

## Disability and fieldwork

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# Disability and fieldwork: A personal reflection

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## Abstract

This short Note offers a personal reflection about disability and fieldwork. It is not about how my disability, a long-term neurological condition, has affected my fieldwork. Rather, it is a series of thoughts about how my mobility issues might impact on my future fieldwork, but not only in a negative sense. The Note primarily discusses some of the ways that, potentially, my disability – which has changed how I interact with the world around me – might actually enhance my research and help to take it in new directions. I wrote the Note primarily for myself and for other researchers with disabilities, whether visible or hidden.

## Keywords

bodies, disability as a research resource, fieldwork, ‘locked out’, plasticity, vulnerability

## Introduction: How I came to write this piece

I am not sure how ‘personal’ we should get in our work and what we write. At what point does it become a matter of self-indulgence or ‘too much information’ to focus on ourselves, as researchers, rather than on those we engage and collaborate with in our research? I am not sure what the answer is, and probably there is no clear-cut answer. I was given the confidence to write this short piece after reading a recent article by Olivera Simić. Her research, like much of my own, focuses on Bosnia-Herzegovina (BiH). Unlike me, Simić is also from BiH. She now lives in Australia, and a large part of her article discusses what it has been like for her not to be able to return to BiH to visit her family and partner as a result of the ongoing COVID-19 pandemic. In her words, ‘my (now Australian) government does not allow me out while other nation states would allow me in. I am “locked out” from the rest of the world’ (Simić, 2021: 403). Her article is honest

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and raw. Parts of it made me feel sad; parts of it I found very touching, especially when Simić talks about her relationship with her partner, her high school sweetheart.

Most of all, the article resonated with me. Like Simić, I would like to go back to BiH, not because I have family there but because I miss it. I miss the relaxed way of life, sitting outside and drinking coffee, seeing mountains and being mesmerized by their beauty and ever-changing hues. I left Sarajevo on 18 March 2020, just after BiH declared a national state of emergency due to the pandemic. I packed in a hurry. Everything felt surreal and out of control. As I headed to the airport in a taxi, the sun shone brightly but I had a heavy feeling in my heart. All of the cafes, usually bursting with life, were closed, and the streets were largely empty. Baker (2006: 181) writes that ‘Further complicating one’s departure is the emotional attachment that may have formed between the researcher and the insiders’. I had already finished my research when I left BiH, but there was no time to say goodbye to anyone; and although I had a return ticket to fly back to Sarajevo 3 months later, somewhere deep inside I knew that probably I would not return anytime soon.

Fast forward to December 2021 and I, like Simić, feel ‘locked out’, but not because of the global pandemic and the policies of the Australian government. Now that the UK Foreign and Commonwealth Office has changed its travel advice for BiH, I could get on an aeroplane and fly back to Sarajevo immediately. Yet, I feel ‘locked out’ by my own body. As I reflect on how to explain this, and to clarify in my own mind what I feel – and why – my thoughts drift back to the pandemic. I think about COVID-19 and its spike protein – the part of the virus that allows it ‘to enter and infect cells’ (Mousavizadeh and Ghasemi, 2021: 160). The various vaccines that have been developed primarily target the spike protein (Ita, 2021: 19), effectively preventing it – a form of ‘lock out’ – from ‘locking in’ to our bodies. I feel ‘locked out’ by a body that is no longer what it was. My body. I think I am afraid of going back to BiH with this body.

## Becoming disabled

In March 2020, I was diagnosed with a neurological condition that has significantly affected my mobility. I need crutches to walk, and even with these aids the frequent sensation of having sandbags or weights attached to my legs means that each step requires huge effort. I like to think of the relationship between my body and the crutches not as one of dependency, but of ‘temporary connections that continually come together’ and, in so doing, ‘enable certain actions and activities’ (Gibson, 2014: 1329). However, there are also things that I can no longer do, or at least not as well as I could previously.

I often catch myself worrying in this regard about fieldwork. I am a qualitative researcher who first started doing fieldwork in 2002, and research is a fundamental part of who I am. Being in the field, interacting with the people I meet, collecting data, looking for connections and meanings in the data – I find all of this hugely satisfying. But now that the connections within my own central nervous system are faulty, the process of undertaking future fieldwork is going to be different. In their own research, Hall and Healey (2005: 447) found that ‘The challenge of physical mobility and negotiation of fieldwork sites emerged strongly as an issue faced by students with a range of disabilities’. This, too,

will be one of my own major challenges, although of course all of us – in different ways – have to deal with ‘negotiating access’ (Mulhall, 2003: 310).

I used to travel everywhere in BiH by bus, relishing the freedom of moving around from place to place with only a rucksack and my laptop, wondering who I would meet and what I would learn. Now, a lot of energy goes into just thinking about how I will get from A to B. I also worry about losing the sense of anonymity that I enjoy whilst doing fieldwork. Aside from those with whom I work directly, no one knows who I am and I have always just blended in. It will be different now. As someone with a visible disability, I stand out in the crowd (or at least I feel as though I do). And my disability is often the first thing that people notice; the very slow and laboured gait, the dystonic movements in my left foot, the frequent rest breaks – an opportunity to stretch out muscles that feel tight, like knotted ropes. ‘Are you ok?’ ‘Do you need some help?’

Yet, as I write, I am reminded of Inahara’s (2009: 56) argument that ‘physical disability is not the “Other” to the able-bodied. Instead there is a diversity of abilities and disabilities in all our negotiations of the world’. I also find comfort in Inahara’s (2009: 59) insistence that ‘The perfect body, which is the able body, is simply not attainable’ – an important message that I would like to see more widely disseminated. What she ultimately suggests is that ‘another system is required; a system that acknowledges a range of bodily differences and that is based on the multiplicity and fluidity of bodies. It is one which also recognizes the vulnerability of all bodies’ (Inahara, 2009: 59–60; see also Finneman [2008: 1] on vulnerability as ‘inherent in the human condition’).

Interesting in this regard is how Shah, herself a disabled researcher, reflects on her own vulnerability. In the context of doing research with a group of young disabled people about their education and career aspirations, she notes: ‘I kept in mind the danger of exposing my own vulnerability and assuming too much commonality of perspective with respondents, without losing empathy’ (Shah, 2006: 212). However, she also regards her disability as part of her ‘personal ontological research resources’ which help her to generate ‘rich quality data’ (Shah, 2006: 217). I like this idea and I find it helpful to think about how my own disability might enhance my research.

## **Disability not as an obstacle to research but as a potential ‘resource’**

Reflecting on his work as a consultant neurologist, Tubridy (2019: 285) insists that ‘One of the most brilliant things about neurology and studying the brain and its dysfunction is that you learn at least one new thing about it every day’. His passion and enthusiasm seep through the pages, reminding me of how I feel when I am doing fieldwork, listening to people’s stories, learning details about their lives. Elaborating on his own learning experiences, Tubridy (2019: 285) explains that ‘Every week at our radiology meeting I will, without fail, see something new on a brain scan or hear a suggested diagnosis from a colleague that I either did not think of or had not seen before’. His reference to seeing immediately catches my attention. The first way that I think about my disability as potentially enhancing my work and research skills relates precisely to seeing.

## Seeing differently

Sometimes we miss things that we were not anticipating; ‘When attention is diverted to another object or task, observers often fail to perceive an unexpected object, even if it appears at fixation’ (Simon and Chabris, 1999: 1060). In their research, which replicated earlier experiments (see, e.g. Neisser and Becklen, 1975), Simon and Chabris created short video tapes of two teams of three players passing a ball to each other, and observers were asked to silently complete a task whilst watching the videos (e.g. to count the number of times the ball was passed among players wearing a white t-shirt).<sup>1</sup> The researchers found that of the total observers ( $n = 192$ ), 46% failed to notice the unexpected event, namely a tall woman holding an umbrella walking among the players, or, separately, a shorter woman dressed in a gorilla suit walking through them (Simons and Chabris, 1999: 1068).

Unquestionably, having significant mobility issues has changed how I see things and what I see. Citing an Israeli saying that ‘things that you see from here, you can’t see from there’, Berger (2015: 230) notes that ‘Reflecting on those differences between what is seen from “there” versus what is seen from “here” may help us identify elements in research that are changed by the changing researcher position’. My disability is now a part of my changing researcher position. It is my ‘here’. The results of Simon and Chabris’ (1999: 1071) aforementioned experiment revealed that ‘Just as we often fail to perceive unexpected events, we often fail to notice unexpected changes to the visual details of our environment’ (Simons and Chabris, 1999: 1071). I do notice these details. I am now much more aware of everything around me – and of everything that is happening around me – than I was previously.

I am curious to know how this will practically translate and carry over to my future research. How will changes in what I see, for example, help me in ‘thinking with’ (Barad, 2011: 127) the world around me? If, as Ullman (2017: 833) underlines, ‘Humans are characters in a cast of many’, what might a posthumanist analysis of the Bosnian war and its legacies look like? If ‘(post)human and non-human matter are inextricably entangled’ (Fox and Alldred, 2020: 125), how might transitional justice – the judicial and non-judicial processes through which societies deal with the legacies of past human rights abuses – capture and reflect these entanglements? How might they incorporate what Haraway (2018: 102) has called ‘[g]enerative, effective multispecies environmental justice?’ I do not pretend to have answers to these questions. The point is that they excite me and they are fundamentally linked to my own personal journey of seeing, as well as negotiating and experiencing, the world around me in new ways.

## Connecting with other bodies

There is a second key way in which I regard my disability as a potential research resource, and one that immediately reminds me of Haraway’s (1991: 178) question ‘Why should our bodies end at the skin?’ Each time I step outside, I pay more attention to what is happening within the surrounding environment, but I also give more attention to the people within it. In the film *Ghost*, the spirit of the late Patrick Swayze’s character, Sam

Wheat, enters the body of Oda Mae Brown, in order to be able to hold his wife Molly one last time. Sometimes when I walk, I focus on the person in front of me, trying, as much as possible, to synchronize my own steps with theirs, imagining that I am that person, inside their body, walking without sandbags and weights.

In the famous Rubber Hand Illusion,<sup>2</sup> ‘watching a rubber hand being stroked synchronously with one’s own unseen hand causes the rubber hand to be attributed to one’s own body’ (Taskiris et al., 2006: 424). The rubber hand, in short, is experienced as one’s own hand. I actively try to experience someone else’s body, someone else’s legs, as my own. Perhaps I am more in tune with other people’s bodies now. I no longer like the expression ‘putting oneself in someone else’s shoes’. Shoes, elegant shoes, shoes with heels, the shoes I used to wear when giving university lectures in order to make myself several inches taller. Shoes are a reminder. Rather than put myself in someone else’s shoes, I try to locate myself momentarily in their bodies, as a ‘corporeal mode of knowing’ (Simonsen, 2013: 16). Indeed, and linked to the discussion about seeing, for Merleau-Ponty perception is itself a fundamentally embodied process (Crossley, 2005: 47). Hence, for example ‘the arm seen and the arm touched, just like the different segments of the arm itself, together perform a single gesture’ (Merleau-Ponty, 2012: 153).

This attention to and attunement with other bodies is significant in the context of my work on conflict-related sexual violence. Specifically, my current research explores some of the ways that victims-/survivors of such violence (which is always entangled with other forms of violence; see, e.g. Boesten, 2017: 507; Kreft, 2019: 230) demonstrate everyday resilience – a process that I locate in the interactions between individuals and their wider social ecologies (Ungar, 2011). I do not assume a priori that female and male victims-/survivors of conflict-related sexual violence – heterogeneous individuals with highly diverse stories – are vulnerable on account of what they have gone through (Clark, 2021). Certainly, however, their multiple experiences of violence have exposed the vulnerability of their bodies. My disability has exposed the vulnerability, albeit in a very different way, of my own body. This does not in any way erase or detract from the many privileges that I have as a white scholar living in the UK – and which I have always been acutely aware of whilst doing fieldwork. But perhaps my own corporeal vulnerability will make me more ‘real’ to some of the women and men I talk to in the field and, at least in some small way, bring our very different worlds a little closer together. According to Bresler (2006: 21), the juxtaposition of narrative and embodiment ‘creates a methodological field that draws on our ability to connect with others to achieve empathic understanding and can illuminate the fluid, embodied nature of lived experience’. I think about my disability as an aspect of embodiment that facilitates my ability to connect with other bodies. Bodies themselves, thus, become an active part of doing research and of communicating, thereby highlighting ‘inter-corporeal, continuing processes of relating to others’ (Lovell and Banfield, 2020: 5).

### *Embracing plasticity*

A final way in which I think about my disability as potentially benefitting and enriching my future research is through the concept of plasticity – a fundamental process in the

brain's own resilience. Indeed, 'resilience implies plasticity' (Feldman, 2020: 136). Our brains lose plasticity as we get older because they do not require the same degree of it that they did when we were learning to walk, talk, read, write, interact with others and so on. To cite the neuroscientist Eagleman (2021: 206), 'Neural networks lock themselves more deeply into place not because of fading function, but because we have had success in figuring things out'. Suddenly becoming disabled means that, to some extent, we have to start again in 'figuring things out', and the point is that 'brains shift only when something is unpredicted' (Eagleman, 2021: 205). My experience of learning to walk again was not predicted and my brain has had to 'shift' and to find new ways of doing things. And most of the time it does a good job. Learning from my brain, in turn, has made me more aware of and more open to exploring and experimenting with 'plasticity' in the context of my own research, in the sense of how I might take it in new directions and step outside my comfort zone.

More broadly, I see plasticity as a research resource. Pitts-Taylor (2010: 639), critiquing plasticity as a neoliberal concept, argues that 'current deployments of plasticity pressure subjects to see themselves not only in biomedical but also in specifically neuronal terms'. I think about the research process itself in neuronal terms. Malabou (2007: 440) notes that synapses within the brain – which are central to the concept of neural plasticity – have the capacity to form or reform the nerve information that they receive. 'This plasticity', she argues, 'prompts the hypothesis that neuronal circuits are able to organize themselves, that is, to modify their connections in the course of perception and learning' (Malabou, 2007: 440). Plasticity in research, thus, is about the neuronal circuits of our ideas and theories, and how we re-organize them to modify and to make new connections.

Significant in this regard is Ulmer's (2015: 1105) reference to plasticity 'as a post-qualitative methodology'. Post-qualitative inquiry – a term which St. Pierre (2011) firstly introduced – is inherently 'plastic' in the sense that it is always a process of becoming (Østern et al., 2021). According to St. Pierre (2018: 604–605), 'the post qualitative inquirer does not know what to do first and then next and next. There is no recipe, no process. This is truly experimental inquiry'. As a disabled researcher, I primarily associate plasticity, therefore, with freedom; freedom to be different, freedom to do something different, freedom to do things differently. St. Pierre (2018: 605) underlines that 'The post qualitative inquirer who has prepared herself must trust herself and do the next thing, whatever it is – to experiment – and to keep moving'. This 'moving', in turn, can itself take a multitude of forms.

## Conclusion and thinking forward

I began this research note by highlighting and reflecting on my sense of feeling 'locked out' of BiH. I am not yet ready to return to the country. For the final month before I left in 2020, I felt 'locked in' (Simić, 2021: 403), rarely able to leave my apartment in east Sarajevo. I remember looking at the mountains from my lounge windows, observing them with fascination and awe, whilst also feeling alone. Trapped.

In her article about not being able to return to BiH, Simić (2021: 418) reflects ‘I feel aimless, like a fish in a fishbowl swimming around in circles. I feel dizzy and heavy with the weight of my whole life. I feel trapped’. An ocean stands between her and her home land. What stands between me and the country that has been a central part of my research for more than a decade is fear, due to a brain that no longer communicates with my legs in the same way that it used to. But that’s the thing about the brain; its ‘magic’, to cite Eagleman (2021: 16), ‘lies not in its constituent elements but in the way those elements unceasingly reweave themselves to form a dynamic, electric, living fabric’. And this is ultimately how I think about research. Whether I continue to do research in BiH, whether I expand in new areas, whether I do less fieldwork in the future, my research is a ‘dynamic, electric, living fabric’ that, notwithstanding my disability, will develop and adapt with me.

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### Notes

1. See <https://www.youtube.com/watch?v=vJG698U2Mvo>
2. See <https://www.youtube.com/watch?v=sxwn1w7MJvk>

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