

Living with Long COVID-19: A Virtual Body Mapping Study

Sara Santarossa¹, Ashley Redding and Dana Murphy

Henry Ford Health System, Patient-Engaged Research Center, Detroit, MI, USA

ABSTRACT

Long COVID-19 has emerged as a significant public health problem, and understanding the long COVID-19 journey is paramount to patient-centered care. Virtual body mapping (VBM) was used to gain a deeper understanding of both shared and differing experiences of patients with long COVID-19. There were 3 VBM sessions (each 2 hours). Session topics included (1) The Long COVID-19 Experience, (2) The Life of a COVID-19 Long Hauler, and (3) Resilience and Coping. Guided and structured by VBM sessions and corresponding exercises, an adapted method for visual analysis influenced by constructivist grounded theory focused on the following data outputs: body maps, testimonios, and keys. Robust data outputs included 19 COVID-19 long haulers who primarily identified as women (N = 15) and of White race (N = 11). Visual data included powerful colors, images, and words to describe the embodied experience of people living with long COVID-19. Textual data narrated journeys of COVID-19 long haulers, providing heartfelt and honest depictions of 'Life before, during, and after COVID-19'. This study adds to the limited literature around in-depth qualitative interpretation of body maps and introduces VBM as a relevant person-centered qualitative method for exploring chronic disease.

KEYWORDS: Arts-based Methodology, Body Mapping, Long COVID-19, Patient-centered, SARS-CoV-2

As of May 2023, the Centers for Disease Control and Prevention (2023) ended the federal COVID-19 public health emergency. Though the declaration has been lifted, the effects of the pandemic are long-lasting, including economic fallout, a shift to digital culture, and serious labor shortages (Delardas et al., 2022; Ng & Stanton, 2023; Robbins et al., 2020). One such prolonged experience is the disease long COVID-19, a condition wherein, after one's SARS-CoV-2 infectious period has passed, the patient has either persistent symptoms or develops new symptomology that can last for months (Raveendran et al., 2021).

Long COVID-19 has emerged as a significant public health problem both in the United States and globally. A global systematic analysis by Hanson et al. (2022) estimates that in the years 2020 and 2021, over 140 million people have experienced long-term effects from COVID-19, with these symptoms being clustered into fatigue, respiratory, and cognitive profiles, with respiratory profiles being the most common (occurring in 60.4% of long COVID-19 cases). Additionally, those

¹ Corresponding author; an Assistant Scientist in the Department of Public Health Sciences at Henry Ford Health and the Scientific Director of the Patient-Engaged Research Center at the Department of Obstetrics, Gynecology and Reproductive Biology, College of Human Medicine, Michigan State University, East Lansing, MI, USA. E-mail: ssantar1@hfhs.org

who were admitted for COVID-19 had a longer median estimated recovery time than those who were not hospitalized (Hanson, et al., 2022). Davis et al. (2021) further corroborate these global findings, noting that those with long COVID-19 continue to experience significant health challenges for over seven months post-infection, precluding their ability to return to normal levels of work and engage in regular daily activities. Further, the authors found that relapse of symptoms occurred in the majority of their participants, and these relapses had varied triggers: physical activity, stress, exercise, mental activity, and menstruation, among other factors (Davis et al., 2021). In this vein, Brown and O'Brien (2021) argue for the conceptualization of long COVID-19 as an episodic health condition, recognizing its fluctuating and multidimensional nature. These authors explain that the symptom clusters characterizing long COVID-19 fluctuate, and this trajectory is similar to the concept of “episodic disability” (Brown & O'Brien, 2021), which is characterized by periods of wellness and periods of significant health challenges (Solomon, 2002). Importantly, patients have increasingly called for the incorporation of lived experiences into research and clinical guidelines, as highlighted by Gorna et al. (2021), to ensure that the complexities of long COVID-19 are adequately addressed in both research and treatment protocols.

Understanding the long COVID-19 journey is paramount to patient-centered care, and various study approaches have been utilized to capture patient experiences. Quantitative work has identified various attributes and predictors of long COVID-19, with one study finding that people who experience long-COVID are more likely to be older in age, female, and have required hospital assessment (Sudre et al., 2021). Other work attempting to quantify the disease had elucidated the incidence of common symptoms (Taquet et al., 2021). Qualitative work has also sought to capture patient perspectives. Qualitative interviews and focus groups with long COVID-19 patients found that feelings of stigmatization, difficulty with accessing and navigating health services, and a need to “prove” the validity of their condition to healthcare providers (Kingstone et al., 2020; Ladds et al., 2020).

Arts-based research has been increasingly used to understand the impact of COVID-19, specifically in populations experiencing health disparities (i.e., children, people with intellectual disabilities, and older adults) (Abdulah et al., 2021; Ferlatte et al., 2022; Kuri & Schormans, 2022). Arts-based research is participatory in nature and connects embodied, visual literacy to more traditional academic research practices (Burnard et al., 2018; Jagodzinski & Wallin, 2013) through which any art form/s is used to generate and interpret or communicate research knowledge (Cole & Knowles, 2008; Parsons & Boydell, 2012). While arts-based research approaches vary, they use art to delve into aesthetic knowledge, which moves beyond a language focus and includes expressions and emotions (Gerber & Myers-Coffman, 2019; Leavy, 2020). Studies have illustrated how participant engagement can be enhanced through the arts-based research method (Morris & Paris, 2022), and participant engagement can lead to improved quality of care, research findings, and healthcare outcomes as well as inspire mutual empowerment (Forsythe et al., 2019; Manafo et al., 2018). A recent narrative review focused on the ways arts-based research has been used with patient engagement in research and the impacts of arts-based research on patient engagement in research (Phillips et al., 2024). The use of arts-based research for patient engagement in research was reported to be decolonizing, shifted power from researchers to people with lived experience, and reduced tokenism (Phillips et al., 2024). Specifically identified was that: “There are ABMs that could be used for patient engagement in research, such as body mapping, that were not found in the existing literature” (Phillips et al., 2024).

Body mapping can broadly be defined as the process of creating body-maps using drawing, painting, or other art-based techniques to visually represent aspects of people’s lives, their bodies and the world they live in (Gastaldo, Magalhães, Carrasco, & Davy, 2012). This approach is meant to overcome some of the challenges associated with traditional health research (e.g., dominated by

verbal communication) (Gastaldo, Rivas-Quarneti, & Magalhães, 2018), and similarly uplift the voices of marginalized groups. Gastaldo, Magalhães, Carrasco, and Davy (2012) explained that body maps

should be analyzed in their integrity, which includes the process of creating it (verbatim and field notes), the body map itself, and the narratives that accompany it (testimonio and key). The purpose of the analysis is not to psychologically evaluate the participants through their art, but to gain insight into certain aspects of their logic, aspirations, desires, material circumstances and ways of handling particular issues. (p. 18)

Notably, in reference to the body maps, there is a dearth of literature in the health sciences and social sciences about methods for visual analysis—a gap this study is poised to address. The present study seeks to uplift the voices of those with long COVID-19, leveraging body mapping methodology adapted to a virtual format (Sara Santarossa, Redding, & Murphy, 2023), and a visual analysis process to gain a deeper understanding of both shared and differing patient experiences.

Methods

We conducted virtual body mapping (VBM) (Sara Santarossa et al., 2023) with COVID-19 long haulers and used visual analysis coupled with Colaizzi's descriptive phenomenological method (Morrow, Rodriguez, & King, 2015). Ethical approval for the study was obtained from the Henry Ford Health Institutional Review Board (#15121-31). All participants provided written informed consent prior to enrollment in the study.

Preparation and Facilitation

The study described here sought to elicit perspectives of adults who self-identified as COVID-19 long haulers and took place between October 2021 and March 2022. Previous body mapping studies have included various sample sizes including 3 (Gubrium, Fiddian-Green, Jernigan, & Krause, 2018), 10, and 25 (Skop, 2016) participants. Based on the previous literature and funding feasibility, nineteen COVID-19 long haulers took part (Table 1). Voluntary response sampling (self-selection) and snowball sampling were used for recruitment as it was cost-effective and allowed for rapid data collection during the pandemic. Most of the COVID-19 long haulers were female and identified as women ($N = 15$) and of White race ($N = 11$) but race/ethnicity and other sociodemographic information were not explicitly collected. Ages ranged from 25 to 75 years old and reports of becoming sick with COVID-19 ranged from March 2020 to November 2021.

Table 1
Participants

Participant Number	Description of Self
1	A female who became sick with COVID-19 in March 2020 while working as a Registered Nurse.
2	A female who became sick with COVID-19 in March 2021.
3	A female who became sick with COVID-19 in 2020.
4	A father and husband in his late 30s who contracted COVID-19 in November of 2020.
5	A mother of two battling with COVID-19 since March 2021.
6	A grandmother, sister, and aunt in her mid-40s.
7	A husband and father in his mid-50s diagnosed with COVID-19 in November 2020.
8	A female who contracted COVID-19 in January 2021.
9	A female who become sick with COVID-19 in April 2020 while working as a nursing assistant.
10	A male in his mid-20s who contracted COVID-19 in 2020.
11	A wife and a mother in her mid-30s, suffering with COVID-19 since March 2020.
12	A healthcare worker who contracted COVID-19 in January 2021.
13	A female in her early- 50s who contracted COVID-19 in November 2021
14	A female in her mid-50s who contracted COVID-19 in March 2021.
15	A Nurse Practitioner who contracted COVID in November 2020.
16	A female in her mid-50s who's been battling COVID-19 since August 2020.
17	A father in his mid-40s who contracted COVID-19 in February 2020.
18	A female in her mid-50s who contracted COVID-19 in April 2021
19	A female in her mid-50s battling COVID-19 since December 2020.

VBM is a term coined by our research team that describes a methodology where each body mapping session took place virtually via Webex (Cisco Systems, Inc., San Jose, CA), wherein traditional body mapping strategies, facilitation guides, and tools/resources were altered to be appropriate for the digital space (Sara Santarossa et al., 2023). A detailed outline of the current study's participant recruitment (and attrition), study protocol, and data collection (i.e., preparation for using VBM and facilitation of VBM sessions) has been published elsewhere (Sara Santarossa et al., 2023).

In brief, electronic medical records, social media, websites, and snowball sampling were used as recruitment strategies. Written consent was obtained from all participants. Participants were reminded that they could elect to cease their involvement in the study at any time without giving a reason. Participants were also reminded at the commencement of and during the sessions that if identifying marks or names were included on their body maps, it could impact maintaining their anonymity. Participants created their testimonios (a condensed personal narrative) as well as a key (a legend that describes the meaning and intent behind visual aspects) for the body map.

Art paper was precut to 3'x 6' lengths for the body maps, and a wide selection of art supplies such as markers, crayons, colored paper, glue sticks, and oil pastels were mailed to the participants in the "Body Mapping Mail Kit" ahead of time. Participants were also encouraged to use "found objects" if they would like, meaning any materials outside of the ones provided to them by the study team. To help keep participants organized and feel prepared, they were also mailed a hardcopy of the "Participant Workbook" (i.e., a coiled book containing space to take notes and complete session exercises, background project information, and an outline of how to prepare for each) and emailed a "Key and Story E-booklet" (i.e., a fillable PDF document). There were 3 VBM sessions, and each was two hours in duration. Session topics included (1) The Long COVID-19

Experience, (2) The Life of a COVID-19 Long Hauler, and (3) Resilience and Coping. Each session had guided exercises that corresponded with the topic, an accompanying slide presentation to guide facilitation, and an opportunity for the participants to work independently on their body maps. The first two sessions included a brief mindfulness exercise (20 minutes) called a “body scan” to aid relaxation and bring attention to the body. The final session included allocated time to share their creations with the rest of the group.

Sessions were conducted by SS (a PhD researcher and Scientific Director of the Patient Engaged Research Center) and DM (the Project Manager for the Patient Engaged Research Center). Both SS and DM received training in body mapping from a certified arts therapist prior to conducting any formal research.

Data Analysis

Analysis was conducted by our research team and the participants. Guided and structured by VBM sessions and corresponding exercises, the analysis focused on the following data outputs: body maps, testimonios, and keys. An adapted method for visual analysis of the body maps (Gastaldo, Magalhães, Carrasco, and Davy, 2012; Skop, 2016) (Table 2) including an analysis of the testimonios and keys (Step 4; Table 2) was used. This adapted method (Skop, 2016) is influenced by constructivist grounded theory. Constructivist grounded theory assumes that participants experience a multitude of realities (Charmaz, 2008). Steps 1-6 (Table 2) were completed to analyze the data outputs presented in the current study. Steps 7 and 8 (Table 2) will be utilized for the development of future publications. All data outputs were analyzed by (SS) and generated initial themes. An iterative approach was then used to refine the themes and data interpretation with the research team members. Any discrepancies were resolved by consensus building, and a final interpretation of the data was developed.

Table 2
Steps in Visual Analysis of Body Maps

Step	Description
1. Familiarization	Rolling out the life-size body maps on a long table to examine all parts of the maps.
2. Organization	Organized the visual data by photographing the body maps and uploading these photographs into NVivo 10 (Lumivero, Denver, CO). This allows the research team to code the physical body maps and use NVivo to consistently organize the codes and memos. Using NVivo allowed for codes from the visual (i.e., body maps) and textual data (i.e., personal narratives and keys) to be compared and merged.
3. Initial codes	Created initial codes based on the similarities and differences in the use of color, themes and discourses, types of representations (e.g., words, picture collages, hand-drawn images), size, repetition, and location of the images and words (e.g., symbols situated inside and outside of the body).
4. Compare to keys and narrative	This process of matching participants' images to their personal narratives is a method of ensuring that the initial codes are grounded in the data. Through this process, we refined the codes by renaming and redefining them to improve the clarity of meaning.
5. Grouping codes into themes	<i>Elements of design</i> which refers to the visual aesthetics of the body maps; this is a conceptual framework borrowed from fine art theory. The elements of design include line (horizontal, vertical, diagonal lines); color; value (the hue and tone of the color); shape (the two-dimensional outline of objects); form (the three-dimensional creation of objections and area through shading); space (the positive space of the object and negative space surrounding the object) and texture. <i>Conceptual content</i> which refers to the healthcare-related themes represented by words and images in the body maps. The <i>tone</i> refers to the mood evoked through the images and words that participants used to represent their positive and negative healthcare experiences.
6. Comparing themes within and across groups	<i>Within groups</i> will highlight that participants shared ideas with each other as they created their maps. <i>Across group</i> commonalities signified both the universality of certain images and metaphors.
7. Intersectionality	Select a variety of salient codes and then examine the differences in these codes (examine differences in gender, age, and race).
8. Focus analysis	Narrow the focus of the visual analysis for the purpose of addressing a specific research question.

In conjunction with the steps outlined above, all data outputs (i.e., body maps, personal narratives, and keys) were analyzed using the patient-centered approach of Colaizzi's descriptive phenomenological method (Morrow et al., 2015). Specifically, to accomplish Colaizzi's method, all data outputs were sent to participants in a PDF via email, along with the final interpretation of the data from the researchers. Detailed findings of Colaizzi's descriptive phenomenological method (Morrow et al., 2015), including direct feedback quotes from participants used in this study, have been reported elsewhere (Sara Santarossa et al., 2023).

Study Quality

The Standards for Reporting Qualitative Research (SRQR; O'Brien et al., 2014) was used to ensure transparency in reporting our qualitative research.

Results

Illustrated below are the qualitative findings from the 19 participants' data outputs (i.e., body maps, personal narratives, and keys). Participants completed 3 VBM sessions, and across those sessions a total of 10 different exercises. "Life before, during, and after COVID-19" was central to the analysis. Below, themes generated from the analysis described previously (Table 2) are organized by VBM exercise and grouped by session. Supportive quotes have been extracted from the personal narratives and keys. Supportive images taken of the body maps have been provided as visual aids.

Elements of Design

Interpretation of the color and value (the hue and tone of the color) on the body maps can be represented in two distinct yet opposing categories: (1) Dark and heavy and (2) Light and airy. Dark and heavy included hues and tones that evoke anger, the unknown, and sadness. For example, Participant 1 described, "The outline of my body is grey and black - how I feel like my body is now (I feel like these colors represent how I feel dark, tired, sickly, and sad)." Light and airy included hues and tones that evoke hope, peace, happiness, and the future. For example, Participant 4 stated:

There are multiple colors throughout the map to describe multiple feelings and emotions. The lighter and brighter colors are for prior to my illness and represents the life I had. While the darker colors represent the darkness, pain and fear I have felt over the last 12 months, I have tried to use these to contrast the different parts of my life that have been changed because of this.

Session 1: "The Long COVID-19 Experience"

The first VBM session provided the opportunity for participants to understand the body mapping process and project expectations as well as create a safe space for the initiation of their artistic venture. This session involved 4 exercises: Introduction to Body Mapping, Body Scan, Body Tracing, and COVID-19 Journey. Two of the four exercises were used in analysis and theme generation; names and brief descriptions of selected exercises as well as themes and supportive quotes are provided in Table 3. Figures 1 and 2 depict supportive images and quotes reflective of the themes that emerged from the exercises in this session.

Table 3
Themes Across Body Maps, Keys, and Personal Narratives Organized by VBM Session 1 ‘The Long COVID-19 Experience’ Exercises

Exercises and brief descriptions	Themes	Quotes
Body Tracing: Shape, posture, and position of the body that is most representative to long COVID-19 experience	Horizontal: bodies that are standing up showing strength and power; arms up representing victory	“On my body map, I stood up straight, trying not to be sad and despondent. I’m terrified of what lies ahead in my life.” (Participant 12) “On two strong feet with arm over head for strength.” (Participant 19)
	Vertical: bodies that are slouched/hunched over showing sadness and loneliness OR laying down showing fatigue and exhaustion	“I am sitting on the ground, slumped over with my head hanging. I feel like this represents how I am when I feel my worst. I feel like I’ve been kicked down by all of this, like I am weakened, and I often feel defeated.” (Participant 1) “In the fetal position, outlined in black and dark colors to represent the feeling of weakness, vulnerability, and frailty of my current life.” (Participant 4)
COVID-19 Journey: visually representing life before, during, and after COVID-19	Coping mechanisms: using physical activity, yoga, meditation, mental exercises	“I’ll be starting hyperbaric chamber sessions next week, which have the potential to help my body heal, and generally make me feel better.” (Participant 7) “Things like art, nature, breathwork, yoga and my faith have all been incredibly helpful in my journey. They have helped shape me into a more whole person through this dark time, too.” (Participant 11)
	Origin story: experiences of how COVID-19 came to be in their lives	“48 hours later, after a battery of tests and enough blood drawn to sink a ship, I was released. There were guesses as to my diagnosis, but nobody knew for certain.” (Participant 7) “I am a home health care nurse who contracted COVID-19 in August 2020. I know exactly when I was exposed. I was listening to heart sounds on a patient in an Assisted Living Facility when she suddenly coughed in my face and eyes. At that time healthcare workers were only required to wear eye protection on confirmed COVID patients.” (Participant 16)
	Conquering COVID-19: experiences of overcoming or having to live with COVID-19	“I pray every night that I will overcome the long haul of Covid I can see me in the future doing things I love...” (Participant 6) “Weeks have gone by and my son asked, ‘Mom you’re still sick?’ He and my husband would take turns feeding me, toileting me and trying to keep me hydrated. I kept assuring them that at this rate, I would be dead soon and to make final arrangements because there is no way a body can stay this sick for this long and survive” (Participant 9) “It saddens me to think of how the medical community has changed. They don’t look at you as a person anymore.” (Participant 14)
	Silver linings: finding positivity amidst the struggles of long COVID	“I celebrate every little improvement and try my best to remain positive. I am constantly reminded how much worse this could be, as I’ve held the hands of multiple patients while they take their last breath from the same virus I have “recovered” from.” (Participant 1)

Note. VBM=virtual body mapping. Detailed descriptions of each exercise can be found published elsewhere (Sara Santarossa et al., 2023).

Figure 1

Example of the Body Tracing Exercise Themes



Note. Body map of participant 4, demonstrating a vertical body tracing. Participant 4 described his body position in the following way in his key: “On my body map there are two different bodies, this was done to show the difference in how I felt before Covid-19 and, how I feel during and after Covid-19. The first is done with the body up right and with good posture, in light and bright colors, the white and yellow outline to represent how I felt prior, and active and happy man that tried to bring myself to be a positive person. The other body is in the fetal position, outlined in black and dark colors to represent the feeling of weakness, vulnerability, and frailty of my current life.”

Figure 2

Example of COVID-19 Journey Exercise Themes



Note. Body map of participant 10, demonstrating a coping mechanism (i.e., yoga) described in the following way on his key: “I attempted to create a yoga mat with a cross... I went through physical therapy to strengthen my body and regain coordination but the exercises were too difficult for me to complete. At one point I was not able to stand up tall and straight due to body weakness and

pain. Yoga was the exercise that I could do periodically and it strengthened my body to the point of me being able to stand tall.”

Session 2: “The Life of a COVID-19 Long Hauler”

In the second VBM session, the focus shifted to creating important elements (e.g., symbols, physical appearance, and relational experiences) on their body maps that were visual reflections of their long COVID-19 experience. This session involved 4 exercises: Body Scan, Personal Symbol and Slogan, Marks On/Under the Skin, and Self-Portrait. Two of the four exercises were used in analysis and theme generation; names and brief descriptions of selected exercises, as well as themes and supportive quotes, are provided in Table 4. Figures 3 and 4 depict supportive images and quotes reflective of the themes that emerged from the exercises in this session.

Table 4

Themes Across Body Maps, Keys, and Personal Narratives Organized by VBM Session 2 ‘The Life of a COVID-19 Long Hauler’ Exercises

Exercises and brief descriptions	Themes	Quotes
Personal Symbols*: pictorial depictions of life with Long COVID-19	Marks on or under the skin: depictions of physical symptoms and their severity, such as flames around lungs, fogs/clouds around brain, weights on limbs; depictions of non-physical symptoms such as confusion, isolation, loneliness	“While the red marks throughout the bodies are for the pain and anguish, I have dealt with while fighting through the unknowns of long covid, they are many and all over my body, from my joints to my brain function and even my heart.” (Participant 4)
	The inner circle: depictions of family and friends, such as holding hands, support being offered, and strength being provided through COVID	“My husband and children were my support structures they were my hope and that's what the rainbow represents. They guided me and helped me see the light at the end of the tunnel when I thought I'd never see it again”. (Participant 5)
	Sense of Hope: depictions of courage and confidence such as hearts, butterflies, feathers, sunshine	“My life has been negatively affected by long-COVID in more ways than I can count. I am still fighting every single day, and I am not giving up hope”. (Participant 1)
Personal slogans*: textual depictions of life with Long COVID-19	Moving beyond: messages of not being constrained/defined by their diagnosis, looking to the future	“In the future I hope this body maps help people find some solace in the fact that there are many of us going through the same issues and we are fighting to find a solution.”(Participant 4)
	Used up: messages of being exhausted by COVID, feelings about their symptoms, and thoughts toward their struggles with long COVID	There are many references to loss of brain and overstimulation. I just work up because I fell asleep typing this. I'm used up.” (Participant 3)
	Live each day: messages of self-reflection, reminders to be thankful, reminders to be kind to self	“I will still always live for today and try to get my previous self to be in the front and have the fetal self-disappear.” (Participant 4)
Self-portrait: visually representing a reflection of appearance; facial expressions and emotions	Fear: scared of the unknown, struggling with what is to come	“To combat ‘the fear of the unknown’ of what was going on with me.” (Participant 11)
	The façade: having to put on a mask, the invisibility of being a long hauler	“I've put that face on and covered up what's really going on for a variety of reasons: fear, shame, wanting to be normal again, needing to be strong for everyone else...” (Participant 11)

Missing self: seeking normalcy, reminiscing on what was the past self

“I’m hoping to appear “normal” to the world. I don’t want them to know that I’m not “hearing” or comprehending what they are saying. Or that, in a split second, I don’t remember what we are talking about. It has left my mind.” (Participant 18)

Build-up and broken down: experiences of feeling weak, ashamed, and having trouble AND experiences of feeling strong, proud, and joyful

“I’ve has several people ask me, “why are you so happy?” I share with them I am a COVID free living witness and I have a testimony to tell!” (Participant 13)

“There is also sadness in the fact that I don’t really know what the future holds as far as my health.” (Participant 14)

Note. VBM=virtual body mapping. Detailed descriptions of each exercise can be found published elsewhere (Sara Santarossa et al., 2023). Personal symbol and slogan creation is considered a single exercise in the body mapping methodology used (Sara Santarossa et al., 2023); however, symbols and slogans have been analyzed separately here. Not depicted here, ‘Marks on/under the skin’ is an exercise in this session, which aims to visualize physical, mental, and emotional impacts of long COVID-19 (Sara Santarossa et al., 2023). As it became a theme for the personal symbols exercise and there was considerable overlap and therefore was not analyzed on its own.

Figure 3

Example of the Personal Symbols Exercise Themes



Note. Excerpts from body maps of participant 5, 8, and 16 (left to right), demonstrating the theme *Marks on or under the skin*. Participant 5, description from key: “The black smoke on my head represented brain fog that I had and still have to this day.” Participant 8, description from key: “cloud = brain fog and memory loss.” Participant 15, description from key: “Brain fog above brain appears regularly but is not constant. This fog cannot predicted nor controlled.”

Figure 4

Example of the Personal Symbols Exercise Themes



Note. Excerpts from body maps of participant 1 (left) and 11 (right), demonstrating the theme *Sense of Hope*. Participant 1, description from key: “People commonly “make a wish” on dandelions, which I am holding in my hand, representing wishful/hopeful thinking.” Participant 11, description

from key: “Early on, I found the image of the caterpillar being in its cocoon in the dark and all alone very comforting. I knew that he must go through that experience in order to emerge as a butterfly. So for me the butterfly represents hope.”

Session 3: “Resilience and Coping”

The third session created a space to reflect on facilitators and barriers during their experience with long COVID-19, develop their personal narratives, and share their body map with the larger group. This session involved 6 exercises: Messages to Others, Body Scanning for Difficulties and Strengths, Support Structures, Drawing the Future, Participant Narrative, and Sharing Creations. Four of the six exercises were used in analysis and theme generation; names and brief descriptions of selected exercises, as well as themes and supportive quotes, are provided in Table 5. Figure 5 depicts supportive images and quotes reflective of the themes that emerged from the exercises in this session.

Table 5
Themes Across Body Maps, Keys, and Personal Narratives Organized by VBM Session 3 ‘Resilience and Coping’ Exercises

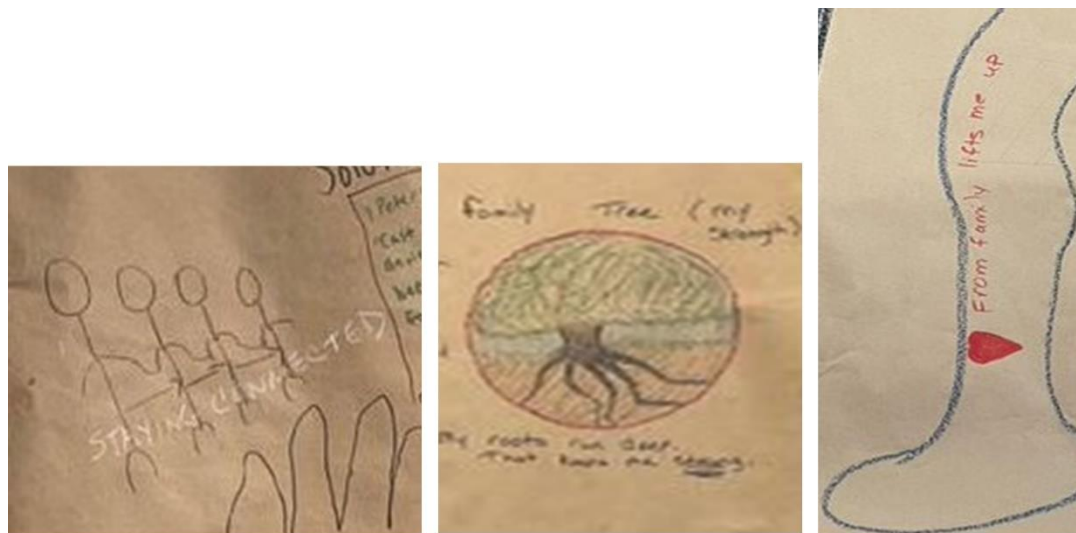
Exercises and brief descriptions	Themes	Quotes
Message to Others: textual displays to the public surrounding Long COVID-19	Long COVID is real: messages of advocacy, of ensuring long COVID is recognized and treated as a medical condition	“COVID long haul is real. I know what I was like before COVID and how I feel now.” (Participant 19)
	Don’t give up!: messages of looking towards a brighter future, staying positive and resilient	“Dealing with the symptoms can be frustrating, infuriating, exhausting, spiritually draining, and life challenging. Don’t give up! The goal is to be able to adapt and live life despite the symptoms.” (Participant 15) “Please, don’t ever stop fighting to get better and stronger!” (Participant 13)
Body scanning difficulties*: visualizing sources of barriers and challenges created by life with long COVID-19	Why me?: negative feelings such as anger and/or sadness around contracting COVID	“I had done so much work in my life on putting in place good rhythms, tackling stress, exercising and being healthy - why had I been the one to get long covid?” (Participant 11)
	Suffering day to day: experiences of change with relationships, activities of daily living, and work, as well as physical anguish with symptoms such as fatigue, paying attention/brain fog	“Relationships have suffered and are now different. I used to be very active walking 3 days a week with friends but since covid I had to stop” (Participant 15)
Body scanning strengths*; Support structures**: visualizing sources of power and assistance created by life with long COVID-19	A higher power: long haulers turning to their faith and spirituality in this time of need	“It’s a dreadful thing to squander the mental power that comes from inside. Having God in my life helps me feel much better and gives me hope for the future.” (Participant 12) “So, even though life is different and difficult at times, I am content in knowing that this is what God has planned for my life.” (Participant 15)
	Self-guardianship: long haulers experiences of cultivating resilience, endurance, strength and care for themselves on their own	“You have to pull your own inner strength before you look to others.” (Participant 14)
	The inner circle: long haulers relying on family and friends	“Friends and family who helped me research senior living/assisted living, went over budget with me,

		explained options of home health care, went to doctors' appointments, asked questions, sought answers, and comforted me when I felt I couldn't go on because living only a partial life sucks." (Participant 3)
	Medical community: long haulers looking to individuals whose work helps maintain their health	"I followed online a number of doctors that had long covid as well. They were and are a huge source of hope for me. They are fighting hard for answers not just for themselves but for all of us suffering!" (Participant 11)
Drawing the Future: visual depictions of what is to come in relation to their long COVID-19 experience	Treatments needed: thoughts of new therapies or finding a cure for long COVID My new normal?: accepting long COVID and forward	"I wish for the things most wish for with long Covid. Resolving brain fog, normal breathing, no chest pain, overflowing energy." (Participant 14) "Find ways to understand and mitigate situations that cause stress and confusion. Accept my new normal." (Participant 19) "Future with semblance of normalcy, with more energy, more disciplined approach to my health and well being." (Participant 17)
	Silver linings: finding positivity amidst the struggles of long COVID, a sense of motivation to keep on going and living life	"Although I'm scared, sad, angry and sometimes confused, I can look towards the future and know that steps are being taken to help those of us that have long Covid."(Participant 18)

Note. VBM = virtual body mapping Detailed descriptions of each exercise can be found published elsewhere (Sara Santarossa et al., 2023). Body scanning difficulties and strengths' is considered a single exercise in the body mapping methodology used (Sara Santarossa et al., 2023), however, difficulties and strengths have been analyzed separately here. **'Support structures' is an exercise in this session that aims to identify key people, institutions, agencies, or other avenues (i.e., support structures) that help support the participant in their daily struggles (Sara Santarossa et al., 2023) . There was considerable overlap when analyzing 'Body scanning strengths' and 'Support structures', so themes for these exercises were combined.

Figure 5

Example of the Body Scanning Strengths; Support Structures Exercise Themes



Note. Excerpts from body maps of Participants 2, 18, and 19 (left to right), demonstrating the theme *The inner circle*. Participant 2, description from key: “PEACE enjoying family.” Participant 18, description from key: “My journey is happy and sad. Grateful and confused. My heart is overjoyed because of the support I have received from family, friends, and my doctor. My roots run deep. That keeps me strong. A big, beautiful tree (family tree) with very large, deep roots.” Participant 19, description from key: “My family gives me unconditional love, which helps me find peace and strength.”

Discussion

The purpose of using body mapping in our study was to engage participants as co-producers of knowledge, critically exploring their unique experience through visual and textual elements while challenging them to search for meaning that represented their life and story as a COVID-19 long hauler. This study explored more than just the process of producing the body maps or the development of a methodology guide but included an in-depth qualitative interpretation, thus filling a gap poised in the literature (Coetzee et al., 2019; de Jager et al., 2016). Future research using arts-based methodologies can utilize the visual analysis process presented here to provide a more rigorous and systematic elucidation of visual data. The robust data outputs of body maps, testimonios, and keys from 19 participants were utilized to holistically analyze the embodied experiences as a COVID-19 long hauler and have created a deeper understanding of both shared and differing patient experiences. Visual data from the body maps included powerful colors, images, and words to describe the embodied experience of people living with long COVID-19. Textual data narrated journeys of COVID-19 long haulers, providing heartfelt and honest depictions of “Life before, during, and after COVID-19.” Together, body maps, testimonios, and keys produced by participants highlighted the “episodic disability” (Brown & O'Brien, 2021) created by long COVID-19 and the juxtaposition of anger, pain, and suffering with hope, silver linings, and strength.

Evidently, one of the biggest sources of barriers and challenges created by life with long COVID-19 is a broad and debilitating symptom profile (Hayes et al., 2021). Similar to findings from previous qualitative studies with COVID-19 long haulers (Hecht et al., 2023; Thomas et al., 2023), our work aligns with previous research that has identified the most prevalent symptom profiles associated with long COVID-19 (Aiyegbusi et al., 2021; Davis et al., 2021; Faghy et al., 2022; Raveendran et al., 2021). Symptoms cited in the current literature include “brain fog,” flu-like symptoms, and gastrointestinal symptoms, among others (Lechner-Scott et al., 2021; Raveendran et al., 2021). The burden of long-COVID is not only physical, as survivors may also experience effects on their relationships, mental health (Kingstone et al., 2020), changes in cognitive functioning (Crivelli et al., 2022), and quality of life (Jennings et al., 2021). Participants in the current study spent time detailing their physical (e.g., fogs/clouds around their head for brain fog) and non-physical (e.g., semi-colon representing suffering with mental health) symptomology artistically using symbols, color, and text. These representations not only aligned with some of the common effects unpacked in the literature but elucidated how each and every person has a unique tapestry of symptomatic experiences and lens through which those experiences are viewed.

The diverse experiences and emotions reported here and in previous qualitative research with COVID-19 long haulers (Hawke et al., 2023; Hecht et al., 2023; Pearson et al., 2022; Thomas et al., 2023) are consistent with broader research conducted via social media across several years of the pandemic (Miyake & Martin, 2021; Santarossa et al., 2022). Changes in self-identity were recognized as part of long COVID in a recent systematic review (Macpherson et al., 2022). As represented here, in the themes from the exercise ‘Self Portrait,’ patients with long COVID-19 feel

as though they need to put on a façade while at the same time sitting with and missing their “past self.” Struggling with current self and identity (Pearson et al., 2022) and the “episodic disability” created by long COVID-19 on personal identity (Thomas et al., 2023) has been indicated in other long COVID-19 research. It has been suggested that adjustment reaction and loss of sense of self could be added as common symptoms of patients with long COVID-19 (Pearson et al., 2022). To advance knowledge and treatment of long COVID-19, further patient-engaged research (e.g., patient-centered clinical comparative effectiveness trials) on understanding the lived experience and pathways to treatment/recovery is needed (Hawke et al., 2023; Hecht et al., 2023; Pearson et al., 2022).

Similar to Thomas et al. (2023) and Hawke et al. (2023) attempting to live with long COVID-19 was depicted here as requiring considerable support mechanisms (e.g., faith, friends and family, and the medical community) that aim to help individuals understand changes in their physical, mental, and emotional health. Unfortunately, many people with long COVID-19 report having struggled to have their condition recognized (Boix & Merino, 2022). Qualitative interviews and focus groups with long COVID-19 patients found that feelings of stigmatization, difficulty with accessing and navigating health services, and a need to “prove” the validity of their condition to healthcare providers were common experiences (Hawke et al., 2023; Kingstone et al., 2020; Ladds et al., 2020). Reflective of this in the body maps, testimonios, and keys produced in the current study, “Messages to Others” focused on advocacy around long COVID-19 “being real” and insisting patients with long COVID-19 need to be heard. Clinically, health professionals are urged to listen, validate, and manage symptomatology among their patients with long COVID (eBioMedicine, 2022).

Limitations

Race/ethnicity and other sociodemographic information were not explicitly collected in the current study and are recognized as a major shortcoming. Of the data collected, the sample was predominately comprised of self-identifying females. Long COVID-19 has a tendency to present more commonly in females than males (Sylvester et al., 2022); however, ethnic minorities have been disproportionately affected by the COVID-19 pandemic (Jalja et al., 2022; Kirby, 2020; Tai et al., 2022) and there is a paucity of long COVID-19 research inclusive of ethnic diversity, male representation, young people, low socioeconomic groups, and small sample sizes (Davis et al., 2021; Hawke et al., 2023; Hecht et al., 2023; Ladds et al., 2020; Macpherson et al., 2022; Thomas et al., 2023). Although comparable to other published body mapping studies (Gubrium et al., 2018; Skop, 2016; Smit et al., 2016), the sample size ($N = 19$) is small. Due to the sampling techniques used in this study, selection bias and, more specifically, volunteer bias are present. Thus, the results are not representative of the entire long COVID-19 population. Future studies need to explore a more diverse sample, and perhaps use random sampling techniques to make findings generalizable.

Conclusion

This study utilized an art-based research method, VBM, to understand the lived experiences of 19 COVID-19 long haulers. Filling a gap in the literature, this study used a rigorous and systematic method for visual analysis. The analysis protocol and findings presented can encourage future researchers to continue to promote quality and reproducibility in qualitative and, more specifically, visual analyses. The body maps helped participants understand and express their long COVID-19 experiences in unique ways that cannot always be expressed verbally or in writing. Participants took various artistic approaches to depict the symptomatology of long COVID-19.

Experiences, emotions, and the impact of long COVID-19 on identity were explored, and support systems were highlighted. Participants want providers to know that their condition is valid and deserving of empathetic care. Importantly, this study adds to the limited literature about long COVID-19 and introduces VBM as a relevant person-centered qualitative method for exploring chronic disease.

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Disclaimer

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Notes on Contributors

Sara Santarossa, PhD is an Assistant Scientist in the Department of Public Health Sciences at Henry Ford Health and the Scientific Director of the Patient-Engaged Research Center. She is committed to using diverse participant-driven methodologies that combine both qualitative and quantitative approaches and has expertise in engaging with diverse communities to improve patient-centered outcomes.

Ashley Redding, MPH is an Epidemiologist in the Department of Public Health Sciences at Henry Ford Health, focused on research methods and data analysis. She facilitates stakeholder collaborations and outreach, and supports with project planning, mixed-method data analysis, and grant and manuscript preparation.

Dana Murphy, BA is the Project Manager of the Patient Engaged Research Center. She manages the Patient Advisor Program, a sustainable, Henry Ford Health system-wide initiative where patients and caregivers partner with stakeholders to advise on process improvement efforts and provide feedback to make healthcare and research more patient-centered.

ORCID

Sara Santarossa, <https://orcid.org/0000-0003-3038-4976>

Ashley Redding, <https://orcid.org/0000-0002-8119-1448>

Dana Murphy, <https://orcid.org/0009-0007-0640-3301>