Pioneering Virtual Body Mapping: A Methodological Guide for Researchers Using a Health-Affected Population as an Example

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ABSTRACT

The rapidity of the COVID-19 pandemic and the ensuing recognition of post-acute sequela of COVID-19 (PASC) or long COVID-19 has created a need to understand the experience of those suffering from this long-term sequela. The purpose of this research was to explore, and uplift lived experiences of patients with long COVID-19. This study had a total sample of 19 participants with long COVID-19 engaged in body mapping, an arts-based research method. Describing the novel virtual adaptations to the body mapping methodology is the focus of this article. The material presented provides researchers with a methodological road map by outlining the virtual adaptations in the preparation and facilitation of the body mapping process, sharing lessons learned in data collection, highlighting considerations for future studies, and summarizing the impact of the findings. Virtual body mapping sessions acted as powerful and emotional events where participants showed true vulnerability describing their experiences with COVID-19, their journey as a long hauler, their places of personal strength and courage, and their dreams for the future. Participants were highly engaged and interested in sharing their art with the broader community. Virtual body mapping is a novel approach to conducting qualitative research in a unique setting and can provide an opportunity for innovative knowledge dissemination activities. While this method may contribute to increased participation and engagement, it may also present challenges, such as lessened accountability and interaction.

KEYWORDS: body mapping, arts-based research, methodology, health, long COVID-19, post-acute sequela of COVID-19.

In the United States alone, over 94 million cases of COVID-19 have been reported as of September 2022 (Centers for Disease Control and Prevention [CDC], 2022). The pandemic abruptly ushered in significant changes to health delivery, including a pivot to telehealth to meet patient needs (Friedman et al., 2022; Suran, 2022). This virtual shift has also been applied to research settings. To comply with pandemic restrictions, research teams found themselves needing to adapt traditionally in-person methodologies to virtual settings in order to heed social distancing constraints as well as prioritize the safety of participants and researchers (Roberts et al., 2021).

Qualitative methodologies, which rely on the researcher's ability to build relationships, establish empathy, and create safe spaces, were especially affected by the sudden shift from face-to-face settings (Archibald et al., 2019). Researchers in this field were forced to adapt their approaches to qualitative data collection and analysis (Tremblay et al., 2021), and many turned to

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virtual methods, including modalities such as emails, video-conference platforms, live chats, and cell phone calls (Roberts et al., 2021; Singh et al., 2022). This uptake in virtual methods, coupled with increased technology use because of the pandemic (McClain et al., 2021), warrants the need to advance current knowledge of virtual methodologies and create additional guidance on the maintenance of rigor and rapport.

The concept of body mapping, defined as "a visual technique that is used to collect qualitative data from participants about their subjective experiences pertaining mainly to bodily experiences" (Coetzee et al., 2019) is traced back to 1987 (de Jager et al., 2016), wherein women in Jamaica were asked to map their reproductive system as a means of expressing their sexuality and conceptualizing their reproductive system (MacCormack & Draper, 2013). Since then, body mapping has gained traction in the social sciences and has been used to understand a myriad of lived experiences (Aroussi et al., 2022; Brodyn et al., 2021; Orchard et al., 2014; Wallace et al., 2018). For example, Brodyn et al. (2021) used the method in a community-based sample of youths who were asked to think about their developing bodies and their relationships to their bodies across time. Aroussi et al. (2022) utilized body mapping to understand violent extremism in local Kenyan communities, noting the ability of the method to uplift marginalized voices. Its unique ability to depict experiences, as well as its use in diverse settings, correctly indicates that body mapping is an innovative approach, generating knowledge that only can be understood in relation to the creators' lived experiences.

At present, three manuals on body mapping have been published (Gastaldo et al., 2012; Skop, 2016; Solomon, 2011). Solomon's manual, created in the context of HIV/AIDS but applicable to other settings, is a group therapeutic tool drawing on the philosophy of art therapy. Gastaldo's et al. (2012) manual, drawing on Solomon's (2011) work, describes how to use body mapping in a "one-to-one" individual research environment. The third manual, created by Skop (2016), pushes the Gastaldo et al. (2012) manual a step further, outlining how body mapping can be used as a research method in group settings.

The purpose of this article is to replicate work done by Skop (2016) where they write of "a methodological road map" outlining the design and implementation of their body mapping research, incorporating lessons learned, and practical and ethical considerations for future studies. We follow a similar format to Skop (2016); however, the current paper describes a novel form of this artistic methodology, what we have coined 'virtual body mapping (VBM)'. We used VBM to identify issues that matter to patient stakeholders (N=19). The voices and lived experiences of those suffering from post-acute sequela of COVID-19 (PASC) or "long COVID-19" have been leveraged through this unique, reflective, and artistic experience. Although led by Henry Ford Health (HFH) in Detroit, Michigan, the virtual nature allowed for stakeholders from throughout Metro Detroit to participate.

Methods

Research Overview

While most patients with COVID-19 survive the infection (case-fatality rate in the US is 1.8%) (Johns Hopkins University & Medicine, n.d.) its symptomatic effects can vary drastically from one individual to another. PASC or long COVID-19, is a crippling aftermath of the pandemic wherein 10-30% of patients diagnosed with COVID-19 continue to experience symptoms after their infection period is over (Kingstone et al., 2020; Ladds et al., 2020). These symptoms, which can include fatigue, shortness of breath, "brain fog," sleep disorders, fevers, gastrointestinal symptoms, anxiety, and depression, can persist for months and can range from mild to

incapacitating (Kingstone et al., 2020). To date there is no formal definition or consensus on terminology for long COVID-19, risk factors for who will experience long COVID-19 are still emerging, and there is uncertainty regarding how to alleviate the symptoms of long COVID-19 (Lerner et al., 2021). The number of people affected by COVID-19 is unprecedented, and although the magnitude of long COVID-19 remains unknown given the diverse number of individuals who have been or will be infected with SARS-CoV-2, the public health impact of long COVID-19 could be profound (National Institutes of Health [NIH], 2021).

Figure 1
Body Map of Participant 3, a Female who Became Sick with COVID-19 in 2020

Our research team pioneered an innovative VBM approach to allow patients with long COVID-19 to describe their journey with this condition, connecting on biological, emotional, and social levels in their narratives and supporting their visualization of problems faced and sources of strengths (Figure 1).

Rationale for Using Body Mapping

While body mapping is a methodology employed in health and humanities literature, its use in a virtual setting, focused on long COVID-19, is novel. Thus, traditional body mapping strategies, facilitation guides, and tools/resources were altered. Virtual adaptations included, but are not limited to, video-conference platform training, session e-resources and PowerPoints, mailing of supplies, and a planned hybrid (i.e., virtual, and in-person components) gallery. All virtual adaptations are discussed in detail below.

Participant Recruitment

Based on previous literature, what was deemed manageable for the research team's timeline, and funding availability, a goal of 25 participants was established. A purposive sample of 36 participants was recruited through various strategies at HFH, the subsequent broader community of Metro Detroit, Michigan, and surrounding areas. Specific recruitment strategies included circulating recruitment assets on HFH social media and webpages and directly emailing patients that were identified in the Electronic Medical Records as patients with long COVID-19 (ICD10 code U09. 9 and flagged by the HFH COVID Recovery Care Program). In addition, a snowball sampling technique was utilized wherein HFH's Patient Engaged Research Center (PERC) circulated recruitment materials to the members of their Patient Advisor Program (N=483 patient and caregivers), asking they share the opportunity with any persons with long COVID-19 they know.

To the study team's surprise, the study inbox was inundated with emails from persons with long COVID-19 who had seen recruitment materials and were hoping for treatment options. Those who were not interested in participating in VBM, but were hopeful for treatment opportunities, were forwarded on to the HFH COVID Recovery Care Program (i.e., a service helping HFH primary care providers treat patients with long-COVID symptoms) and offered the opportunity to put their email in a 'COVID-19 mailing list' for future available research endeavors.

Table 1
Virtual Body Mapping Session Protocol for Patients with Long COVID-19

	Group 1	Group 2	Group 3	Group 4	Group 5
Location	Virtual	Virtual	Virtual	Virtual	Virtual
Time	Oct-Nov/21	Nov-Dec/22	Jan-Feb/22	Jan-Feb/22	Feb-Mar/22
# of initial interested participant	5	5	10	5	8
# of completed participants	3	3	7	1	5
# of sessions	3	3	3	3	3
Session frequency	Bi-weekly	Bi-weekly	Bi-weekly	Bi-weekly	Bi-weekly
duration	2 hours	2 hours	2 hours	2 hours	2 hours

All communication with interested participants (N=36) occurred through email and digital consent forms were sent via REDCap (Research Electronic Data Capture). There was attrition during the data collection, wherein only 20 participants completed all body mapping sessions and successfully returned materials to the research team for analysis (Table 1). Reasons for attrition varied across groups. In Group 1, after expressing initial interest, two participants were lost to follow up and did not complete the consent form. In Group 2, one participant completed consent, was mailed supplies, and attended a portion of the first session, but could not commit fully due to work schedule and dropped out of the experience. Another participant in Group 2 completed all sessions but did not return mail their body map and, after several attempts, could not be reached by the study team. Two participants in Group 3 were lost to follow up and did not complete the consent form, whereas another completed consent, was mailed supplies, but did not sign into virtual sessions and was thus lost to follow up. In Group 4, three participants were lost to follow up after signing the consent form, with one stating they were too sick to participate and asked to drop from the experience. Lastly, in Group 5 all three participants were lost to follow up after signing the

consent form and being mailed their supplies. A single participant was excluded from final analysis as not enough information surrounding the content on their body map was provided. The final data corpus was 19 body maps, stories, and keys.

Data Collection

VBM involved two phases of data collection: preparation and facilitation. Not discussed in this article is the extensive qualitative analysis done on all data components (i.e., body map, story, and key) as well as analysis completed on the audio/video recorded sessions for all groups. The remainder of the article aims to elucidate the VBM process to assist researchers who are interested in using this method.

Preparation for Using Virtual Body Mapping

Art activities outlined in Gastaldo's et al. (2012) body mapping manual were adapted to fit the research topic of patients with long COVID-19 (Appendix A).

Other preparatory tasks included members of the research team receiving virtual training on body map facilitation from a certified art therapist. In this training, the research team members created their own body maps using a virtual platform - acting as a test for feasibility of the activities (time allocation, simplicity of instructions, supplies provided, adapted virtual exercises). This training provided the research team members an opportunity to walk through the entire body mapping process physically and emotionally from start to finish, gaining the experience of the patient/participant. In addition, the training covered how participants can visually express healthcare experiences. It included how to anticipate the emotional triggers that can occur during this process, as well as how to develop prevention and intervention strategies to maximize the emotional safety of individual participants and the group. Lastly, this first-hand experience allowed the research team to make the appropriate revisions for body mapping in a virtual setting. These adaptions included developing VBM session-specific PowerPoint presentations. These presentations were created to help participants follow along in the virtual setting. For example, during session exercises, helpful prompts of what participants should be working on, or cueing words/phrases would stay on the screen while participants were able to go off camera and work on their body maps.

Additional adaptations included creating a 'Body Mapping Mail Kit' that would be distributed to each participant via post mail. The Body Mapping Mail Kit included a variety of art supplies, a 3'x 6' sheet of brown art paper (for the body map), a protective mailing tube which would serve as the vehicle by which participants would return/send their body maps back to the research team upon completion, and a Participant Workbook. The Participant Workbook was created to support participant engagement during all the sessions and mirrored the VBM session-specific PowerPoint presentations. The Participant Workbook included spaces for participants to take notes, provided information about the purpose of the project and how to prepare for each session, and space to complete in- and out- of session exercises. The Workbook acted as a rough draft of the final Key and Story E-booklet. Participants were encouraged to describe any/all key information regarding the creations they included in their body map at that time.

Moreover, based on participant feedback from Groups 1 and 2, a 'Key and Story E-booklet' (i.e., a fillable PDF document) was created to help organize output generated from session exercises allowing the key and story to be developed concisely. The E-booklet was emailed to all participants in all remaining groups prior to their third and final VBM session. The E-booklet included definitions of what was meant by 'key' and 'story' and instructions on how to create these data

elements. For example, participants were prompted to create their story using their body map as a guide, and to go through the Participant Workbook to craft the final body map key. Participants were reminded that the information provided through the story and key would be displayed with their body map artwork to help the audience understand their body map and long COVID-19 journey. This additional participant resource allowed participants to type out the final draft of their key and their story, keeping it neat and organized, and email it back to the research team directly.

Adaptations for VBM also involved how the study team prepared participants for their experience, prior to their first session. Webex was used as the VBM platform, thus informational and practice sessions were held by the research team to ensure participants felt comfortable utilizing this tool. Mirroring the content provided in the Participant Workbook, a summary email, including detailed session breakdown, was sent prior to each session to ensure participants were adequately prepared.

Facilitation of Virtual Body Mapping Sessions

All session exercises and objectives are outlined in Appendix A. Each session had one facilitator, who led the group through the outlined exercises, and at least one assistant, who was able to support participants with technical issues and monitored the group chat feature on the Webex platform. It was emphasized throughout each session that the experience was a 'safe space' and that questions could be asked at any point (e.g., come off mute, utilize the chat feature, email the study team privately). For all sessions, while participants logged in (at the onset of the session) the facilitator and assistant had their cameras on, asked all participants to remain on mute, and the specified session PowerPoint was displayed on the screen. Before every session began, participants were reminded of what was outlined in their written consent forms, including the fact that all sessions are audio/video recorded (for future analysis purposes). In addition, to be mindful of time, session exercises had a predetermined time limit allotted to them. Below, each session and subsequent session exercises are described in further detail.

Session 1: The Long COVID-19 Experience. This initial session acted as a time to develop trust, clarify the study focus, understand the body mapping process and expectations, and begin the artistic journey. The facilitator transitioned into a welcome slide where participants were primed with an understanding that much of the first session would involve administrative tasks, and the facilitator encouraged participants to turn on their camera in the hopes of building group cohesion. Next, the facilitator and assistant(s) took time to introduce themselves and their roles/responsibilities.

Following introductions, four group expectations were outlined and included: 1) Social space (i.e., the environment was meant to be a friendly and positive; even though sessions had a facilitator, the participants were really the leaders of the experience), 2) Ask questions (i.e., curiosity was welcomed and encouraged; emphasized that there are no irrelevant questions), 3) No judgement (i.e., it was emphasized that the participants did not need to be an "artist", that there would be no criticism, and outputs were not being analyzed in a way that was based on artistic skill), and 4) Do your best (i.e., highlighting that this was an individual experience and a space for reflection). Background information was provided on the projected outcomes and outputs of the project, including the funding mechanism and the impact the data would have on long COVID-19. The body mapping methodology was then described by way of examples found in the literature.

Time was then taken to remind the participants of how they were to prepare for the session. Participants were provided with a pre-session checklist (e.g., received Body Mapping Mail Kit), a list of suggestions for finding their ideal workspace (e.g., quiet place free of distractions, hard surface for drawing on, etc.), and helpful tips (e.g., they would need to trace their body and may

find it helpful to have a partner assist). Supplies received in the Body Mapping Mail Kit were reviewed and participants were encouraged to, in addition to the art mediums provided, use "found objects" (e.g., personal photos, magazine pictures, mixed media, etc.). Participants were encouraged to use as few or as many art media (Figures 2).

Figure 2
On the left, an example of a body map using mix media supplies such as pictures, text, textured paper, markers, and found objects. On the right, an example of a body map using only markers.
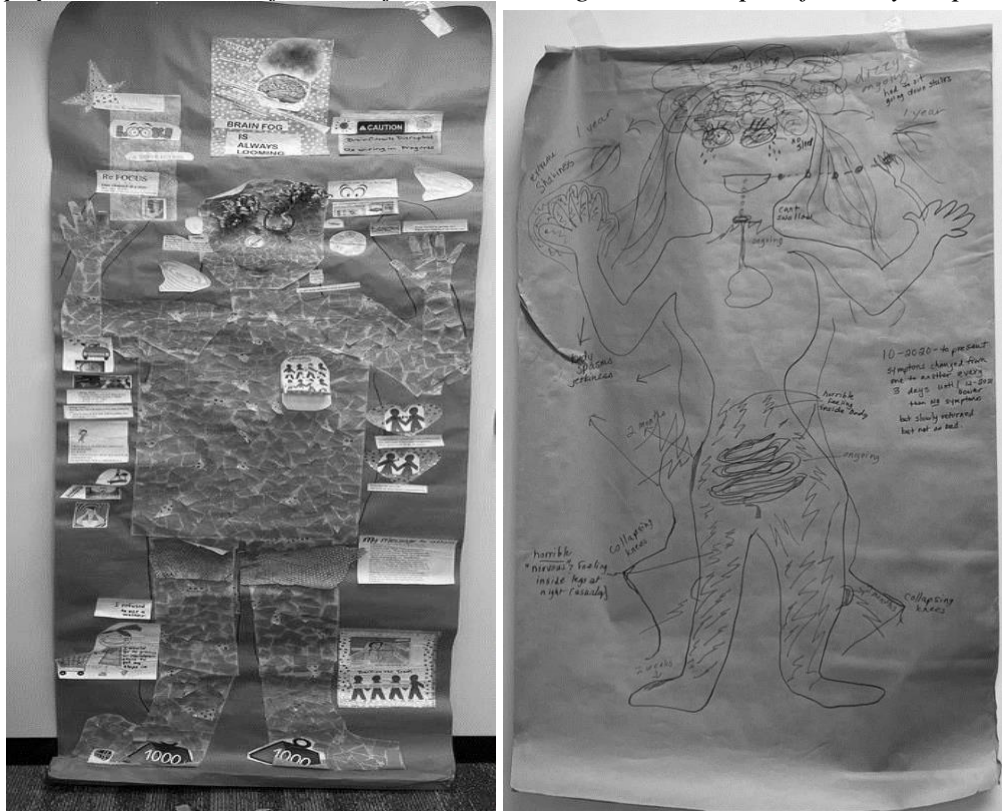
Session exercises ensued (Appendix A) using PowerPoint slides to visualize instructions and prompts. Following the completion of the session exercises, participants were asked to use their Participant Workbook (the facilitator would indicate the pages to utilize) and record, in words, how they portrayed their long COVID-19 journey on their body map. The facilitator also prompted the participants to use the Participant Workbook exercise pages to help organize the portrayal of their long COVID-19 journey on their body map using the following categories: body posture, colors, lines/texture, and shapes/symbols.

Lastly, participants were provided their homework activity and reminders for the second session. Homework involved creating a personal symbol and slogan related to their COVID-19 journey that would be shared with the group at the next session. A definition was given for 'symbol' and 'slogan', along with examples of each. Reminders for the next session were given, including completing their homework activity and gathering additional art mediums for the body maps. Participants were encouraged to complete any of the Session 1 exercises they did not finish but were asked not to work ahead on any of the Session 2 objectives/exercises. In addition, a list of mental health resources was emailed to the group to aid in supporting with any emotions or feelings which arose.

Session 2: The Life of a COVID-19 Long Hauler. The second session began with a group check-in, gathering any comments, concerns, or questions from the participants. Group expectations outlined in Session 1 were re-visited. Like Session 1, participants were provided with a pre-session checklist (i.e., completing Session 1's homework) and a list of suggestions for finding their ideal workspace. A recap of Session 1 was provided, which briefly reviewed all the previous session exercises. Again, as in Session 1, session exercises ensued (Appendix A) using PowerPoint slides to visualize instructions and prompts. Participants were prompted to utilize the Participant Workbook, and their homework activity and reminders for Session 3 were provided. Homework included preparing a brief message to others regarding their long COVID-19 condition. Reminders were similar to Session 1.

Session 3: Resilience and Coping. As in Session 2, this third and final session began with a group check-in, review of group expectations and preparatory tasks (e.g., homework, workspace, preparation to share and describe body map to the larger group), and a recap of the previous session exercises. Just like Sessions 1 and 2, Session 3 exercises ensued (Appendix A) using PowerPoint slides to visualize instructions and prompts, and participants were prompted to utilize the Participant Workbook as well as the Key and Story E-booklet. In this final session, participants were asked to share their body map with the larger group. The facilitator instructed the participants to come on camera and walk the other group members through an explanation of what had been created. In this final session, homework included completing all unfinished session exercises, finalizing the body map, and composing their story and key using the Key and Story E-booklet.

Lastly, very clear instructions were provided to participants on how to return all assets within a 1-week timeframe of session completion. Participants were instructed to email the completed Key and Story E-booklet back to the project team. Participants were further instructed to physically mail back their body map and Participant Workbook, using the protective mailing tube, which had been originally sent to them housing project supplies. The protective mailing tube had been pre-labeled with return address information.

Data Analysis

An adapted method for body mapping analysis (Gastaldo et al., 2012; Skop, 2016) was used, including a visual analysis as well as a content analysis of the written text of the keys and stories, will be published elsewhere. The authors, however, feel it is important to emphasize the patient-centered approaches used in analysis as it adds another layer of novelty. Colaizzi's descriptive phenomenological method (Morrow et al., 2015), which involves bringing findings and phenomenon found by the researchers back to the participants for confirmation, was utilized. Specifically, to accomplish Colazzi's method, all data (body maps, keys, and stories) were sent to participants in a PDF via email. Participants were asked to review the data and then fill out a short digital survey. Embedded within the survey was a visual of all the themes identified previously by the research team. The survey contained three questions, with the first asking participants to rank (from 1-100) the accuracy of the researcher's themes, followed by two free-text response questions asking about any themes that were missed and overall feedback on the researcher's interpretation of the data. Based on the feedback collected from participants, the researchers can go back and modify earlier steps in the analysis. This "respondent validation" or member-checking is highly valued by the authors as it allows the participants the opportunity to analyze the data alongside the research team and provides a meaningful and intentional experience in the study's process.

Results

Though the purpose of this paper is to outline the novel body mapping method used, a summary of key findings is shared here to provide context to the reader surrounding the various outputs of this project. This study found that life before, during, and after COVID-19 were central to the analysis. Many of the participants described their journey with COVID-19 by sharing coping mechanisms and silver linings. For example, participant 1, a female who became sick with COVID-19 in March 2020 while working as a Registered Nurse stated:

> *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.*

Oftentimes messages of hope and advocacy were somehow woven into their art, and many highlighted a need for more treatments, research, and a clinical understanding of long COVID-19. For example, participant 14, a female in her mid-50s who contracted COVID-19 in March 2021, shared: "I wish for the things most wish for with long Covid. Resolving brain fog, normal breathing, no chest pain, overflowing energy." All the participants used symbols, shapes, colors, textures, and line work to represent aspects of their journey, with many visually representing their symptomology. For example, symbols such as flames in lungs, knives representing pain, and clouds showing brain fog were used by participants.

Table 2
Participant open-ended responses to satisfy Step 7 of Colazzi's method

"You were pretty much spot on"
"The interpretation of the data allowed me to get a glimpse of how the other long haulers felt and experienced life after the illness."
"I think the data you interpreted is very good and detailed."
"I'm very pleased and I thank you ALL for being such beautiful and caring souls, to the known and unknown participants!! I also look forward to participating in future COVID 19 studies and/or focus groups to help others in anyway I possibly am able to!! Please note; I truly believe, we all we're able to make it through COVID 19 on the living/life side, because of God's Grace, Mercy and God's shield/protection!!!!"
"I think the interpretation was good, all of the stories are so similar that it makes it difficult to pick up on the small differences."
"The body map was phenomenal for all the participants. I do appreciate the opportunity you all gave me thank you so much."
"I think you did a good job. It was comforting to see that I'm not alone."
"I think that it was well put together everyone Thoughts and concerns were presented"
"In my opinion as someone struggling with the aftermath of Covid 19, you have interpreted the data to the letter."
"From my own experience, and listening to the other participants in my group, I'd say you've got it covered!"
"It looks good to me"
"Looking at the chart it seems pretty reasonable. Thank you."

Of the 19 participants who completed their body mapping data and were sent the themes to review and provide feedback, 12 completed the survey aimed to satisfy Step 7 of Colazzi's method (Table 2). In response to how accurately the themes depicted the data a median score of 95.5/100 was provided. Overall, participants believed the themes represented the data and they were thankful for the experience, thus no modifications to the earlier steps in the analysis occurred.

Lessons Learned

As an important part of reflexivity and ability to replicate the VBM methodology in the future, lessons learned are discussed. The inclusion of training from an art therapist was critical to the authors deeper understanding of arts-based research methodologies and is highly recommended for anyone seeking to employ VBM. Moreover, recommendations for supporting IT literacy of participants is encouraged and has been mentioned in the literature surrounding video interviewing methodologies (Lobe et al., 2020). As mentioned above, informational and practice sessions were held by the research team to ensure participants felt comfortable utilizing the WebEx platform, which ultimately allowed the virtually session to run smoothly. The authors have learned that although the virtual nature of this project was positive for participant engagement, it also created less accountability and may not be as interactive as in-person sessions. Future projects wishing to utilize VBM should consider adding an additional session or more time during sessions to allow stakeholders to share more about their experiences, their body maps, and to engage further with others in the group. Another thought would be to host an optional in-person session which would serve to foster social support and comfort among participants, as they could physically meet those who will be in their online sessions in conjunction with building rapport with the session facilitator.

Conclusion

To date, the 19 body maps with their accompanying stories and keys have been exhibited in a curated gallery space in Detroit, Michigan. The exhibit, entitled the "COVID Body Mapping Gallery: An Immersive Experience of Patient Perspectives" ended its month-long run with a reception event where the participants and their families, clinical providers, and the broader community were invited to engage. The reception event had 83 attendees and featured an art therapy workshop (Figure 3). All attendees of the reception event signed a media release form, and all participants provided informed consent for their body map data to be photographed for use in further knowledge dissemination and exchange endeavors. In addition to this in-person exhibit and reception event, all body map data is also housed in a virtual gallery format (https://bit.ly/PERCBodyMapping) so that the artwork and patient perspective can live on and reach a vast and diverse audience.

Pioneering VBM as a methodology has contributed to the field of qualitative inquiry, healthcare research, the science of engagement with patient participants, and understanding long COVID-19 from a real-life perspective. The virtual adaptations discussed here highlight innovative practices that further push the boundaries of how body mapping and other arts-based research modalities can be used. Specifically, the catchment area in which participants can participate is vastly expanded using a virtual format. For example, researchers seeking to understand health afflictions on a global scale can bring together participants from differing regions or countries to compare perspectives in a creative medium. Ultimately, VBM is a methodology that can be implemented by a research team looking to explore health indicators or perceived health risks. It's a way to gather data about participants' personal health journeys—as well as the social, political, and economic influences in their lives. VBM can be used to engage participants in a critical

examination of the meaning of their unique experiences, which cannot simply be achieved through talking. The compilation of output from this VBM experience will be used to generate patient-centered research questions about long COVID-19, a condition where very little is currently known.

Figure 3
Images taken at the COVID Body Mapping Gallery: An Immersive Experience of Patient Perspectives.

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Disclaimer

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References

Archibald, M. M., Ambagtsheer, R. C., Casey, M. G., & Lawless, M. (2019). Using Zoom videoconferencing for qualitative data collection: Perceptions and experiences of researchers and participants. *International Journal of Qualitative Methods*, *18*, Article 1609406919874596. https://doi.org/10.1177/1609406919874596

Aroussi, S., Badurdeen, F. A., Verhoest, X., & Jakala, M. (2022). Seeing bodies in social sciences research: Body mapping and violent extremism in Kenya. *Qualitative Research*. Advance online publication. https://doi.org/10.1177/14687941221096598

Brodyn, A., Lee, S. Y., Futrell, E., Bennett, I., Bouris, A., Jagoda, P., & Gilliam, M. (2021). Body mapping and story circles in sexual health research with youth of color: Methodological insights and study findings from adolescent X, an art-based research project. *Health Promotion Practice*, *23*(4), 594–608. https://doi.org/10.1177/15248399211039796

Centers for Disease Control and Prevention. (2022). *COVID data tracker*. https://covid.cdc.gov/covid-data-tracker/#cases_totalcases

Coetzee, B., Roomaney, R., Willis, N., Kagee, A. (2019). Body Mapping in Research. In: Liamputtong, P. (eds) Handbook of Research Methods in Health Social Sciences. Springer, Singapore. https://doi.org/10.1007/978-981-10-5251-4_3

de Jager, A., Tewson, A., Ludlow, B., & Boydell, K. (2016). Embodied ways of storying the self: A systematic review of body-mapping. *Forum: Qualitative Social Research*, *17*(2), Article 22. https://doi.org/10.17169/fqs-17.2.2526

Friedman, A. B., Gervasi, S., Song, H., Bond, A. M., Chen, A. T., Bergman, A., David, G., Bailey, J. M., Brooks, R., & Smith-McLallen, A. (2022). Telemedicine catches on: changes in the utilization of telemedicine services during the COVID-19 pandemic. *Am J Manag Care*, *28*(1), e1–e6. https://doi.org/10.37765/ajmc.2022.88771

Gastaldo, D., Magalhães, L., Carrasco, C., & Davy, C. (2012). *Body-map storytelling as research: Methodological considerations for telling the stories of undocumented workers through body mapping*. http://www.migrationhealth.ca/undocumented-workers-ontario/body-mapping

Johns Hopkins University & Medicine (n.d.). Coronavirus resource center: Mortality analyses. https://coronavirus.jhu.edu/data/mortality.

Kingstone, T., Taylor, A. K., O'Donnell, C. A., Atherton, H., Blane, D. N., & Chew-Graham, C. A. (2020). Finding the 'right' GP: A qualitative study of the experiences of people with long-COVID. *BJGP Open*, *4*(5), 1–12. https://doi.org/10.3399/bjgpopen20X101143

Ladds, E., Rushforth, A., Wieringa, S., Taylor, S., Rayner, C., Husain, L., & Greenhalgh, T. (2020). Persistent symptoms after Covid-19: Qualitative study of 114 "long Covid" patients and draft quality principles for services. *BMC Health Services Research*, *20*(1), 1–13. https://doi.org/10.1186/s12913-020-06001-y

Lerner, A. M., Robinson, D. A., Yang, L., Williams, C. F., Newman, L. M., Breen, J. J., Eisinger, R. W., Schneider, J. S., Adimora, A. A., & Erbelding, E. J. (2021). Toward understanding COVID-19 recovery: National Institutes of Health workshop on postacute COVID-19. *Annals of Internal Medicine*, *174*(7), 999–1003. https://doi.org/10.7326/M21-1043

Lobe, B., Morgan, D., & Hoffman, K. A. (2020). Qualitative data collection in an era of social distancing. *International Journal of Qualitative Methods*, *19*, 1–8. https://doi.org/10.1177/1609406920937875

MacCormack, C. P., & Draper, A. (2013). Social and cognitive aspects of female sexuality in Jamaica. In *The cultural construction of sexuality* (pp. 155–177). Routledge.

McClain, C., Vogels, E. A., Perrin, A., Sechopoulos, S., & Raine, L. (2021). *The Internet and the pandemic*. Pew Research Center. https://www.pewresearch.org/internet/2021/09/01/the-internet-and-the-pandemic/

Morrow, R., Rodriguez, A., & King, N. (2015). Colaizzi's descriptive phenomenological method. *The Psychologist*, *28*(8), 643–644.

National Institutes of Health. (2021). *NIH launches new initiative to study "Long COVID"*. https://www.nih.gov/about-nih/who-we-are/nih-director/statements/nih-launches-new-initiative-study-long-covid

Orchard, T., Smith, T., Michelow, W., Salters, K., & Hogg, B. (2014). Imagining adherence: Body mapping research with HIV-positive men and women in Canada. *AIDS Research and Human Retroviruses*, *30*(4), 337–338.

Roberts, J. K., Pavlakis, A. E., & Richards, M. P. (2021). It's more complicated than it seems: Virtual qualitative research in the COVID-19 era. *International Journal of Qualitative Methods*, *20*, Article 16094069211002959. https://doi.org/10.1177/16094069211002959

Singh, H., Tang, T., Thombs, R., Armas, A., Nie, J. X., Nelson, M. L. A., & Gray, C. S. (2022). Methodological insights from a virtual, team-based rapid qualitative method applied to a study of providers' perspectives of the COVID-19 pandemic impact on hospital-to-home transitions. *International Journal of Qualitative Methods*, *21*, Article 16094069221107144. https://doi.org/10.1177/16094069221107144

Skop, M. (2016). The art of body mapping: A methodological guide for social work researchers. *Aotearoa New Zealand Social Work*, *28*(4), 29–43. https://doi.org/10.11157/anzswj-vol28iss4id295

Solomon, J. (2011, March 21). Living with X": A body mapping journey in time of HIV and AIDS. *Facilitator's Guide. Psychosocial Wellbeing Series*. https://www.comminit.com/hiv-aids-africa/content/living-x-body-mapping-journey-time-hiv-and-aids-facilitator%E2%80%99s-guide

Suran, M. (2022). Increased use of medicare telehealth during the pandemic. *JAMA*, *327*(4), 313. https://doi.org/10.1001/jama.2021.23332

Tremblay, S., Castiglione, S., Audet, L.-A., Desmarais, M., Horace, M., & Peláez, S. (2021). Conducting qualitative research to respond to COVID-19 challenges: Reflections for the present and beyond. *International Journal of Qualitative Methods*, *20*, Article 16094069211009679. https://doi.org/10.1177/16094069211009679

Wallace, H. J., McDonald, S., Belton, S., Miranda, A. I., da Costa, E., da Conceicao Matos, L., Henderson, H., & Taft, A. (2018). Body mapping to explore reproductive ethno-physiological beliefs and knowledge of contraception in Timor-Leste. *Qualitative Health Research*, *28*(7), 1171–1184. https://doi.org/10.1177/1049732317750382

Notes on Contributors

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Appendix A

Patients with Long COVID-19 Detailed Outline of Virtual Body Mapping Sessions

	Session Exercises	Objectives of Exercise for Participants	Prompts provided to Participants by Facilitator on the PowerPoint Slides	Homework Activity
Session 1	The Long COVID-19 Experience			
	1: Introduction to body mapping	1: To understand the relationship of body mapping to the goals on the overall project; remove intimidation related to drawing.	• Examples of body maps • Examples of showcasing body maps • Introduce art materials and how each can be used	Create a personal symbol and slogan.
	2: Body Scan	2: Brief guided meditation session (20 mins) for participants to understand where they are holding physical and/or emotional pain or limitations	• Find a comfortable position • Turn off camera off to help focus • Use Participant Workbook to record what was experienced	
	3: Body tracing	3: To outline the participant's body in a posture that is most characteristic of how they feel in relation to their long COVID-19 experience.	• Need brown paper and the material you want to trace your body • Shape, posture, and position of the body represents your covid19 experience • Tracing can be done with a partner	

	4: COVID-19 journey	4: To explore the representations of the participant's life before, during, and after their experience with COVID-19.	• How can you represent your journey visually?
			• Think about yourself before, during and after COVID- what is important for an audience to see? To feel?
			• Any feelings/emotions from body scan you can use to represent on your map?
			• What has changed for you physically, emotionally, mentally…?
			  o Have relationships changed?
			  o Have abilities changed?
			  o Has your body changed?
			• Has your mind changed?	

Session 2	The Life of a COVID-19 Long Hauler			
	1: Body Scan	1: Brief guided meditation session (20 mins) for participants to understand where they are holding physical and/or emotional pain or limitations.	• Find a comfortable position • Turn off camera off to help focus • Use Participant Workbook to record what was experienced	Prepare message to others regarding your long COVID-19 condition.
	2: Personal symbol and slogan	2: To represent participants' diverse COVID-19 journey using a symbol that is meaningful to them; to understand what motivates or what perspective participants have on life using a slogan.	• Group discussion for whomever is comfortable sharing • Incorporate your symbol and slogan onto your body map	

	3: Marks on/under the skin	3: To represent the impact of long COVID-19 visually and holistically.	• Explore the impacts of long COVID-19:
			  o Physical
			  o Mental
			  o Emotional
			  o Others are specific to you
			• Explore experience with healthcare providers
			• Explore experiences with relationship in your life
			• Reflect using your body scans
			•	

	4: Self-portrait	4: To encourage participants to carefully look or think of themselves in relation to how they appear to the world.	• Reflect on how you think you appear in the world • Develop what your face is saying, showing, and/or expressing • Do you feel you appear differently to different groups of people? • How could you show this on your body map?	

Session 3	Resilience & Coping			
	1: Message to others	1: To capture a message that the participant would like to give to the public about his/her experience.	• Group discussion for whomever is comfortable sharing • Incorporate your message onto your body map	Complete body map and Key and Story E-booklet, return assets to project team.
	2: Body scanning for difficulties and strengths	2: To represent the impact of long COVID-19 and personal relations, access to services that may promote/inhibit wellbeing, health disparities; to locate and visualize participants' place of personal power and strength.	• Identify key experiences that you have faced as a COVID-19 long hauler • Select key experiences to represent; think about symbols or images to capture such experiences • Make connections between your other drawings and the body (e.g., lines, arrows, etc.) • Where in your body and/or environment do you get the strength to overcome the challenges you have faced?	

	3: Support structures	3: To identify key people, institutions, agencies, or other avenues (i.e., support structures) that help support the participant in their daily struggles.	• Identify people or things that support you:
			  o Pick a representative color or symbol
			• Elaborate on these supports:
			  o What do they do to support you?
			• What does it mean to feel supported?	

	4: Drawing the future	4: To explore what participants are moving towards, their goals, and what they are striving for in relation to their long COVID-19 experience.	• What do you think will happen? • Where do you think you will be? • How do you imagine your future? • What is your vision, your goal or your dream? • What are you working towards?	
	5: Participant narrative about the story the body map tells	5: To capture the participant's experience in the way they would like it to be told to others.	• Stand back and look at your body map. • Create your story using your body map as a guide.	
	6: Sharing Creations	6: To provide an opportunity for the participant to briefly analyze his/her work and identify gaps/missing elements.	• What is your favorite part of your body map? • What is a part of your body map that speaks to you the most? • What part of your body map is the most motivational or inspirational for other to see?	

Note. Adapted from Gastaldo et al. (2012)