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On Trauma in Research on Illness, Disability, and Care

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Containing

At this moment, I feel this work in my body. I am simultaneously amped up and shaky, and exhausted, like I could just fall into a deep sleep. My reaction to triggering situations has often been wanting to sleep immediately. But oddly, I am also electric right now. It's a strange feeling, like it's all just sitting under the surface. I carry with me the things that broke me, all that I could not tell people because no one could understand, what I felt, how I coped, the darkness in that coping. And now I am carrying the things that my participants also feel they cannot tell people . . . because they are actually telling me. And I'm containing them all.

In the summer of 2020, I began virtual interviews with forty-four spousal or partner caregivers across the country. Because my late partner died in 2010, I was about a decade out from my own experiences, far enough to feel safe to do the work. My aim was to get the stories of caregivers, and when possible, to get stories from their partners as well. During 2021, I was able to make visits to four different couples in four different states. This provided me with additional observations to go along with caregiver interviews, as well as opportunities to interview disabled partners. I asked my participants to tell me what their caregiving looked like, how it was accomplished using technologies at home, as well as what they thought about disability and illness, their own disabilities (many caregivers were also disabled themselves and having to forgo meeting their own needs), and how they navigated health care and home care in the United States, where disabled people are largely abandoned structurally. It was especially powerful to hear how some caregivers, with disabilities stemming from conditions like multiple sclerosis or heart failure, were providing care in the context of near-total structural abandonment. There was no help from publicly funded programs, and because of the pandemic, they couldn't rely on the unpaid help of others out of fear of exposure. In addition to this, most struggled with depression, anxiety, and even PTSD before the pandemic. Years of caregiving in a society that devalues it meant that they were taking medications for depression and anxiety, many exhibited a flat affect, and some were emotionally labile during interviews. I am still grappling with how to talk about their trauma as intentionally debilitating (Puar 2017) and how caregiving in a society hostile to it disables people. This was particularly true for the participants in my study who were caring in the context of terminal illness. Several of my participants' partners died during the course of our conversations.

Throughout the project, I grappled with how to contain my own trauma and grief. I had a vague idea that my closeness to all this would be an asset in the work, but my disciplinary training in sociology also told me to never let it seep in, to keep it contained and controlled so that I could stay "professional." This makes me think of Katherine McKittrick's brilliant book *Dear Science and Other Stories*, where she writes, "Discipline is empire" (2021, 36). There is such baggage in the discipline of sociology about being a "legitimate" social science. In the past, the discipline tried to achieve this through claims of neutrality (Emerson 2001), as though neutrality were the same thing as rigor. But it was largely feminists in the field who intervened to challenge this kind of thinking, and the discipline's qualitative research standards took a "reflexive turn" (Biber 2013; Craven and Davis 2013; Jaggar 2013). As an interdisciplinary scholar, trained in feminist scholarship and disability studies, I have more freedom to be honest in my writing and to develop new ways of instituting rigor. Rather than an obsession with neutrality or the establishment of rigor through distance, I instead dive into my closeness as a way to engage more authentically with the project. This reflects feminist sentiments from these interdisciplinary enterprises that hold that the self we bring to the work is integral to the research process and "closeness" to the topic is not an assumed liability but rather simply something that needs to be accounted for, or even an asset. Being more honest about my own experiences and what I bring to the project also reflects my commitment to using research to make people's lives better, to center care, connection, and justice. How can we care, connect, and seek justice without bringing our full selves? Thus, in addition to navigating trauma, I also juggled navigating the various (inter)disciplinary spaces I work in, from sociology to disability studies. As a result of my emotional ties to the topic, some of the questions that emerged in fieldwork related to affective relations, connection, and rapport and at times complicated the vague goal of "professionalism."

Because of my own experience caregiving, I explored literature on trauma-informed research methods and trauma stewardship to guide me in developing a way to center care in my methods with other caregivers. To start, it might be useful to define care. Nancy Folbre and Erik Olin Wright (2012) talk about care as having distinctive features, that it is interactive and supportive. That is, the work is infused with concern for the well-being of those involved, and specific practices are undertaken to actualize this. Joan Tronto talks about care as "a species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life sustaining web" (1993, 103).

To enact such care, then, I thought carefully about both my orientation toward it and the practical ways to infuse it. I drew from trauma-informed interviewing, which takes into account that participants might be experiencing trauma. This literature is generally embedded in social work or detective work in policing when interviewing crime victims; some of the techniques have to do with allowing for silence during interviews, having resources ready, carefully planning the phrasing and flow of questions, and so on. There are a few examples of people thinking through the application of some of the principles to qualitative research, especially as it relates to reflexivity (e.g., Dempsey et al. 2016; Bosworth, Hoyle, and Dempsey 2011; Mitchell-Eaton 2019). That is, rather than just think about care as an affective state I bring to the interviews, I embedded specific techniques, as I detail later, into the work. I also made sure not to frame everything related to disability and care as negative. Being trauma informed doesn't mean just focusing on loss or grief; it also means celebrating and documenting survival, creativity, growth. Besides, the concept of trauma stewardship (Lipsky and Burk 2009) states that trauma has impacts that can be named and managed. While it's important to be present with others in their experiences, we must also acknowledge the effects of trauma on ourselves while we do the work and pay careful attention to it.

Seeping

July 2020

I held back in today's interview. The tears welled up and a few fell, but it was through sheer force of will that I did not collapse into guttural sobs. When we ended the call, I came out of the bedroom where I had been interviewing, found my partner in the other room, and said, "That was intense. I just cried a little during that interview, but I didn't want to be unprofessional." How is it that that was my first thought? The word *unprofessional* echoes out.

In interviews, my participants and I talked together. I told every single one of them that I was doing the work because I care about and want to investigate the structural issues shaping their experiences, but also that I was once a caregiver. This was information I gave them matter-of-factly because I felt they should know the personal and professional reasons why I wanted to do the project. It felt respectful. After all, I was asking them questions that were deeply personal, intimate, and could be upsetting. All of them said to me how much of a difference it made to know I had been through a similar experience, how they felt they could tell me things because of this disclosure. A few of my participants' partners died during fieldwork. Sometimes we were done with our interviews and they'd reach out to tell me. For others, it happened between our phone calls.

I would speak with someone one week and by the next their partner was dead, and they were grieving, deep in the beginning stages. This too was familiar territory for me; I did not feel awkward or unable to respond. My experiences meant I could be supportive of my participants in ways that other researchers likely could not have. As time wore on, I became more comfortable with crying in front of them, with them. And some of them told me things they did not tell anyone, and they would say, "I know you understand." So I began to ask myself, what if when we are interviewing those we may share a similar experience with, we see these seepages of relationality, of connection, not as "unprofessional" (what does that mean anyway?) but rather as connective, authentic? As investment in our participants, tying their lives to ours and pushing back on more standard or commonplace social science narratives that advocate the idea of separating "the researched" and "the researcher," the "objective" or "neutral" social scientist and the data? Regardless of the topic, are we not also our lives? Our feelings? And when relevant, our traumas and what we bring to our work?

November 2020
In today's interview, tears flowed from both of us. I have learned to grieve with my participants. She told me a story about falling asleep standing up in the elevator in the hospital after a long, frightening few days there where the situation was brutal. There were only six floors to her stop, but she somehow slept for just a minute, standing up, between floors 1 and 6. And this hit me in the gut. I am often aware of how sometimes I can only recall the shape of a memory, a haloed feeling, gauzy. I'm sometimes separate, walled off from all that happened. And the treatment I had for trauma, eye movement desensitization and reprocessing, can also cause you to stop being able to remember things as clearly. While it's all still deep within me, it is not quite on the surface. But it can be surfaced in very specific situations. This was one of them. I was suddenly bone-tired and on the floor of urgent care trying to get some sleep while my partner was waiting to be admitted to a floor. I could feel the warmth of one of the crisply woven white blankets from the blanket warmers that the nurses kept in the back of that unit. The tidbits from participants in the interviews would lead me back to my own memories. Sometimes I would have to catch my breath, as I felt a memory, just a sensation really, rising in my torso. When the interview ended, I would squint backward, to bring it up again and sob. Other times it felt like it had slipped away from me, but then it would still hit me later without warning, usually that night in a dream. My late partner, J, has appeared in my dreams more in the last few months than in the last few years. There's a closeness to her I feel again.

The early interviews in the project were the beginning of my containing everything. I didn't just contain that hour-long interview, I contained the decades. I learned about myself during these conversations with participants. I discovered memories I had long split off from, confirming how far into a dissociative state

I had been in during much of the caregiving. In this way, I learned about my own grief from my participants. The more people I interviewed, however, the less panicked or concerned I became about any tears that might come. Early on, I tried to keep myself really walled off, trying to be as contained as possible, but the more interviews I did, the easier it got for me to be more emotionally authentic. If I felt tears, I let them come quietly, in a way that did not take up space from my participants. It was a slow seep. I learned to be real but not overtake the interaction. I would subtly reach my arm out to the table next to me for a tissue, dab my cheek, and keep going, nodding at my participants over video, letting them know I am listening, I am feeling, to please go on.

Mitigation Techniques

What I want to do now is turn to the obligation of care we have for ourselves and each other when we are engaged in research. In undertaking qualitative research, we are not only tasked with accurately representing participants' lives, but we must also do so with care and empathy. How can we accurately represent people's lives if we do not care for them and sustain them during our interactions with them in fieldwork? And if we do not care for ourselves, we cannot come to the material safely. For me, in this particular project, care was both the topic of the research and the guiding ethos. Forefronting and confronting my own trauma and how it was brought alive in the process of interviewing participants was crucial for mapping myself in the work, but also in order to learn how to care for myself and them. It means taking enactments of care for myself and my participants seriously and enacting them in a systematic way.

Self-Care in Research

I quickly learned that I was stepping into complicated emotional terrain and I needed to be equipped to navigate it. The first thing I did was institute practices of self-care. This primarily took the form of boundaries around the timing and scheduling of fieldwork, as well as the development of rituals before and after interviews. For example, interviews were limited to one, sometimes two, a day because I found them emotionally exhausting. So I learned how to pace myself and protect my emotional health. Thus, I limited interviews to specific hours of specific days. This meant that I could know that every Tuesday and Thursday afternoon would look a certain way and I could rest in between. I rarely broke my scheduling rules unless a participant's schedule just could not accommodate these limits. It was comforting to know I had boundaries around my days and when things were scheduled. I also always left room for interviews to go very long. One of my first interviews was one of my longest, lasting over two and a half hours. I started blocking off two and a half hours for every interview. Most did not go that long, but it was a way to care for myself, to give myself room, to build slowness into my calendar. These things helped to significantly lower my anxiety.

Taking care of myself by developing rituals for before and after interviews during my fieldwork was also key. Many of the interviews were deeply affecting and retraumatizing for me on multiple levels. I needed to take care of myself so that I could enter the interview space in a way that was safe and healthy for everyone involved. This required being deliberate about self-care before and after. I would set up a comfortable interview space, make a cup of tea, and take some calming breaths. I would have all the things I needed ready—my computer, my notebook, tissues. This created a bit of a sanctuary for me to do some reflection and check in on how I was feeling, center my breath, and enter into the interview in a calm state. I also built in time after the interview to decompress and to memo immediately after. In many qualitative methods, memoing is a strategy for capturing your thoughts and feelings after an interview, observations of how it went, how you felt, and what you thought. Once I finished my memo, I would often close my laptop and cry. Then I would move into a debriefing stage. To do this, I would reach out to a friend, a colleague, or my partner and ask for care; space to just cry and vent, to say aloud what some of my responses were. I was always careful to do so without breaking confidentiality; it wasn't about the content of the interview per se, but my response to it. Building in these emotional buffers around the work meant I could keep showing up to hear stories in a way that was safe.

Care for Participants

We have a responsibility as researchers to enact care for our participants. This is not about paternalism, but rather about creating a two-way flow of care, taking care of ourselves so we can have good boundaries in the work and taking care of each other so that everyone can participate in interviews or fieldwork and feel cared for and sustained while doing so. During my fieldwork, I developed a set of systematic techniques for providing care. This was not just the affective work during the interview itself but specific operational strategies.

The first time I interacted with my participants was a recruitment phone call. For this call, I asked them to set aside about fifteen minutes to talk with me so I could go over the project, make sure they met the study criteria, and talk about the consent forms and other logistics. I went over what the study was about and revealed to my participants that I have some personal familiarity with what they've been through. Disclosing this positionality was part of keeping them safe. I was asking them questions about things that may potentially be very traumatic, or something they are actively grieving about. I wanted them to know that they would not need to do the additional work of managing my responses or worrying about being judged. This came from my own experience; when my partner was alive, I was hesitant to talk to people who "didn't get it." So I just generally explained to my participants that I had been a caregiver for five years before my partner died; I did not go into any detail. Participants all told me that it was a relief to talk with a researcher who might "get it."

Another part of keeping participants safe and caring for them was being clear on the details. Since many were in complex and traumatic situations, I would care for them by telling them that they would not have to remember any of the details from the consent form I was about to go over because they would have a copy of it. I assured them I would email them with clear instructions. I went over the information smoothly and conversationally, and when it came time to set up the appointment for an interview, I reminded them the day before by contacting them. I then followed up after the phone call with an email that summarized what we said and what was next in terms of the appointment date. I gave them my cell phone number and encouraged them to call or text with any questions.

When it came time to do the interviews, I worked hard to create a safe interview environment through specific techniques. Drawing on trauma-informed interviewing techniques, I told them up front that I might ask questions that were upsetting or the conversation could get into areas that were difficult. I told them that we could stop at any time and that it was OK if they didn't want to answer something. I found it useful to open with getting a picture of their lives, how and when they met their partner, how they cared for each other. This helped participants to remember who they were, who their partner was, and it also gave me information about their personality, their class or education background, and so on in the process. I also made sure to expect nonlinearity. Trauma refracts time through a prism in ways where events can be split off and their stories might jump around in time or be told in circuitous ways. I did not problematize this or try to shape it into something linear when they were in the middle of talking. Rather, I gently tried to piece together any timeline puzzles, sometimes going back at the end of an interview and saying I wanted to clarify something.

The affective labor in interviews was also strategic. I stayed open and soft; I would ask a question but let them talk about what they wanted. It was important to let things unfold and to be patient. Most of all, I created space. It was OK to be silent, to cry. I followed them where they went while balancing this with moving through interview questions. A lot of this affective work is simply staying gentle. I also ordered my questions in particular ways. I started with these broader openings to get to know them, then moved into the middle section, where the more traumatic aspects are likely to be discussed. I ended with demographics or other questions that were "easy," because everyone was tired by then. It was important to not ask participants to answer traumatic questions at the end when they were tired.

The Potential Damage Caused by Weaponizing Trauma

For many caregivers and disabled people, there is indeed loss and grief, and sometimes trauma comes along with it. But it is crucial that we hold these truths without devaluing and disrespecting the experience of disability. While attending to trauma and caring for participants and ourselves is important, it should not be done in a way that contributes to narratives of disability as tragic. Disability, illness, and caregiving are whole and human experiences; and part of their wholeness might include trauma. But in an ableist society that often *only* sees disability as tragic, we must tread carefully. How can we acknowledge trauma without slipping into what we might call "trauma porn," or "perverse fascination with other people's misfortune" (Meley 2019)? How can we acknowledge trauma without promoting the idea that disability is misfortune, rather than simply human experience? As Keah Brown (2021) put so well on Twitter, "Pity is so cheap. The true way we can move disability and illness involved narratives forward is to stop treating [disability and illness] like they're the worst possible things and more like the lived experience that inform the way fully realized humans navigate the world."

In academic work on care, and in caregiver advocacy circles, there is a tendency to center "caregiver burden," which has become a dominant concept for understanding the experiences of caregivers. Caregiver burden as a concept is a product of ableism. It strips disability and illness from its social context, positions it as *only* burdensome, and positions caregivers as nondisabled (when many are disabled themselves) and burdened *because of someone's disability* rather than because disabled people and their caregivers are both largely structurally abandoned. Care could be conceptualized as something so much more nuanced than "burden" if context were meaningfully included. For example, one might note that if home- and community-based services and long-term support services were adequately funded, income caps for disabled people raised, and so on, disability and care would be far less of a "burden." Yet if I run a search for "caregiver burden" in Google Scholar, there are more than four hundred thousand papers, primarily reviews of caregiver burden literature and caregiver burden scales and inventories to measure how burdened someone is, and so on. In addition, caregiver narratives or memoirs often exploit this burden frame. In writing about a *New York Times* story that celebrated a man murdering his wife and then killing himself when she had Alzheimer's, Alice Wong reminds us of how caregiver burden is used to excuse such horrors: "[In] cases like this, many people cite caregiver 'burden' as an explanation, [but that] assumes that [one] spouse is solely responsible for care and decision-making" (Wong, Brown, and Leebron 2020). Once again, the "burden" is equated with disability, and it is seen as so bad that disabled people should die rather than someone (in this case a spouse) being left alone to carry that burden. But this frame completely erases the structural conditions that devalue both disability and care and therefore create these circumstances. In caregiver memoirs, trauma is easily engaged with shallowly, forgoing critical engagement with disability policy or social context. In these cases, caregiver burden tropes slip into the realm of trauma porn, which highlights *only* the trauma and individualizes it, removing all social context.

So how can we both acknowledge trauma and infuse care into our work, but do so in a way that doesn't rely on and perpetuate flattened narratives of tragedy? What I would like to talk about in this last section are strategies to take trauma seriously but that don't fall into the trap of individualizing disability and reducing it to a tragic, pitiable phenomenon. For example, during interviews, I was careful to use affective techniques that normalized what people told me. I did not respond in horror. I nodded and validated, and created an environment where participants could talk about bodies and needs, but this was not upsetting or pitiable. Instead, I responded as though these were perfectly expected aspects of life (which they are). Second, I balanced our focus. I did this by asking participants to send me photos of their homes and the technologies and tools they use in care and in making homes accessible. Inevitably, caregivers had not thought about these as creative practices, as disability world-making (Hamraie and Fritsch 2019). When they did send me photos and we talked through the novel things they and their spouses were crafting together, how they mastered or adapted certain technologies, they were astounded (indeed, many were delighted!) at their own inventiveness, their partner's inventiveness, and how disability spurred these ideas. Thus, we balanced talking about the hard things with the generative.

I also asked questions about how they cared for each other, how they collaborated with their partners because they cared and contributed too. As a whole, trauma-informed methods do not need to be about focusing solely on loss or grief; they can also celebrate strength, creativity, and relationality. I asked questions related to collaboration and creativity as a way to move from a damage-based to a desire-based frame. This reflects Eve Tuck's work, where she writes that desire-based frameworks push against narratives of damage: "In damaged-centered research, one of the major activities is to document pain or loss in an individual, community, or tribe. . . . Common sense tells us this is a good thing, but the danger in damage-centered research is that it is a pathologizing approach in which the oppression singularly defines a community . . . research that operates, even benevolently, from a theory of change that establishes harm or injury in order to achieve reparation" (2009, 413). In contrast, Tuck argues, desire-based frameworks are interested in "understanding complexity, contradiction, and the self-determination of lived lives . . . by documenting not only the painful elements of social realities but also the wisdom and hope. Such an axiology is intent on depathologizing the experiences of dispossessed and disenfranchised communities so that people are seen as more than broken and conquered. This is to say that even when communities are broken and conquered, they are so much more than that—so much more that this incomplete story is an act of aggression" (416).

Finally, in analysis, contextualize, contextualize, contextualize. The goal is to tell our participants' stories, but not at the price of ignoring the politics of how we got here. Attending to trauma does not necessitate a freefall into a "tragedy" narrative of disability or illness. The stories of participants can be used to reveal how unjust and inadequate our systems are. Furthermore, conceiving of care as only an emotional or affective process (trauma, damage, burden) without attention to the structural apparatuses is destined to be exploitative. Instead, we have to attend to the conditions that dictate the circumstances of disabled people's lives and the contours of care. Doing these things pushes back on ableism and limits the potential for stories that involve trauma and disability or illness to be "saturated in the fantasies of outsiders" (Tuck 2009, 412).

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