



When you can't find the words: Using body mapping to communicate patients' experiences of Long Covid

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ARTICLE INFO

Keywords:

Long Covid, COVID-19
Patient communication
Body mapping
Patient support
Chronic illness

ABSTRACT

The aim of this paper is to reflect on the value of body mapping in supporting patients to communicate their everyday experiences of Long Covid. Body maps are life-sized drawings of bodies and body mapping is used to discuss experiences through guided questions and answering those questions using colours, images and other prompts. This short paper focuses on the first of four body mapping workshops of this study, which was conducted in June 2023 in London with 4 participants in collaboration with Long Covid Support. Our preliminary results suggest i) body mapping can offer novel insights into patients' experiences of Long Covid, ii) the method may be effectively applied as a tool for patients to communicate their symptoms and overall experiences to practitioners, friends, and family members, and iii) body mapping may be adapted to offer peer support as part of Long Covid advocacy. This has significant potential application as a resource for healthcare professionals and patient-led peer support and Long Covid advocacy work.

1. Introduction

Over 2 million people in the UK are currently experiencing Long Covid, where symptoms persist longer than 4 weeks after the initial confirmed or suspected SARS-CoV-2 infection (ONS, 2024; see also Ziauddeen et al., 2022). The range and severity of symptoms people experience can vary widely, and there are limited diagnostic and treatment options available (Michelen et al., 2021). Recent studies have begun to shed light on the numerous clinical symptoms (Whitaker et al., 2021; Sivan et al., 2022), the underlying mechanisms (Davis et al., 2023), and predictive factors for developing Long Covid (Sudre et al., 2021). Some qualitative studies have analysed patient wellbeing beyond physical symptoms, including quality of life and access to healthcare services and support (Baz et al., 2023; Macpherson et al., 2022; Ziegler et al., 2022). However, little is known about patients' holistic experience of the illness, including symptoms, access to services and support, impacts on work and home life, and how Long Covid has shaped the way patients view themselves. People with Long Covid often struggle to express themselves due to cognitive dysfunction, fatigue and, put simply, a lack of words to describe how they feel. They may also experience stigma, which can both discourage them from sharing their experiences and prevent them from being heard when they do speak (see also

Pantelic et al., 2022). Moreover, many patients have reported that healthcare providers are dismissive about patients' symptoms (Buttery et al., 2021; Ireson et al., 2022; Clutterbuck et al., 2024), which has added to the overall mental burden they face.

Responding to Callard and Perego (2021: 268) call for patient knowledge 'to be incorporated into how COVID-19 is conceptualised, researched, and treated', our research team, in collaboration with the patient-led charity Long Covid Support, has conducted interviews and body mapping to analyse women's diverse experiences with Long Covid. The focus on women reflects the fact that the prevalence of self-reported Long Covid symptoms is significantly higher in women (ONS, 2024). Moreover, studies have shown that women face, more often than men, dismissive attitudes by doctors, and women are less likely to be treated for chronic illnesses (Kolmes and Boerstler, 2020).

Body mapping is a research method used in social sciences and medical research as well as in art therapy to understand individual and collective experiences of different social phenomena, including experiences of health. Body mapping workshops allow participants to express their experiences by drawing, writing, and collaging their responses to a set of guided questions onto a life-sized outline map of their body, facilitating the sharing of their stories with others. It is an arts-based and qualitative research method particularly well-adapted for working with

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<https://doi.org/10.1016/j.healthplace.2024.103302>

Received 22 January 2024; Received in revised form 14 June 2024; Accepted 19 June 2024

Available online 10 July 2024

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people who may struggle to put their experiences into words (Boydell, 2021; Greenhough et al., 2024; Jokela-Pansini, 2022).

Between June 2023 and February 2024, we conducted four body mapping workshops in London and Oxford with a total of 13 Long Covid patients and three online follow-up meetings. Participants were recruited through our network of Long Covid research and advocacy groups. Ethics approval was granted by the University of Oxford Central University Research Ethics Committee, based at the School of Geography and the Environment. Conscious of how Long Covid may affect participants' abilities to participate, they had the possibility to interrupt or rest anytime, and food and refreshments were offered. We also worked to provide a space which limited the possibilities of reinfection, testing ourselves before running the workshop, wearing masks if requested and ensuring an open space with good ventilation. This short paper draws on initial findings and fieldwork notes from our first workshop conducted in June 2023 with four participants. The aim of this paper is to outline how body mapping may help people with Long Covid to communicate the impacts of the illness. Our preliminary findings are that: (i) body mapping as a research method can offer novel insights into patients' experiences of Long Covid; (ii) there is scope for the method to be effectively applied as a tool for patients to communicate their symptoms and overall experiences to practitioners, friends, and family members; and (iii) body mapping may be adapted in the future to offer peer support as part of Long Covid advocacy.

2. Research: Body mapping as a research tool for visualising patients' experiences of Long Covid

We are sitting in a small waiting area with coffee and biscuits, talking through the experience of running our first body mapping workshop. We have seen first-hand the challenges people with Long Covid can face even getting to and participating in our in-person workshop and have been privileged to share their insights into the many other challenges they face in seeking to explain their experiences to an often sceptical outside world. What this exercise brought home was the lack of a language to express the impact of Long Covid. Patients rely on words with the closest related meaning, which often end up diminishing the severity of the actual symptom – for example, 'fatigue'. Fatigue infers a meaning similar to 'tiredness', but the actual experience is often drastically worse and feels more like a 'deep sickness'. Another example is the word 'brain fog' which patients felt didn't capture how debilitating the cognitive symptoms can be (Fieldwork notes and reflections, July 2023)

Body mapping, we found, provided an alternative way of capturing and representing patient experiences to a purely verbal account. Given the holistic nature of the illness and the wide variety of symptoms people experience, the body map acts as a useful prompt through which participants could catalogue symptoms, for example, how the illness fogged their brains (Fig. 1), limited their mobility due to issues with their lungs (Fig. 3), or disrupted their digestive systems (Fig. 4). Besides symptoms, participants talked about their overall feelings (Fig. 1: 'How I feel') and adapting to their new lives (Fig. 2). Furthermore, by giving participants the option to draw their bodies however they wished, for example, lying on their side, with or without hairstyles or mobility aids, we avoid beginning with an assumed 'normal body'. It can also help us to understand the factors that limit patient testimonies, allowing them to use text, images and other prompts and taking their own time carefully collaging their maps, which may be helpful for supporting patients with illnesses beyond Long Covid. In addition, the space beyond the body became an important feature of the maps, where patients identified wider structural factors, including experiences of employment, access to care and (in)accessible infrastructure which had significant impacts on their day-to-day lives (see Fig. 1: 'There is no treatment, the Long Covid clinic let me go as too sick for rehab').

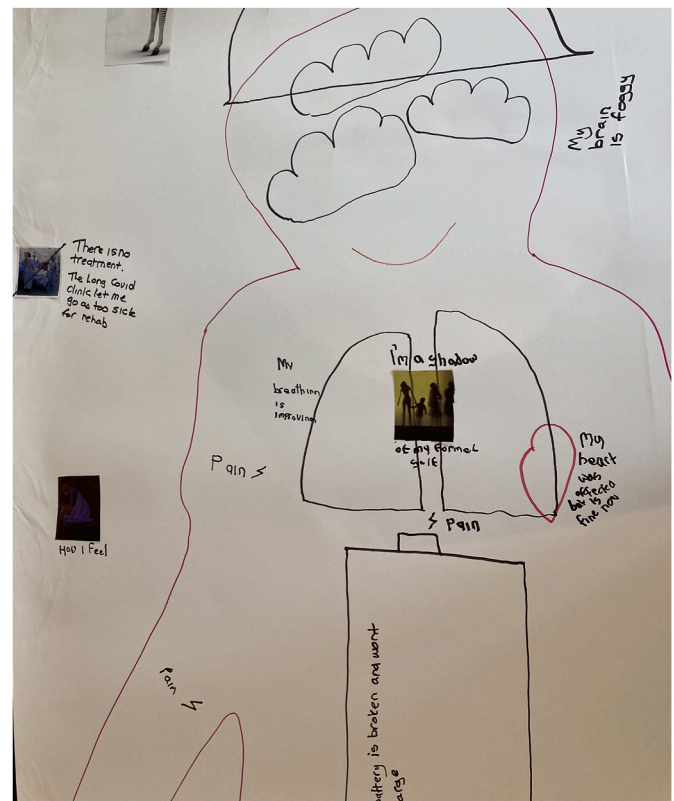


Fig. 1. Molly's body map.

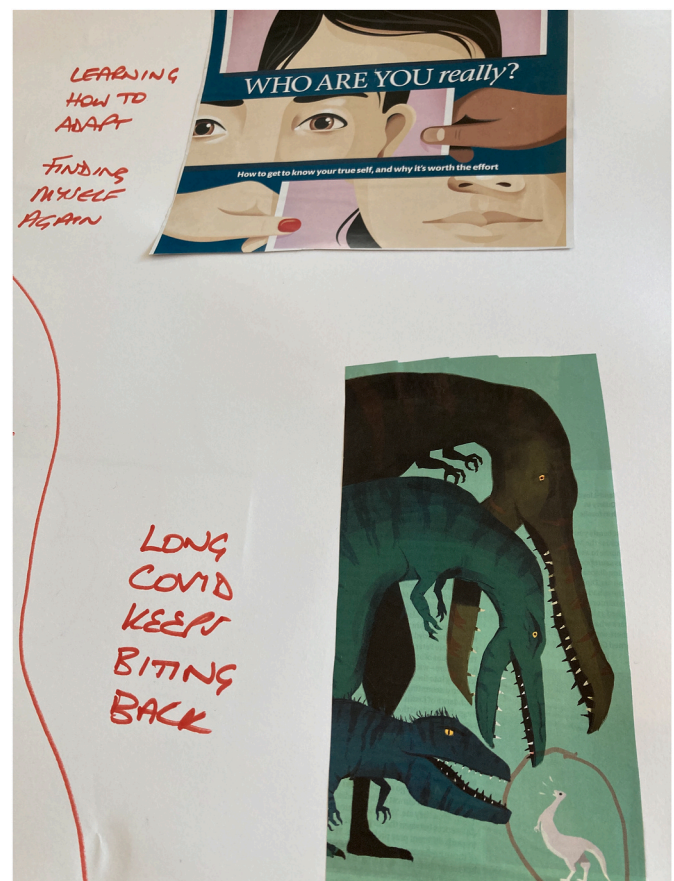


Fig. 2. Phoebe's body map.

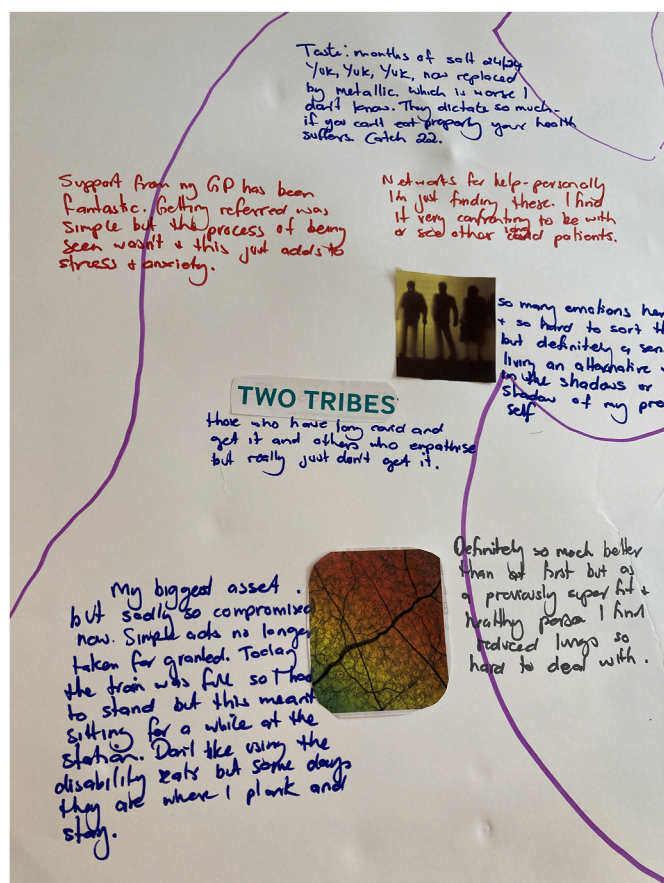


Fig. 3. Caroline's body map.

3. Practice: Body mapping as a tool to communicate symptoms and overall experiences to healthcare professionals, friends, and family members

The challenge is, one of our collaborators from Long Covid Support says, there are currently very few medical tests available, and even fewer that are accessible on the NHS which prove you have Long Covid. Instead, clinicians must rely on the testimony of patients to identify the range, scope and severity of symptoms. Those same symptoms, including for many: a sense of brain fog, a struggle to recall the right words and an often overwhelming, debilitating level of fatigue, make it hard for patients to deliver testimonies which truly capture the extent of their illness. Consequently, healthcare professionals may underestimate the impact of Long Covid, leading some to act in ways which leave patients feeling dismissed, unheard and without the referrals or advice they need to access the treatment and support that is available. It also contributes to the difficulty of communicating the experience to friends and family, exacerbating the feeling of loneliness many people with Long Covid experience. (Fieldwork notes, July 2023)

Since 2020, medical practitioners have established guidelines and recommendations for assessing Long Covid patients in primary care (Greenhalgh et al., 2022). General practitioners play a key role in deciding the medical support patients receive. However, assessing patients can be challenging because of the variety and fluctuating nature of symptoms (Michelen et al., 2021) or, as one patient put it, the illness 'keeps biting back' (see Fig. 2). In the UK there are established guidelines which encourage those delivering health care to integrate patient experience into the design and delivery of healthcare interventions (NHS, 2013). However, the data gathered to inform such practices often relies heavily on surveys and verbal feedback, such as collecting patient stories. To study chronic illnesses, practitioners sometimes use pain maps, allowing patients to locate and visualise in which parts of their

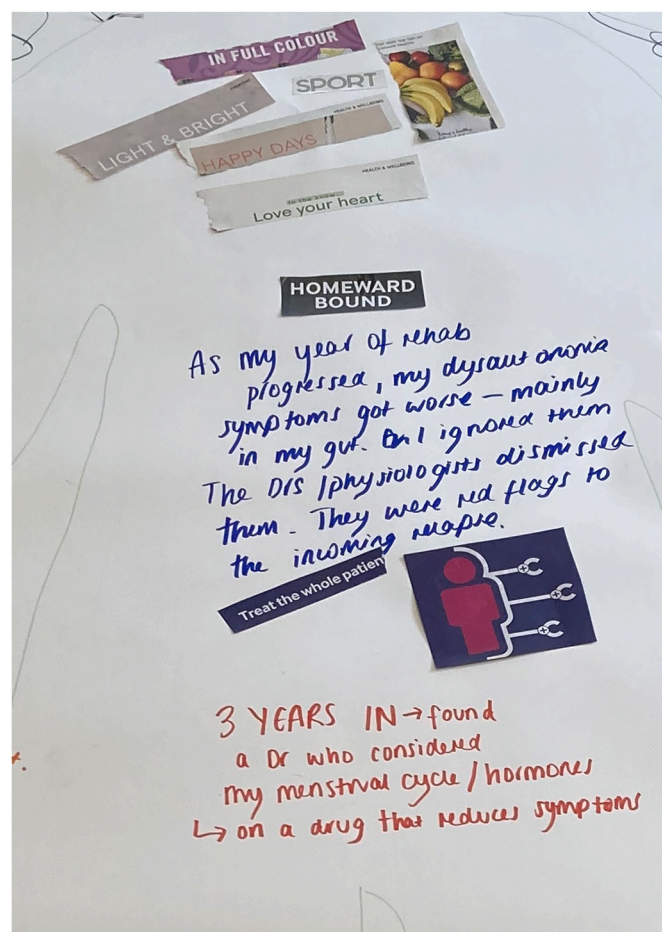


Fig. 4. Lisa's body map.

body they experience pain and how it feels (von Baeyer et al., 2011). In a similar way, body-mapping tools could be adapted for use with patients with Long Covid in a clinical context, allowing both clinicians and patients to more comprehensively record Long Covid symptoms and their impacts on patients.

4. Patient support: Body mapping as a tool for Long Covid peer support

Our participants found the experience very powerful and felt so many people could benefit from it. How many of these workshops could we do, we ask? How could we make them accessible to more people? Could we do them online? With bigger groups? (Fieldwork notes, July 2023)

Our first workshops showed that a key benefit of body mapping was to provide people with Long Covid a space to share and discuss their experiences with others. Patients were more likely to feel validated and listened to because they knew those around them shared similar experiences – a space of psychological safety (see Fig. 3: 'I find it very comforting to be with other patients'). This in and of itself can be an important intervention, considering that Long Covid may have a substantial impact on mental health (Houben-Wilke et al., 2022). Mullard et al. (2023) have highlighted the importance of peer support for Long Covid patients and have identified three different forms of peer support (service-led, community-based and social media). Body mapping, led by patients themselves, could offer an additional form of peer support effectively blending these different forms. Further, this approach can be adapted to virtual settings to allow greater access.

However, we should remain mindful that body mapping can also bring up difficult and painful feelings (Boydell et al., 2021) and

potentially trigger worsening symptoms and Post Exertional Malaise (PEM). Moreover, patients with severe symptoms will have difficulty participating as the method requires physical and mental activity, energy and concentration. We therefore stress that body mapping needs to be undertaken with care and by trained facilitators, and are exploring the possibility this method could be developed into a toolkit for patients to become facilitators of their own body mapping workshops, supporting their peers in sharing, mapping, and communicating their experiences to healthcare clinicians, friends, family, and co-workers. We would also be keen to explore with medical practitioners how useful this tool may be for them in facilitating diagnosis and patient care.

The workshops reminded us of the limitations of body mapping when working with chronic illness patients experiencing different and fluctuating symptoms. One participant had difficulty lying down to draw the outlines of her body due to her lung problems, and a few others said they would have appreciated the possibility of standing and hanging the body map on the wall. In this context, too, peer support was crucial, and participants helped each other. One participant helped another with limited mobility assistance to lie down to draw their outline and benefitted from an accessible setting. We have integrated participants' feedback into the planning of future workshops. For example, participants requested online sessions; for others, the demands of online meetings would make such a session inaccessible. We remain mindful that for some, the energy needed to participate in this kind of workshop is just not possible at the moment and seek to publish our findings widely to make them accessible to all (updates available on visualisinglongcovid.org).

5. Conclusions

A holistic view is critical when illness so comprehensively disrupts everyday life. A person's experience of Long Covid goes far beyond the symptoms they experience. Our pilot work suggests body mapping may serve as a research tool for visualising patients' experiences of Long Covid, which can be more reflective than a purely verbal account. Moreover, body mapping can provide novel insights into chronic illnesses beyond more traditional interview methods because it allows patients to use both images and text to communicate their experiences. Body mapping also has potential application as a resource for both clinical practice and patient-led peer support, but further work is needed to adapt this tool for use in a wider variety of settings, including online, and at scale.

Funding information

This study has been funded by the Swiss National Science Foundation, Switzerland, grant number P500PS_206554.

CRedit authorship contribution statement

Maaret Jokela-Pansini: Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Beth Greenhough:** Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Conceptualization. **Oonagh Cousins:** Writing – review & editing, Writing – original draft, Formal analysis. **Jo Dainow:** Writing – review & editing, Writing – original draft, Formal analysis.

Data availability

The data that has been used is confidential.

Acknowledgements

We would like to express our thanks to all the participants of the

workshop. We are grateful to Long Covid Support for helping to prepare and organise the workshop. We would also like to thank Perspectum, who, together with Long Covid Support, helped recruit participants and hosted our workshop at the Royal Society. Thank you also to Michael Natt for insightful comments on an earlier version of the manuscript, as well as to the reviewers whose feedback helped shape the argument of the paper.

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