly from week 3–13, and then once a month for the rest of the year. On day one, participants

received two prompts: 1) “what were your first symptoms?” and 2) “please journal, in as many or as few words as you’d like, the problems you’ve been experiencing over the last few days. It may help to think about your body from head to toe. a. What is new? b. What has gotten worse? c. What has gotten better? d. What hasn’t changed? e. Are you having emotional challenges? How is your personal and work life?” After the first day, participants received only the second prompt. Participants were free to respond however they felt appropriate; there were no instructions in terms of what information or level of detail to provide. Additionally, researchers could not follow up with individual participants for additional information or clarity. For the population included in this study, the data collection window was approximately August 2020 to February 2022. This study focused on journal entries collected over the first six weeks post infection (see [Supplementary Table 1](#) for the complete list of questions asked through the MCD app).

2.4. Data analysis

Journal entries were coded using Atlas.ti version 22. A thematic analysis approach was used to code and analyze the journal entries [26,27]. Our coding approach was a three-step process. First, the codebook was developed using a mixed deductive and inductive process; deductive development leveraged an existing codebook created for another portion of the MCD study, and inductive codebook development incorporated new codes that emerged when reviewing a subsample of the journal entries. Second, we ensured reliability between coders: all journal entries for 15 participants were coded by two members of the research team and intercoder reliability was found to be high. This ensured reliability when independently coding the remaining journal entries, which were divided between the two research team members. The third step involved regular analysis meetings, where the research team iteratively updated the codebook and code definitions using consensus-based decision-making, discussed code use, and examined emerging patterns based on code prevalence and the overlap between codes. Overlap between codes was determined by the frequency of code co-occurrence after coding. Any changes to the codebook made during these meetings were then applied to all previously coded journal entries.

Our analysis used a theoretical approach [26] driven by our research question and focused on exploring the most prominent emotional codes, social codes, and code family intersections, although coding entailed additional codes and code families not discussed in this manuscript (see [Supplementary Table 2](#) for the complete codebook). Each code and all associated quotations were reviewed and grouped by theme. Themes were reviewed by the research team and verified by checking them back against the data.

2.5. Ethical considerations

The full study protocol was approved by Providence St. Joseph Health Institutional Review Board (IRB# 2020000467) on July 17th,

Table 1
Sample characteristics.

	Sample Characteristics (n = 100)	Population Characteristics ^a (n = 2231)
Age (%)		
18–29	14%	402 (18%)
30–49	45%	953 (43%)
50–64	32%	593 (27%)
65+	9%	283 (13%)
Race/Ethnicity (%)		
Asian	3%	65 (3%)
Black	0%	42 (2%)
Hispanic/Latinx	18%	282 (13%)
Multiracial	6%	145 (7%)
Other	1%	60 (3%)
White	68%	1533 (69%)
Missing	4%	103 (5%)
Sex (%)		
Female	79%	1688 (76%)
Male	20%	461 (21%)
Other	0%	2 (<0.1%)
Missing	1%	80 (4%)
First Sick Date (m/d/y)		
Date range of when first sick	8/7/20–1/17/22	6/30/20–2/1/22
% Participants who Submitted Journal Entries by Sick Week		
Week 1	58%	50%
Week 2	89%	88%
Week 3	76%	79%
Week 4	52%	57%
Week 5	43%	41%
Week 6	31%	35%
Ave Length of Journal Entry (words)		
Ave number of journal entries per participant over first 6 weeks	7	7
Ave length for individual entry	58	54
Ave length for all journal entries submitted per participant	374	354

^a Population corresponds to participants who wrote at least one journal entry in the 95th percentile of journal length (at least 72 words long).

2020 and conformed to the principles of the Declaration of Helsinki. All participants were informed of the voluntary nature of the study and their right to withdraw at any time with no consequences for their ability to receive care from the health system. Written informed consent to participate was obtained through the MCD app for all participants. Data were handled confidentially and anonymously.

3. Results

3.1. Participants

Sample characteristics are displayed in Table 1. Most of the sample was under age 50 (59%), White (68%), and female (79%). The randomly selected 100 participants first tested positive for COVID-19 between August 2020 and January 2022, and they submitted journal entries between the date they first tested positive and six weeks later (August 2020 to February 2022). Journal entries were submitted by participants across all six weeks, although more participants submitted entries in the second (89%) and third (76%) weeks following their first sick date. On average, participants submitted seven entries over the first six weeks. The average journal entry length was 58 words and average cumulative number of words across all of their individual entries was 374. The characteristics of our sample largely mirror those of all respondents in the 95th percentile of journal length.

3.2. Themes

Our analysis identified two main themes: in addition to physical symptoms related to COVID-19 illness and recovery, participants also 1) experience a variety of emotions related to COVID-19 and 2) have social factors that influence their COVID-19 illness and recovery. Additionally, our analysis highlighted that these themes are often overlapping and co-occurring. Each of these themes is detailed below along with examples of their overlapping nature, and this information is summarized in Table 2.

3.2.1. Theme 1: participants experience a variety of emotions related to COVID-19

First, we were interested in whether people talked about emotions in their journal entries regardless of the prompts provided in the app, which focused primarily on physical symptoms, but did include a reference to emotional challenges at the end of one prompt. The term “emotions” is used here to encompass psychological experiences related to subjective feelings (“I feel anxious”), physiological responses (“my anxiety is making my heart race”), and behaviors (“I can’t stop pacing because I’m so anxious”) reported by participants. Over three-quarters (78%) of the sample mentioned at least one emotion associated with COVID-19 illness and recovery; the most common emotions mentioned were expressions of anxiety, isolation, depression, gratitude, and frustration. Entries that discussed emotions did not talk about them independently; many of the emotion mentions overlapped with other emotions (when participants said things such as “I’m frustrated because I’m lonely”) and/or discussions of physical symptoms (when participants said things such as “I’m depressed because of my cough”). Although emotions were discussed throughout the first six weeks, more emotions were shared during the first three weeks following MCD enrollment (data not shown). Below we summarize the most commonly mentioned emotions and highlight examples of where emotions overlapped.

Expressions of Anxiety. Many participants expressed feelings of anxiety by using words such as anxiety, concern, worry, and fear related to their COVID-19 illness and recovery. They talked about concerns regarding specific physical COVID-19 symptoms, symptoms that lingered, fear about not surviving COVID-19, getting COVID-19 again, and exposing others to COVID-19. Participants also expressed worry about when and/or whether they will be able to return to normal life and activities, expressing doubt that they may not ever return to what was normal before COVID-19.

“Getting very anxious over being so sick and not feeling improvement...3 weeks today..a very long time to feel so poorly.”

Expressions of Anxiety and Isolation. Expressions of anxiety and feelings of isolation were often expressed together, particularly when describing the emotional toll of being alone in quarantine or how being with the same person for an extended period weighed on their emotional health.

Table 2
Theme summary.

Theme	Subtheme	Overlapping Subthemes ^a
Participants Experience a Variety of Emotions Related to COVID-19	Expressions of Anxiety	Overlap with Isolation
	Isolation	Overlap with Expressions of Anxiety and Expressions of Depression
	Expressions of Depression	Overlap with Isolation
	Gratitude	Overlap with Isolation and Expressions of Depression
	Frustration	Overlap with Isolation and Expressions of Anxiety
Social Factors Impact COVID-19 Illness & Recovery	Work	Overlap with Gratitude and Expressions of Anxiety
	Family	Overlap with Gratitude, Expressions of Anxiety, and Isolation
	Other Social Factors	Overlap with Gratitude, Expressions of Anxiety, and Isolation

^a The subthemes named in this column are areas of significant overlap, but all subthemes had at least one instance of co-occurrence with all other subthemes, highlighting the complexity of the COVID-19 patient experience.

“It has been difficult to remain isolated from my family especially on Christmas. I am staying in my room so I wasn’t able to be with my husband or children. I have been feeling anxious and sad.”

Isolation. Feelings of isolation were described with words such as isolated, quarantine, alone, separated, no contact, and stuck in room/house. Participants experiencing isolation spoke about it both physically and socially. Physical isolation was related to the required quarantine period where they could not be around others and living in a separate space away from housemates and loved ones. Social isolation included separation from their social support network (e.g., loved ones, friends, society at large) and missing social gatherings and events (e.g., birthday, holidays, funerals).

“I am emotional about the isolation. Talking and receiving notes from my kids through my bedroom door is heartbreaking.”

Isolation, Expressions of Anxiety, and Expressions of Depression. Isolation was frequently coupled with expressions of anxiety and/or depression (e.g., stress, worry, boredom, irritability, and crying more easily).

“Being isolated for so long, having low energy, and now stricter restrictions, there’s not much to look forward to. Feels like the movie *Groundhog’s Day* - every day a repeat of the last. That’s probably making me feel more lethargic than is warranted.”

Expressions of Depression. Participants used words like sad, joyless, hopeless, defeated, and drained to describe their experiences and feelings related to depression. Others mentioned crying or feeling like crying to signify how they were struggling with COVID-19 illness and recovery. Others talked about not having much to look forward to.

“My biggest issue now is depression. My progress is so slow it is difficult to know if I am making progress at all. At this point I don’t think that I will be 100% before December. That is depressing for me because I am a very active person who loves to surf and stand up paddle.”

Expressions of Depression and Isolation. Similar to expressions of anxiety, many participants talked about depression and isolation together: depressed that they must isolate and have limited or no social interactions.

“My depression has gotten worse, due to me being such an active/social person and having to sit inside and wait for it to go away is upsetting.”

Gratitude. Although many emotions expressed in the entries carried a negative connotation, some people did share expressions of gratitude during COVID illness and recovery. Words like grateful, thankful, blessed, incredible, helps that, and positive were included in this emotion. Gratitude related to lessening or resolution of physical symptoms or feeling lucky that they had a relatively mild case of COVID-19 was common. Participants also expressed gratitude when they were able to return to normal activities.

“I am thankful I managed to avoid complications and hospitalization. [...] Day 11 finally felt like a normal person again, taste and smell returned just in time for Thanksgiving dinner! Still some fatigue but was still able to cook pumpkin donuts and pumpkin pie.”

Gratitude, Isolation, and Experiences of Depression. Expressions of gratitude also followed descriptions of other emotions, like isolation and depression. For instance, participants would share challenging situations and close out the entry with a reason they were grateful.

“I’m missing my usual social life. But physically, I feel lucky.”

Frustration. Often participants used words such as frustrated, mad, irritable, cranky, angry, and impatient to describe feelings of frustration related to COVID-19 illness and recovery. Feelings of frustration were occasionally directed at someone (e.g., “so mad that my partner got me sick”), directed at a physical symptom (e.g., “I’m frustrated that I’m in pain”), or were indirect (e.g., “I’m just so mad to have to deal with this”). Participants also expressed frustration when they could not complete normal activities, such as exercising, household chores, caregiving, or work.

“Over the last few days the only problems i’ve been having are emotional ones. i’m overwhelmed and very stressed with everything. it feels like everything irritates me and even the smallest thing can trigger my anger at times.”

Frustration, Isolation, and Experiences of Anxiety. Frustration was often coupled with expressions of isolation and anxiety.

“I’m very irritable and frustrated. I can’t even use the time in isolation to complete home tasks or projects.”

3.2.2. Theme 2: social factors impact COVID-19 illness & recovery

Next, we explored how social factors were discussed in the journal entries regardless of the prompts provided in the app, which focused primarily on physical symptoms, but did include a reference to participants’ personal and work lives. Social factors were mentioned by 81% of participants during COVID-19 illness and recovery; these mentions had both positive and negative connotations. Like emotions, social factors were not mentioned independently of other COVID-19 symptoms and experiences. In fact, many of the social factor mentions overlapped with discussions of emotions (when participants said things such as “I’m nervous that my coworkers will judge me for getting COVID”) or physical symptoms (when participants said things such as “Because of my fatigue, I’m more dependent on my family for help”). Social factors were most frequently mentioned in the first three weeks of illness (data not shown). Below we describe the three most common social factors described and identify places where these factors overlapped with emotions.

Work. Some participants talked about having to miss work due to COVID-19 illness, but this took on different forms depending on accommodations available within their workplace.

Work and Gratitude. Some participants were able to work from home, and, of those participants, some mentioned gratitude for workplace policies that allowed them flexible working locations and schedules while recovering from COVID-19. This was especially important for participants who described challenges related to cognitive and physical fatigue that made it difficult to return to normal work performance.

“Today, since I feel horrible, I will be taking the rest of the day off. My supervisor is amazing. Phenomenal.”

Work and Expressions of Anxiety. Some participants described more constraining workplace policies and unaccommodating co-workers and managers, where they felt pressure to return to work before they were ready or fully recovered. Mentions of work often co-occurred with expressions of anxiety related to going back to work. This included feeling anxiety about exposing colleagues, potential performance issues, and feeling stigmatized by other coworkers for getting COVID-19. A few participants also expressed financial anxiety because they had been isolating and not working for a period of time.

“I am afraid to return to work as I work directly with the public. I am positive that is where I contracted the virus even though we are both vaccinated. My boss seems very cavalier about Covid-19, even though we have had numerous staff test positive before opening and now me after. No public announcement was made. Numerous staff people are not masking and we cannot require masks.”

Family. Family and loved ones were defined broadly and included participants’ spouses and partners, significant others, children, parents, siblings, and grandparents. Interactions with family members were both positive and negative.

Family and Gratitude. On the positive side, family members cared for participants and provided them with food and for their basic needs while sick. Family co-occurred with mentions of gratitude, as participants felt lucky and grateful for the presence of their family and the support they provided during challenging times. Some participants’ whole households got COVID-19 at the same time; for these individuals being sick together provided comfort since no one had to isolate or be separated.

“My whole household is sick and I think that is less stressful, it would be harder if some of us were negative. I have full confidence that everyone in my household will come through this just fine in the end. All of us have had relatively mild symptoms.”

Family, Expressions of Anxiety, and Isolation. On the negative side, participants described challenging interactions with family members, such as being exposed to COVID-19 by family, fear of exposing family members, and feeling pressure from family members to keep up with normal household duties while sick. Additionally, participants described sadness and grief when being separated from family in order to isolate.

“Mad and frustrated to be dealing with this. My spouse exposed me and I’m so mad at him. He thinks it’s no big deal (he’s positive too) with cold like symptoms. He thinks this is just a cold. He won’t let me rest and I have a young child to take care of too.”

Other Social Factors. About a third of participants mentioned other social factors, including friends, religion, and unspecified social interactions (e.g., vague mentions of social support that did not identify the support group, such as “food was dropped off”).

Other Social Factors and Gratitude. These other social interactions provided emotional support and encouragement through phone calls and text messages, helping participants navigate COVID-19 illness and recovery.

“I still keep in contact with people in my personal life via FaceTime and text and have had a lot of support and people who will drop stuff off for me which helps me stay motivated.”

Other Social Factors, Expressions of Anxiety, and Isolation. Some participants expressed disappointment with friends that did not stay in touch when they got sick or when friends demonstrated signs of stigmatizing or judging the participant. Participants with these experiences expressed feelings of anxiety and isolation.

“I also noticed my friends were not good about keeping in touch with me during my quarantine. Which made me feel worse! I felt like they all thought I was a lepper! Like I did this to myself!”

4. Discussion

Using participants’ free-text journal entries, this study sought to understand and describe the emotional and social experiences of individuals who contracted COVID-19 during the first six weeks after their infection. Although the provided journal prompts were largely focused on physical symptoms, they did mention emotional challenges and personal life or work impacts. Participants could share whatever was on their mind regarding their current experience with COVID-19, which provided a unique opportunity to understand the evolution of disease symptoms (physical and emotional), as well as the holistic impact of COVID-19 as participants discussed their experiences navigating societal dynamics, the workplace, and daily responsibilities.

4.1. Implications for health care delivery

Our study found that participants experience complex emotions and social factors in addition to physical symptoms during COVID-

19 illness and recovery. This aligns with one of the few U.S.-based qualitative outpatient studies conducted by Rofail et al., which found that the impact of infection was “not attributed to any singular symptom ... but rather to the holistic experience of COVID-19 infection” [11]. Furthermore, these complex emotional and social factors often appear simultaneously and have both positive and negative elements that co-occur (such as when participants said things like “It’s frustrating to not be able to run yet, but I’m grateful I can start to do household chores” or “I’m sad to be isolating away from my partner, but my family and friends have been so supportive”), which highlights the complexities of the patient experience navigating COVID-19 infection. Researchers have started to conceptualize a framework for how emotional and social experiences might be connected; in a meta-analysis of COVID-19 qualitative research, Zhang et al. identified five interrelated themes highlighting the psychological challenges and changes patients experienced: complex psychological course, impact of the disease on the body, expectations of support, coping strategies, and post-traumatic growth [18]. This framework is further supported by our study, which demonstrates that even when journal prompts were primarily oriented towards physical symptoms, patients also describe their emotional and social experiences. Additionally, a qualitative outpatient study in Canada by Dainty et al. found that patients with relatively mild cases of COVID-19 who were contacted by health care and public health officials were appreciative of the phone calls they received from physicians, but they often did not receive answers to their questions or consistent information from different sources, which further contributed to feelings of anxiety [28]. Taken together, these findings support the need for a whole-person approach to supporting COVID-19 recovery that centers patients’ emotional and social needs in the treatment approach. This is particularly informative for nurses, clinicians, and those creating treatment plans for COVID-19 patients.

Our findings also suggest that social networks may influence an individual’s experience of COVID-19 illness and recovery, which is important considering that most of the data was collected when policies were in place to reduce the spread of COVID, such as stricter quarantine practices and limited social interactions. Although our study was not able to explore the association between social support and improved outcomes for COVID-19 patients, previous research has explored the role of social supports on the self-management of other chronic diseases, including diabetes, asthma, other pulmonary diseases, and heart disease [29–33]. A recent study of South Korean residents, including those who had COVID-19 infection-related experiences and those who did not, found that the presence of social support was a protective factor for peritraumatic distress and depression related to COVID-19 [34]. These studies highlight the positive relationship between social support and self-management strategies. This is a finding supported by our study, but we also found that the experience of social support varies based on type of support and context in which support is provided. This suggests that future research on COVID-19 should explore the types of support that patients found most beneficial, for whom, and under what circumstances. Furthermore, given the breadth of different social networks that COVID-19 patients engage with and receive support from (e.g., family members, neighbors, online communities, faith communities), nurses and clinicians should consider the social network diversity of their COVID-19 patients and tailor treatments and recovery strategies to each individual’s unique set of circumstances.

4.2. Policy implications

Finally, these findings highlight the role that policy plays on patients’ experiences with COVID-19 illness and recovery. Participants noted the particular role of workplace policies (and lack thereof) on their COVID-19 recovery experience. Because there was not a coordinated effort to support people returning to work after they recovered from COVID-19, participants expressed a continuum of experiences related to work. For example, some participants felt supported to work from home, work flexible hours, or return when they were healthy; in contrast, others felt stressed and frustrated by the need to return to their jobs given fears that they would be fired, concerned about economic and housing precarity that was exacerbated by not having paid sick leave, and worried about losing employer-sponsored health insurance. Lee et al. describe the concept of “loss spirals” to indicate how members of socially vulnerable groups are more likely to suffer both negative psychological impacts from the pandemic and financial hardship, which can reinforce one another [34]. In the U.S., there were limited efforts to provide social and financial supports as participants navigated systems due to COVID-19 illness across states where MCD was offered. Some states created programs to support individuals who tested positive or were exposed to COVID-19 by proactively reaching out to offer connections to medical health, behavioral health, and social services [35]. However, no one in the present study directly mentioned these programs by name. More widespread and coordinated policies and programs are needed to better address these social components of COVID-19 illness and recovery, particularly for those from socially vulnerable groups to prevent potential “loss spirals.”

4.3. Study strength & limitations

This study is one of a few qualitative studies that prospectively explores the COVID-19 experience through participants’ own narratives during both illness and recovery. MCD data collection started in 2020 and will continue until July 2024, which contrasts with many previously published studies that focused exclusively on the beginning of the pandemic. This means that our sample represents different points in time in the pandemic and different COVID-19 variants. The study sample included in this analysis was also larger and included more varied patient populations than many existing studies, including 100 participants made up of both hospitalized and non-hospitalized patients. Data was collected longitudinally, allowing for insights on the patient experience at multiple timepoints, and open-ended text responses allowed for the expression of experiences directly from patients in their own words. Finally, our geographic focus is a strength, as many existing studies are limited to patients outside the U.S., even though the U.S. has one of the highest numbers of confirmed cases by country [36].

While our study benefited from numerous strengths, it also faced multiple limitations. To be part of our sample, MCD participants

had to test positive at a facility within the multi-state health system. This may have meant that our study sample was sicker than the average COVID-19 patient because they sought out testing from a medical facility, or that we largely missed the experiences of those (including the uninsured) who tested positive at home or at another medical location and those who may be more likely to lack benefits like paid leave from work. Additionally, the MCD platform was only offered in English at the time of data collection, which further limits our sample and may not reflect the experiences of people who speak other languages. Furthermore, by limiting our sample to the 95th percentile of journal entry length and those who engaged with the platform multiple times, we might have further removed individuals with limited English proficiency and literacy, limited our sample to those who are more comfortable with written communication and potentially more technologically inclined, and biased our sample to those who are more comfortable with and interested in engaging in research. While this approach provided us with nuanced descriptions of participants' experiences, we were unable to analyze trends in experiences over time because not all participants submitted an entry each week and the percentage of participants submitting weekly entries declined over time. Decline in entries may have occurred for a variety of reasons, including having a relatively quick recovery and deciding to no longer engage or having a more serious infection that prevented participation in the app on an ongoing basis during participants' first six weeks of illness. Likely due to a combination of these and other factors, our sample is younger, more female, and has a larger proportion of White participants than the larger MCD population (data not shown). Finally, the design of the MCD platform did not allow the researchers to follow up with participants regarding their responses or to seek additional clarification when journal entries were unclear or ambiguous. While the focus of the MCD app and its prompts were oriented towards participants' experiences with COVID-19, we were unable to verify the relationship between participants' journal entries and their COVID-19 infection rather than other health conditions or personal experiences. Future research could address some of these limitations by expanding the sample criteria to include participants with only one entry, entries with fewer words, or entries submitted more than six weeks after participants' initial infections. Conducting follow-up interviews could also address some of these limitations by giving researchers the opportunity to ask participants questions and better understand their complex experiences.

5. Conclusion

Our research contributes to the current body of evidence documenting the complexity of experiences for individuals testing positive for COVID-19 by furthering demonstrating how COVID-19 can disrupt every aspect of someone's life: physical health, emotional wellbeing, and their interactions with those around them. Understanding these complexities and how they interact are necessary steps to inform health care delivery and policy approaches to treat those experiencing the short- and long-term effects of COVID-19.

Ethics statement

The full study protocol was reviewed and approved by Providence St. Joseph Health Institutional Review Board (IRB# 2020000467) and conformed to the principles of the Declaration of Helsinki. Written informed consent to participate was obtained through the My COVID Diary app for all participants.

Data availability statement

The datasets generated and/or analyzed during the current study are not publicly available due to identifying participant personal and health information. Additionally, data collection is still ongoing. Due to the difficulty in de-identifying qualitative data we are unable to make this data readily available to others. In the future, fully de-identified portions of other datasets collected through the broader My COVID Diary project may be made publicly available.

CRedit authorship contribution statement

Natalie Kenton: Writing – original draft, Methodology, Formal analysis, Conceptualization. **Benjamin Gronowski:** Writing – review & editing, Formal analysis. **Daniel Fish:** Writing – review & editing, Data curation. **Keri Vartanian:** Writing – review & editing, Supervision, Funding acquisition. **Ari Robicsek:** Writing – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.heliyon.2024.e28930>.

References

- [1] Centers for Disease Control and Prevention. COVID Data Tracker. Published August 8, 2022. Accessed August 7, 2022. <https://covid.cdc.gov/covid-data-tracker/#data-tracker-home>.
- [2] Z. Al-Aly, Y. Xie, B. Bowe, High-dimensional characterization of post-acute sequelae of COVID-19, *Nature* 594 (7862) (2021) 259–264, <https://doi.org/10.1038/s41586-021-03553-9>.
- [3] T.Y.M. Leung, A.Y.L. Chan, E.W. Chan, et al., Short- and potential long-term adverse health outcomes of COVID-19: a rapid review, *Emerg. Microb. Infect.* 9 (1) (2020) 2190–2199, <https://doi.org/10.1080/22221751.2020.1825914>.
- [4] K. Vartanian, D. Fish, N. Kenton, B. Gronowski, B. Wright, A. Robicsek, Integrating patient-reported physical, mental, and social impacts to classify long COVID experiences, *Sci. Rep.* 13 (2023) 16288, <https://doi.org/10.1038/s41598-023-43615-8>.
- [5] R. Norouzadeh, M. Abbasinia, Z. Tayebi, et al., Experiences of patients with COVID-19 admitted to the Intensive care units: a qualitative study, *J Patient Exp* 8 (2021), <https://doi.org/10.1177/23743735211007359>, 2374373521100735.
- [6] S. Sahoo, A. Mehra, V. Suri, et al., Lived experiences of the corona survivors (patients admitted in COVID wards): a narrative real-life documented summaries of internalized guilt, shame, stigma, anger, *Asian J Psychiatr* 53 (2020) 102187, <https://doi.org/10.1016/j.ajp.2020.102187>.
- [7] E.I. Santiago-Rodriguez, A. Maiorana, M.J. Peluso, et al., Characterizing the COVID-19 illness experience to inform the study of post-acute sequelae and recovery, *Int. J. Behav. Med.* 29 (5) (2022) 610–623, <https://doi.org/10.1007/s12529-021-10045-7>.
- [8] H.M. Son, W.H. Choi, Y.H. Hwang, H.R. Yang, The lived experiences of COVID-19 patients in South Korea: a qualitative study, *Int. J. Environ. Res. Publ. Health* 18 (14) (2021) 7419, <https://doi.org/10.3390/ijerph18147419>.
- [9] N. Sun, L. Wei, H. Wang, et al., Qualitative study of the psychological experience of COVID-19 patients during hospitalization, *J. Affect. Disord.* 278 (2021) 15–22, <https://doi.org/10.1016/j.jad.2020.08.040>.
- [10] S. Ahmadi, S.F. Irandoost, A. Ahmadi, J. Yoosofi Lebni, M.A. Mohammadi Gharehghani, N. Baba Safari, Explaining experiences, challenges and adaptation strategies in COVID-19 patients: a qualitative study in Iran, *Front. Public Health* 9 (2022), <https://doi.org/10.3389/fpubh.2021.778026>.
- [11] D. Rofail, N. McGale, A.J. Podolanczuk, et al., Patient experience of symptoms and impacts of COVID-19: a qualitative investigation with symptomatic outpatients, *BMJ Open* 12 (5) (2022) e055989, <https://doi.org/10.1136/bmjopen-2021-055989>.
- [12] N. Ziauddeen, D. Gurdasani, M.E. O'Hara, et al., Characteristics and impact of long Covid: findings from an online survey, *PLoS One* 17 (3) (2022) e0264331, <https://doi.org/10.1371/journal.pone.0264331>.
- [13] M. Akbarbegloo, M. Sanaeefar, P. Majid, M. Mohammadzadeh, Psychosocial care experiences of patients with COVID-19 at home in Iran: a qualitative study, *Health Soc. Care Community* 30 (1) (2022) 264–274, <https://doi.org/10.1111/hsc.13399>.
- [14] S. Aliyu, J.L. Travers, A.A. Norful, M. Clarke, K. Schroeder, The lived experience of being diagnosed with COVID-19 among black patients: a qualitative study, *J Patient Exp* 8 (2021), <https://doi.org/10.1177/2374373521996963>, 2374373521996963.
- [15] A. Jesmi, Z. Mohammadzade-tabrizi, M. Rad, E. Hossainzadeh-younesi, A. Pourhabib, Lived experiences of patients with COVID-19 infection: a phenomenology study, *Med. Glas.* 18 (1) (2021) 18–26, <https://doi.org/10.17392/1247-21>.
- [16] T. Li, Y. Hu, L. Xia, et al., Psychological experience of patients with confirmed COVID-19 at the initial stage of pandemic in Wuhan, China: a qualitative study, *BMC Publ. Health* 21 (1) (2021) 2257, <https://doi.org/10.1186/s12889-021-12277-4>.
- [17] V.T. Tran, C. Riveros, B. Cleprier, et al., Development and validation of the long coronavirus disease (COVID) symptom and impact tools: a set of patient-reported instruments constructed from patients' lived experience, *Clin. Infect. Dis.* 74 (2) (2022) 278–287, <https://doi.org/10.1093/cid/ciab352>.
- [18] H. Zhang, F. Xie, B. Yang, F. Zhao, C. Wang, X. Chen, Psychological experience of COVID-19 patients: a systematic review and qualitative meta-synthesis, *Am. J. Infect. Control* 50 (7) (2022) 809–819, <https://doi.org/10.1016/j.ajic.2022.01.023>.
- [19] M. Kürtüncü, A. Kurt, N. Arslan, The experiences of COVID-19 patients in intensive care units: a qualitative study, *Omega: J. Death Dying* 87 (2) (2023) 504–518, <https://doi.org/10.1177/00302228211024120>.
- [20] M. Missel, C. Bernild, S.W. Christensen, I. Dagyan, S.K. Berg, It's not just a virus! Lived experiences of people diagnosed with COVID-19 infection in Denmark, *Qual. Health Res.* 31 (5) (2021) 822–834, <https://doi.org/10.1177/1049732321990360>.
- [21] R.Z. Shaban, S. Nahidi, C. Sotomayor-Castillo, et al., SARS-CoV-2 infection and COVID-19: the lived experience and perceptions of patients in isolation and care in an Australian healthcare setting, *Am. J. Infect. Control* 48 (12) (2020) 1445–1450, <https://doi.org/10.1016/j.ajic.2020.08.032>.
- [22] E. Callaway, What Omicron's BA.4 and BA.5 variants mean for the pandemic, *Nature* 606 (2022) 848–849, <https://doi.org/10.1038/D41586-022-01730-Y>.
- [23] Chen C, Haupt SR, Zimmermann L, Shi X, Fritsche LG, Mukherjee B. Global prevalence of post-acute sequelae of COVID-19 (pasc) or long COVID: a meta-analysis and systematic review. medRxiv. Published online November 16, 2021. doi:10.1101/2021.11.15.21266377.
- [24] S. Rudrum, R. Casey, L. Frank, et al., Qualitative research studies online: using prompted weekly journal entries during the COVID-19 pandemic, *Int. J. Qual. Methods* 21 (2022) 16094069221093138, <https://doi.org/10.1177/16094069221093138>.
- [25] K. Vartanian, D. Fish, B. Gronowski, N. Kenton, A. Robicsek, Patient-reported outcomes for fully vaccinated COVID-19 patients over 6 Weeks: the experiences of clinical breakthrough cases, *The Patient - Patient-Centered Outcomes Research* 16 (2023) 105–116, <https://doi.org/10.1007/s40271-022-00605-8>.
- [26] V. Braun, V. Clarke, Using thematic analysis in psychology, *Qual. Res. Psychol.* 3 (2) (2006) 77–101, <https://doi.org/10.1191/1478088706qp0630a>.
- [27] G. Guest, K. MacQueen, E. Namey, *Applied Thematic Analysis*, SAGE Publications, Inc., 2012, <https://doi.org/10.4135/9781483384436>.
- [28] K.N. Dainty, M.B. Seaton, B. O'Neill, R. Mohindra, Going home positive: a qualitative study of the experiences of care for patients with COVID-19 who are not hospitalized, *CMAJ Open* 11 (6) (2023) E1041–E1047, <https://doi.org/10.9778/cmajo.20220085>.
- [29] A.T. Brooks, R.E. Andrade, K.R. Middleton, G.R. Wallen, Social support: a key variable for health promotion and chronic disease management in Hispanic patients with rheumatic diseases, *Clin. Med. Insights Arthritis Musculoskelet. Disord.* 7 (2014) 21–26, <https://doi.org/10.4137/CMAMD.S13849>.
- [30] M.P. Gallant, The influence of social support on chronic illness self-management: a review and directions for research, *Health Educ. Behav.* 30 (2) (2003) 170–195, <https://doi.org/10.1177/1090198102251030>.
- [31] J. Koetsenruijter, N. van Eikelenboom, J. van Lieshout, et al., Social support and self-management capabilities in diabetes patients: an international observational study, *Patient Educ. Counsel.* 99 (4) (2016) 638–643, <https://doi.org/10.1016/j.pec.2015.10.029>.
- [32] A. Lenferink, J. van der Palen, T. Effing, The role of social support in improving chronic obstructive pulmonary disease self-management, *Expert Rev. Respir. Med.* 12 (8) (2018) 623–626, <https://doi.org/10.1080/17476348.2018.1489723>.
- [33] J.L. Strom, L.E. Egede, The impact of social support on outcomes in adult patients with type 2 diabetes: a systematic review, *Curr. Diabetes Rep.* 12 (2012) 769–781, <https://doi.org/10.1007/S11892-012-0317-0>.
- [34] Y. Lee, Y. Hyun, M. You, H. Lee, J.O. Han, S. Seo, The effect of resource loss on depression and peritraumatic distress during the early period of the COVID-19: considering the pandemic-situational and social context, *BMC Publ. Health* 23 (1) (2023) 760, <https://doi.org/10.1186/s12889-023-15628-5>.
- [35] Washington State Department of Health. Care Connect Washington. Published 2022. Accessed September 15, 2022. <https://doh.wa.gov/emergencies/covid-19/care-connect-washington>.
- [36] World Health Organization, WHO Coronavirus (COVID-19) Dashboard (2022). Published, <https://covid19.who.int/>. (Accessed 7 August 2022).