7

care embodied: speaking from a nonbinary, crip, menstrual body

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reading guide

This chapter aims to sensitize you to the affordances, needs and multiplicities of your body, and to how these emerge together with particular environments. Throughout the chapter, prompts are offered to encourage you to engage with your own embodiment and with moments of care related to it. Autoethnographic vignettes guide the reader by pointing to particular experiences of in/visibilities, vulnerabilities and interdependencies of bodies in and beyond academic spaces. The chapter contributes to discussions of reflexivity by exploring the ways in which our various bodyminds are (not) cared for contributes to liveability, and by asking how (academic) spaces might be made more liveable for different bodies.

prompt 1:
(re-)connect with your body: close your eyes if comfortable. take three deep breaths, inhale through your nose and exhale through your mouth, sighing it out. take a minute to tune in to your body. how does it feel right now?

letting the bodies speak

We are all made up out of a variety of different bodies which are embedded within each other, and in turn are embedded in their environments. For example, I reside in nonbinary, disabled (crip), menstrual bodies. It is from this embodiment that I make sense of the world; it is from this embodiment

that I make knowledge. I am queer in multitude, not only in terms of both sexuality and gender, but also as all these embodiments are marginalized positionalities disrupting the norm that is cishet, White, male. I am crip in multitude: I am chronically ill (I have Myalgic Encephalomyelitis/Chronic Fatigue Syndrome [ME/CFS]) and I am Autistic.

To capture the multitude nature of our bodies, I adopt and adapt Annemarie Mol's term *the body multiple* throughout this chapter. These multiple bodies hold their own meanings and experiences, which intra-act and thus influence and affect each other. However, they cannot be separated from each other. They are entwined, fluid. As Mol states: 'The *body multiple* is not fragmented. Even if it is multiple, it also hangs together' (2022, 55, emphasis in original). Furthermore, my use of body includes the mind (also known as bodymind), as they are not separate entities.

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prompt 2:
close your eyes and take a deep breath again. tune into your embodiment. which are the bodies that you inhabit? how many? how are they different from each other? in what ways are they alike?

This body of mine is cyclical, not only in reference to the menstrual body. Much like my gender, my body is fluid; not one day is the same. Its functions and abilities shift over time, and are often difficult to predict. Moreover, my body is White and therefore comes with a whole lot of privilege that is embedded in anything I do, write or say – including this chapter. Thus, even while speaking from my 'multiply marginalized embodiment' (Hubrig and Cedillo 2022, 1), I continue to benefit from privilege. My Whiteness speaks louder, and is more easily heard, than my nonbinary, crip, menstrual peers who are Black or people of colour. Therefore I am attentive to the racial dynamics embedded in this conversation and aim to use my voice to reimagine an equitable future (present) in which all bodies are cared for.

This chapter looks at what it means to do research from the body multiple. Asking, how can the multilayered nature of the body be translated to reimagine – to queer – a liberating and expansive practice of care?

There is no denying that care has been a popular topic over the last few years, making its way into all kinds of fields and practices in academia. No wonder, as we have been globally and collectively going through a pandemic unprecedented within our times. Moving through this care crisis exposed many layers of the uncaring and tough environment that is currently experienced, which in turn has left a deep need for a more caring climate. Within academic contexts, care is aimed to theorize, expand and reimagine it. Lindén and Lydahl (2021, 3) write that care promises 'caring agencies'

and potentialities as well as a critical lens 'needed to interrogate and disrupt enduring and intensified injustices and damages'. What is often missing here is the engagement with disability studies, crip theory and most definitely disabled people, while, as Leah Lakshmi Piepzna-Samarasinha writes, 'we are the ones who know, more than anyone, the technology of how to actually care' (2022, 36). Therefore, I write this chapter not only from a disability-informed framework, but from my embodied plural experience and existence as a crip, nonbinary person. Thereby giving a voice to those bodies that experience (receiving and giving) care, and offering an embodied perspective of – and on – care. As it 'highlight[s] not only that things *could be* otherwise, but that they *already* are so, if we attend closely and attentively to the daily doings of care already existing alongside predominant ideals' (Lindén and Lydahl 2021, 8; emphasis in original).

Moreover, this means I am applying the body as method. Centring my body multiple as method is a way of doing strongly reflexive research. Strong reflexivity as described by Andrea Ploder (2022, 26) relies on the researcher's vulnerability as it centres their own experience, 'using their entanglements with the field as a decisive source of data and interpretation'. Because of this, Ploder argues it is an epistemological necessity in creating (academic) environments in which kindness and care is centred. Moreover, it is a queer way of doing research. As Ploder writes:

> Like queer theory and practice, strongly reflexive research blurs categories and genres, embraces art as a valuable theoretical and practical tool, resists orthodox methodologies, is inventive, creative, messy, and personal. These features, combined with the central role of the researcher's own experience, make it a valuable choice for queer social research. (Ploder 2022, 27)

Thus, it allows for the messiness of the body, the chaos of the mind, the flow of it all, and above all emphasizes the overlapping intra-action between the plethora of identities we inhabit, blurring the lines between them; merging them together.

Centring the body multiple in research environments and academia in general, offers an inevitable and necessary slow-down in a system that values productivity and capital over care and community – a system that universities and academic institutions are inherently part of, and perpetuate. Moreover, allowing somatic awareness within our practices of reflexivity extends a renewed presence for the material – not only research material but especially our corporeal materiality – which allows for a more holistic approach to practising our situationality and politics of location as researchers and academics. Thus, being with the body extends a valuable contribution to creating more liveable worlds in academia.

prompt 3:
tune inwards again. envision or recall an environment in which your bodies might ask for care? how do your bodies ask? do some require more care than others? what do they need today? can you take a moment to offer it?

vignettes

These entries have been written in the beginning of 2023 over a time period of two months, the course of two menstrual cycles. Starting out, I had planned to write daily entries on the three aspects of my body multiple: crip, nonbinary and menstrual. However, through writing them I found it was impossible to separate them (as they, of course, are not separate in essence). It depended on the day which of my bodies/embodiments was more centred that day. Its central presence defined through the environment(s) and interactions of that day.

Cycle day 8 – very confronted with my gender. being in an environment where i'm not 'out' as nonbinary is hard. especially when the environment is grasping on to the binary so hard. it feels like it's shouting 'you do not, cannot, exist'! my body is on edge, anxious here. waitress feeling weird about giving the pink cup to [my youngest nephew] cause he's a boy and apparently she thinks the oldest is a girl (because of his long hair?). the toilets that are unnecessarily gendered – to the extreme. 'ONLY GIRLS' (above the wheelchair accessible toilet, even); 'femme'; 'men to the left because the women are always right'. I stand out in this crowd because i am different. i am other. this crowd is my family.

Cycle day 1 – felt it immediately: my period would start today. it is hard to describe, but it is a specific kind of pain/ache in my lower stomach and my legs. different pain than usual. splitting headache. different than usual. my body being called back to bed, but i had plans so i took two painkillers and went on my way anyway (should not have). did not stay out long, though. did not feel any cramps, which could be because of the painkillers but my cramps are usually still felt even with painkillers, so it might be another pain-less period (not without, but less). same as last cycle. that is new. was called 'lady' today, which irritated me. just feels so unnecessary.

Cycle day 28 – end of my cycle. menstruation is near and its faint callings are heard throughout my body. my joints especially. shoulders are tense. energy sluggish. focus short-lived. headache loud and demanding. my body is calling for rest. i listen.

Cycle day 22 – in bed with my partner all day. we went dancing last night – at a queer party. never felt so free in my being, my body. visibly queer, visibly nonbinary – a sense of belonging unmatched. the prize paid for this belonging is the exhaustion and fatigue felt today (and coming days?), but i am claiming it to be worth it. i don't get that many opportunities to be out in queer spaces.

Cycle day 17 – outside in the park today. my body held by the grass, the trees, the sun. it is here i feel most myself; connected. whole. my body is at peace – my mind quiet.

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prompt 4:
envision or recall your body multiple in different (research) situations (for example, in your office, during teaching, during fieldwork, at conferences) how do your bodies feel seen (or not) in these situations? which aspects/versions/functions of your bodies are visible in these situations? how does it feel to be seen in these ways?

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on in/visibility

What is visible and what is invisible? Who determines what (and who, and how) is seen? In/visibility is a recurring theme in my embodiment. My crip body is invisible, most of the time. Invisible in the sense that I am not visibly disabled: I do not use a wheelchair or other mobility aids for example. Therefore my disability is/goes unseen, except for the few times I do use my walking cane. My disability, however, is visible to those who *care* to really see me as it *is* visible in the amount of times I have to sit down, slow down, for example. It is visible in my planning, my social schedule (close to non-existent), and the shortness of my days. Its in/visibility depends on how you look at it.

It leads me to Johanna Hedva's seminal essay, 'Sick Woman Theory' (2016), which is an acknowledgement to the feminization of needing (receiving) care and providing (giving) care. As they write: 'the most anti-capitalist protest is to care for another and to care for yourself. To take on the *historically feminized* and *therefore invisible* practice of nursing, nurturing, caring' (2016, part 6; my emphasis). Hedva's figuration of the Sick Woman speaks to the systemic gendering of disability, and challenges this as the Sick Woman is not just a woman; it is both a non- and multi-gendered entity. My nonbinary, crip, menstrual body is a Sick Woman. Moreover, Hedva speaks to the invisibility of disabled people as a systemic oppression: the way the system is built, disabled bodies are excluded from many places, including activism. As Hedva points out the importance of being seen in order to be seen as a political agent within

the current system, they also challenge the legitimacy of this, asking: what does it mean, then, to not be seen? And, most importantly, how can we create change if/when we are not seen, or made invisible?

Same goes to my menstrual body: that, or when, I menstruate is invisible. A body's ability to menstruate is not visible, yet often assumed. The sexed and gendered aspect of menstruation means that people see my assigned female at birth (AFAB) body and assume I am woman, and therefore that I menstruate. The (social) assignment to womanhood means my queer, nonbinary body is also in/visible, which is illustrated in being referred to as 'lady'. This assumption is similar to my crip body, except that people assume I am able-bodied, thereby invisibilizing my disabled reality.

As I wrote in the entry, this period allowed me to go out (albeit with painkillers) and thus be seen. Unfortunately, that included being misgendered. My body was read, but I was not really seen. Usually, when on my period, the pain makes me unable to get out of bed. I retreat into myself, stay inside, isolate. It is confronting for the paradoxal in/visibility to be this loud in this menstrual time-space. I do not wish to be seen in this particular body.

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prompt 5:
sense into the body that feels most vulnerable. how does this vulnerability manifest within your inner body? what happens to your breath, your heart? how does it manifest outwards? does your posture change? which environment feels most safe to your vulnerable body/bodies? offer a loving self-touch to those vulnerable parts.

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on vulnerability

The in/visibility of my bodies affects their vulnerability. For example, the assumption of able-bodiedness on my crip body means I am vulnerable to going over my boundaries. Sometimes by choice, sometimes by force – oftentimes a combination of both. But my boundaries – the boundaries of my bodily ability – and their permeability, is determined by accessibility (or lack thereof), and therefore much more than a topic of self-care.

'The norm of human life is to be, or to aspire to be, invulnerable' (Scully 2014, 206). Johanna Hedva also points this out and theorizes that to see illness as temporary, it also reduces care to be temporary. They write:

> What is so destructive about this conception of wellness as the default, as the standard mode of existence, is that it invents illness as temporary. When being sick is an abhorrence to the norm, it

> allows us to conceive of care and support in the same way. Care and support, in this configuration, are only required sometimes. When sickness is temporary, care and support are not normal. (Hedva 2016, part 5)

Both my menstrual body and crip body are fluidly debilitating (from a medical perspective), however the practices of care are not limited to when they need it the most. Preventive practices of care are always present.

My menstrual body, my crip body and my nonbinary body are vulnerable in their own ways. Vulnerable as they are typically seen as unreliable, fragile, less than. Because these bodies are non-normative in our current system, they are considered to be 'specially vulnerable'. As Jackie Leach Scully writes in 'Disability and Vulnerability' (2014, 205): 'they have greater chance than others of being subject to harms. Special vulnerability can mean that people are more vulnerable to specific kinds of harm or that they are just more likely to experience harms in general'. To illustrate, the ability to menstruate has historically been presented as a reason not to let those menstrual bodies be in positions of power.[1] The crip, disabled bodymind is considered vulnerable due to 'bodily instability', its dependence on care, among many other reasons. The nonbinary, queer (all bodies under the trans★[2] umbrella) body is vulnerable to harm stemming from queerphobia, from microaggressions to verbal and/or physical violence. However, as Scully points out in her research, this assigned vulnerability is more often than not 'contingent on social or environmental factors' (2014, 208) rather than inherent, thereby engaging with vulnerability from the political/relational model of disability.

As a nonbinary person, menstruation remains a loaded experience and topic for me, as it continues to be framed in cis-womanhood. By doing this research, I learn to care for myself. To see my menstrual body for myself; reimagining it in a frame that feels good to me. One that does not harm me, or does not cause (or at least, less) harm (dysphoria). And by doing so, I create an environment of care for other menstruating people for whom the experience, the topic, is also a vulnerable one. Speaking on, and from, my menstrual experience that is also queer and crip, allows for a more nuanced understanding of what constitutes the menstrual experience. Thus, acknowledging the cycle's debilitating potential/reality for many, without further pathologizing menstruation.

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1 For years, patriarchy has labelled Woman as sick and unfit due to hormonal fluctuations. Disguised under various labels (hysteria, hormonal hostages) women were put aside because they did not fit into the normative standard of a healthy or able body.

2 Trans★ is used as an umbrella term to include all genders outsides of the cis-binary.

prompt 6:
how can this practice of listening, tuning in, help you build a practice of care for yourself as well as those around you? how do your bodies multiple depend on each other? does caring for one of your bodies affect (care for) the others?

interdependency

Interdependency is an imperative aspect of care. As the Care Collective write in *The Care Manifesto* (2020, 30), 'we need to break the destructive linking of dependency with pathology and recognise that we are all formed, albeit in diverse and uneven ways, through and by our interdependencies'. Care cannot function one-sided: there needs to be a reciprocity, a mutual dependence, between those who receive care and those who give care. Moreover, these categories of receiving and giving are not fixed: every body needs to be cared for in one way or another, from time to time. Whether it is being called 'lady', being in an environment rigidly perpetuating the gender binary, or being fully acknowledged in my queerness by other queer people, these relations inform – to a certain extent – how I inhabit my body. All of them are confrontations of sorts, and affect my experience. As Stacey Alaimo writes in 'Trans-Corporeal Feminisms and the Ethical Space of Nature' (2008, 255): 'the human body is never static because its interactions with other bodies always alter it'. Not only do these interactions (including interactions with more-than-human bodies) affect the experience, they also alter the materiality of my physical body, for example, causing (or diminishing) stress and a dysregulated nervous system. This in turn also impacts on the different aspects of the bodies I inhabit: regular or chronic stress influences the menstrual cycle, my crip body gets depleted even faster.

Within the disability justice movement and community, these interdependencies are known as care webs. In their book *Care Work* (2018) Leah Lakshmi Piepzna-Samarasinha emphasizes the importance of recognizing that this form of mutual aid has long been practised and formed by Black, Indigenous and brown communities. I would argue that the relation between my nonbinary, menstrual, and crip body is another form of care web; they inform each other's caring needs. Sometimes – as in the case of going out to the queer party – my crip body takes a backseat in order to care for my nonbinary body. My menstrual body is also part of this; at the end of my cycle this would not have been possible for the fatigue (crip body) would have been amplified. Of course, it is not ideal but it is also reality, as most queer and/or night spaces are not accessible. So choices have to be made.

Part of this care web are the people around us. It is essential for me to have people with me who I feel safe with to take care of me. People who know to check in with me, to remind me to check in with myself: am I going over my boundaries and is it time to go, or can I stay a little longer? Do I need to adjust something in order to stay? And the importance of aftercare: staying in bed for at least a day (I usually need at least two days, due to post-exertional malaise) after a long night out dancing, paired with other care practices such as food and drinks or (self-)massage, for example, to replenish my bodies. The more I can practice this with the help of others, the easier it becomes to do by, and with, myself. And vice versa, it also allows me to do this for and with others. Thereby establishing a supportive and sustainable cycle of giving and receiving care.

Of course this is not limited to social gatherings or recreational activities. This can be (and perhaps should be) practised during academic gatherings, research work, and so on. How to frame your work so it does not spill out into the other parts of your day, your life? Especially when researching something close to us, or when we find ourselves more entangled with our research than expected perhaps, it is imperative to integrate care practices that work for us into our work, our relation to our research – whether we are working with other humans, the more-than-human realm, textual or otherwise – so that we may stay centred within our bodies as we are in relation with, and thus affected and altered by, our practice.

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prompt 7:
take a moment to close your eyes again while imagining a more liveable world for your body multiple. how does it feel in your body? does your breathing change? what happens to your shoulders, your stomach? how does your body feel when you think of the current academic environment? notice any differences.

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reflection

Care is, in its essence, an embodied experience. Therefore, only theorizing care is not viable, as it can only do so much. As Lindén and Lydahl Mol write, 'Care is not something to be judged "in general terms and from the outside, but *something to do, in practice*"' (2021, 4; my emphasis; quoting Mol et al 2010). Thus, while doing research and thinking about care, it is crucial to centre its *experience*. Therefore, thinking with the body – doing research with/from the body – contributes to creating liveable worlds by speaking from the source; the heart of the matter. It highlights current practices of care, and it indicates how these are lived; how they are experienced, and how they affect the body – the materiality of it.

In the process of writing this chapter, I went through a period asking for a profound need for care, even more than usual. I found myself in a burnout which urged me to stop working. In spring 2023, I got diagnosed with Autism and shortly after my relationship ended. I was thrown into a grief cycle. Grieving the relationship, everything that came up from being diagnosed relatively late in life, and grieving the things I had previously 'lost' due to being chronically ill which I thought I had already processed before. I was in a state of processing so much loss that my bodymind just completely shut down. It told me to stop everything else, and focus on the recovery process.

The paradox of trying to write a chapter about care and centring the body during research, and simply not being able to write anything because my body needed to be centred, is definitely not lost on me. I had to let go of the intellectualized concept of 'this is such an interesting position to be writing from, I should write this all out', and actually let go and stop working on this chapter altogether. To give myself the permission to do so was much harder than I had thought. Many times my care-coach urged me to let the entire project go – at least until I had recovered. At first, I kept trying to find ways to continue working on this chapter, as well as another paper I was in the process of publishing – working with a reviewer and revising my original text. I asked for accommodations in both situations. And here I was confronted (once again) with the general inaccessibility of academia for divergent bodyminds. You can read my chapter in this book because the editing team behind this project met me where I needed to be. The care that we all talk about in this book, this project, was actually practised. The other paper will not be published. There, they told me it was all fine, but did nothing to change the process for me. Their actions did not meet their words, as is so often the case. After tuning into my body, I made the decision to not proceed the publishing/editing process with them. The stress it put on my bodymind was not worth the exposure of getting my paper published.

During my burnout, I got to practice and live the questions I propose in the introduction. I learned to truly prioritize the needs of my bodies by holding space to consistently check-in with them, learning to listen and translate to what they were telling me. Some of the practices that were needed for me, once I felt ready to slowly start doing some work again: work for a maximum of 30 minutes on the days I could, properly frame the periods of time I would spend doing work (through scent, taste, sound, space, and so on), practice a short guided meditation for focus before work, and a qigong somatic practice to release and re-centre afterwards. By taking all this time to reconnect with myself, I also transformed the way I was in relationship to others by not overextending my social battery, practising expressing my boundaries, and sharing somatic practices with my friends.

The fact is, and remains, that every bodymind needs care and everyone (human and more-than-human) would benefit from reframing and reimagining care – from outside of a neoliberal capitalist system which sees care as not normal, and thus temporary (see Hedva 2016). The temporality of care is accentuated in the 'post-COVID' era; how quickly we were urged (and willing) to collectively be in denial about its declining threat; how quickly masking was dropped; how quickly hybrid education and work was deemed too costly and unnecessary. Even during the pandemic, what was a perfect opportunity to prioritize and practice caring interdependency, became a polarizing event underlining the abundant carelessness embedded in our current societal structure as 'neoliberalism is uncaring by design' (The Care Collective 2020, 10). It is my hope that this iteration of my personal experience of embodying care might add to answering the questions: How can we translate the bodies' messages to create care practices that embrace and celebrate interdependencies between humans and the more-than-human? How can we reimagine those practices into a politics of care that center the embodied experience and its diversity?

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prompt 8:

tune back into your body. notice where you may be holding tension after reading. are your shoulders and/or jaws clenched? release them. take a moment to observe how/if these prompts offered any insights and/or energy shifts. integrate this knowledge by taking three deep breaths, in through the nose and out through the mouth.

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