

# Living a full life

Embodiment, disability, and ‘anthropology at home’

Hannah Gibson

## Abstract

What might anthropology and fieldwork look like if the anthropologist’s body, considered to be one of their ‘tools’, is not able-bodied? This piece of writing explores the intersection of disability and anthropological fieldwork, within the specific experience of doing anthropology at home. By interrogating the tension between academic advancement and disability, I challenge the expectation that traditional anthropologists must be able-bodied. In turn, this highlights the potential of being a vulnerable researcher.

## Keywords

disability, fieldwork, ethnography, partial connections, anthropology at home

Next to my head, my alarm goes off, awakening me from a nap that has become an essential part of my daily life. On the empty side of my bed lays the journal I wrote interview reflections in earlier in the day, open to the half empty page where I stopped mid-sentence because, today, it hurts to hold a pen. The voice recorder lays next to my journal, containing the rest of my thoughts I recorded after my body had given up trying to write them.

It hurts to blink, my head pounds. I still smell the lavender from the balm I had applied to my temples, following to the advice of a friend. A deep breath in, and I think how I never

really liked having my senses overtaken by such a prominent scent. Cursing softly under my breath, I roll over onto my back and contemplate getting up. I had hoped the sleep would have given me some energy, but I was so depleted in the first place. Sleep is never fully restorative: when I fall into bed I am battling pain that sinks its sharp teeth into my bones. These few short hours are simply a short respite from weary fatigue, but still a welcome one. It replenishes my reserves just enough to continue, just enough to create the illusion of wellness.

I could rest this evening, but I don't know if I'll feel worse tomorrow. That's the problem with an unpredictable illness; it could always be worse. I have a list of things to tackle: finish those notes, confirm an interview time tomorrow, write my six-month PhD progress report, read a fellow graduate student's literature review for a writing workshop tomorrow, do the washing, cook and eat dinner, and check in with my father who has been sick recently. I remember that my sister wanted to FaceTime me so I could see and chat with my eighteen-month-old nephew.

It takes me twenty minutes from waking to actually sit up, and I reach tentatively for the ginger beer on my nightstand, sipping the tepid liquid to try and curb the nausea. My medicine bag sits open, sheets of pills half strewn within it, the necessary medicine jumbled in with the 'just in case' options. Next to it, a half-drunk cup of tea from this morning, when I was trying to get ready to drive the hour for an interview with an intended mother (a woman who will be having a baby via surrogacy) who had experienced years of miscarriages and heartache in her pursuit of a family. I recorded the majority of the three-hour interview but also focused on making mental notes of important unspoken aspects that could be documented afterwards: The deep timbre of her laughter as she tried and failed to settle her eighteen-month-old baby girl born via surrogacy, who climbed all over her. How her hands managed to multitask without looking, grabbing a drink cup and toy from the floor where the baby had tossed it, as she described the moment she was handed her daughter for the first time. All those intricate details gleaned only through attentive observation. I had ignored my pain during the interview, focusing on this family who were giving their time and story to me. Now, hours later, the adrenaline had drained from my body and I was struggling to gather enough strength to get through the rest of the day.

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Within this one day, all my identities converged so abruptly that I could not separate them. A daughter, an aunt, a PhD student, a fieldworker, and a chronically sick thirty-year-old woman, each identity is non-negotiable. As a sick academic, I reside between two worlds that

interlink but require distinctively different forms of attentiveness. At any given time, I am partially my chronically sick self, partially an anthropologist.

For my PhD in cultural anthropology, I am studying surrogacy in New Zealand. I decided to do qualitative research in the country I live in because it was imperative that I have access to myriad support systems, particularly medical. However, choosing to do ‘anthropology at home’ means that during my data collection period, I have not stepped away from the expectations of a graduate student. Attending seminars and writing workshops is thought to equip us with skills beyond academia as well as complement the solitary life of a PhD student. Participating in reading groups is optional but is encouraged, as it widens a student’s knowledge base. And the other parts of my life do not fall away when I am conducting interviews or spending time with participants. My life outside of data collection remains in the background; in my calendar sit reminders of expectations others have on my time and attention simply because I am still physically here, residing in my house, turning up to my office on occasion, and answering my phone. Trying to dedicate myself to this pivotal part of my anthropological research and trying to live a ‘full’ life pulls me in opposing directions constantly. I am in a perpetual tug of war between what I feel would benefit me academically and what is realistic for a chronically sick body.

But what happens to this tension if we rethink what ‘anthropology at home’, or any qualitative research, might look or be like? The phrase usually evokes spatial proximity between one’s home and research field site. Yet there is also a more intimate corporeality to consider. As graduates engaged in qualitative research we become aware early on that our most important ‘tool’ is our physical and mental selves, which allow us to go into the field and sit alongside others, see the world from their perspective, document their stories, and occupy whatever space they allow us to. Collecting data is thus a very embodied experience. We must rely on our bodies. And on our minds. We hone our skills of observation in order to recall details about the connections we make with our participants, though we rarely talk about how cognitive skills become impaired when we are tired.

Conceptualising our bodies and minds as ‘tools’ is laden with ableist and dare I say masculinist assumptions about the anthropologist’s physical self and capabilities. This ideal is conveyed in undergraduate classes, in ethnographies about anthropologists travelling to foreign lands and ‘establishing rapport’ and engaging in ‘deep hanging out’ with others. Ethnographies, lectures, and conversations with mentors and peers have given me the impression that fieldwork is a rite of passage, that some form of ‘culture shock’ is expected. We are encouraged to accept this traumatic ‘entry’ into the field as a given. I do not see my body represented in anthropological literature. Although I was assured by a few mentors that it would be possible to undertake postgraduate research if this was my goal, I never got the impression in the wider community that an anthropologist could be as I am.

On paper, my academic output and achievements speak for themselves. I am organised, independent, capable, and reliable. In private, my life is filled with countless boxes of medicine, pain that renders me almost incapable of walking, lived in a body that battles to do simple tasks on the bad days. Icepacks, painkillers, blanket, phone, heat in all its forms. Small movements, shallow breaths, one minute at a time. On these days, I am an unconventional, unexpected anthropologist, undertaking fieldwork with a body that is not ‘made’ for the physical demands imagined as required for ethnographic research. If the researcher’s tool is their body and mind, then my toolkit never felt fully equipped. I have to find ways to compensate for constantly low energy levels, physical pain, and frequent exacerbations of my illnesses. Whilst other people generally rely on being healthy enough to conduct the research they set out to do, what is reliable for me is my precarious health; it is a constant and predictable part of my life. Demanding accommodation, as interwoven with my fieldwork as the rest of my life is, it brings a new meaning to ‘doing anthropology at home’.

The clincher is that I do not actually look sick except to the discerning eye, and in an academic environment this means that I often feel embarrassed when I have to disclose any limitations I have because others look surprised, and at times, put out. According to Williams and Mavin (2015, 127), disabled academics often develop strategies to ‘meet normative expectations shaped around the assumed ideal [non-disabled] worker’. In academic institutions, showing vulnerability is not something that is encouraged or taught. For myself, even in the most accepting of atmospheres, having a body that does not fit in with a full-time schedule means that I often sit at the periphery of conversations despite the kindest of intentions of friends or colleagues to include me. Sometimes, just showing takes all my strength. There has been no greater challenge than accepting that I cannot leave my bodily struggles at the door when I enter a room, like leaving my books in my office when I go off on a research trip across the country. My physical pain transgresses all spaces; it disrupts and demands to be acknowledged in every situation.

I sometimes wonder what my research or life would look like if I had a different body. What are the implications for those of us who cannot immerse ourselves fully because our bodies demand more self-care or because we are looking after loved ones? In 2018, Friedner, Kasnitz, and Wood wrote a blog post for *Anthroendum* in which they shared what they wish they had known about anthropology as a discipline and disability:

I wish I had known that research by a disabled person on disabled people will automatically be classified as ‘autoethnographic’.

I wish I had known that disabled people don't fit the classic model of anthropologists, and I would have to spend energy making space in the discipline for myself.

I wish I had known that I would be ideologically (in addition to physically) unable to do fieldwork in a setting where access for physical disabilities is limited.

I wish I had known that anthropologists still assume that other anthropologists will be normatively speaking and hearing; that because my speech is different, I am somehow assumed to be an unintelligible subject (and not a colleague).

I wish I were facing hiring/advancement/tenure requirements without disability discrimination, or that somehow such discrimination could be taken into account.

One thing I have been considering in response to the blog post is whether I too wish I had known how structurally ableist anthropology is. If I had known, I do not know if I would have ventured past my first class. I remember leaving my social work training for anthropology because I hoped it would be a more physically suitable career. The irony is not lost on me. Perhaps, my assumption that I would 'fit' in anthropology made me quicker to challenge the discipline's assumptions (only visible to those who do not benefit from them) of what an anthropologist's body must be capable of doing. At the same time, my mentors have made me feel like I deserve a place at the table. Still, writing this makes me feel vulnerable, aware that it may impact on my desirability as a job candidate, particularly because academia is precarious even for the able-bodied right now.

I have been using a more literal interpretation of Strathern's (2005) concept of 'partial connections' to think through my experiences in fieldwork, my relationship with my participants, and how kinship relations are configured in surrogacy relations. She argues that we only ever make partial connections in life; where there is connection, there is a gap, and where we see similarity in things or people around us, there is difference, and vice versa (Strathern 2005, 26). The point of the concept is not to celebrate relativity but to trace how connections and disconnections are created and cut across multiple situations (Candea et al. 2015, 15). In my research, I observe that a surrogate mother forms a partial connection to her foetus. She acts on behalf of another woman, without taking on the role of the 'real' or intended mother. She is thus partially connecting to the foetus but disconnecting from any role she might have with her own children. This allows the intended parents to establish their own connection to the baby, which are also in many ways partial. In this sense, I argue, disconnections do not necessarily equate to the cessation of relationships but create spaces for other connections to be formed.

I create partial connections as I navigate my days as an anthropologist. It feels like my identity is split, perhaps because I have never felt I could give myself fully to the physical demands of the discipline. Yet it is this very disconnection from a healthy body that allows space for a partial connection with my research participants over our shared suffering or mutual understanding. While it is important to focus on what our participants have to say and not put ourselves in the spotlight, it is also sometimes appropriate and mutually liberating to share, to connect in a moment, even as fleeting as it may be. Throughout my research, the boundary between my embodied experience of illness, loss, and pain and my participants' stories of desire, loss, and pain is blurred. Although we can never really know the depth or interior of someone else's suffering, on some level we recognise ourselves in the other.

Behar (1996, 4) writes that this form of self-exposure is productive: 'when you [speak] vulnerably, others respond vulnerably'. Like Behar's fieldwork experiences in Spain and Cuba, I have found that sharing a bit of myself with people helped me to break down the researcher-researched divide to a certain degree, and my participants opened up more. One contacted me after another participant told her that my medical experiences mean I have no womb or ability to carry a child. She wanted to talk to me, she said, because she did not want to share her story with someone who only had an intellectual interest; she felt my involvement went beyond mere curiosity. Not being open about my own medical experiences would be akin to saying, 'I want to know your pain, but I am unwilling to share mine'. This makes me wonder if my vulnerability is the price to pay for being able to collect such rich data. But they are not just data: they are messy, sad, hopeful, joyful, and painful stories. They are the teardrops, the blood of each pregnancy loss, the image of the embryo on the monitor as it is placed into the womb of a surrogate, and the hands of the surrogate and the intended parent, held so tightly. Somehow, when people invite me in their world, and I sit down, and we have a moment when we say 'me too', my own story becomes intertwined with theirs, even if our suffering is not the same. In this sense, my struggles are productive and full of potential for creating connections, however partial, with others. The divides between researcher/participant and between home/'the field' are blurred.

My personal experiences have given me empathy for others on a level I might not have had without them, and it enriches my ethnographic reflections and writing. My research participants and I find solidarity that is a step beyond rapport. But the value of this sits alongside the effort it takes to make good fieldwork possible. Hearing stories, travelling, hanging around for hours – all of these deplete energy. My body interrupts and requires attention, screaming for rest or pain relief. On bad days, I feel like I tarnish every space with potential unreliability. On good days, I appreciate what my meagre health does give me, and

am learning to honour the nuances of my body. I no longer hush it to be quiet but work with it, valuing the opportunities it gives me.

## About the author

Hannah Gibson is completing her doctoral thesis in cultural anthropology at Victoria University of Wellington, New Zealand, where she is also currently a teaching fellow. Her research explores how traditional and gestational surrogacy are practiced in New Zealand, including among those who navigate transnational reproductive services and surrogacy. Her thesis introduces the concept of ‘shadow legalities’ to depict how people create and follow guidelines and quasi-rules for various (re)productive processes that lack any official framework or support. Her research engages with the field of science and technology studies and with legal, critical kinship, medical, and reproductive anthropology.

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