

ILLNESS METHODOLOGY FOR AND BEYOND THE COVID ERA

Melissa Kapadia, Lecturer, University of Pennsylvania

In 2016, documenting the practice of researching while chronically ill, I wrote what I termed Chronic Illness Methodology (CIM), an embodied set of practices that centers the ill researcher and their needs. My argument was that researching while ill was not simply a practice rooted in necessity for ill researchers, but an important framework that shaped the work itself. This has echoed the work of Critical Disability Studies and Crip Theory scholars who have argued that (a) when Disability Studies is limited to the study of people with disabilities, it can often treat disability as an object of study rather than a way of knowing; (b) the inclusion of research and activism *by* people with disabilities can make Disability Studies “critical” via the important framing of methodologies and pedagogies through the lens of disability epistemologies; and (c) crip-of-color scholarship and analysis can point us to the ways that queer and of-color feminist thinkers have always viewed and applied critique via intersectional lenses (Kim, 2017; Minich, 2016). In other words, researching while ill is not the study of illness and its effects, but the application of ill lenses and ways of knowing to the practice of research.

Of course, the naming of methodologies that better fit researchers’ worldviews and lived experiences is by no means “new.” It is part of a radical tradition that includes queer and indigenous researchers, researchers of color, disabled researchers, and others whose ways of knowing challenge traditional paradigms with histories rooted in white, cisgender, able, masculine, “normative” ways of knowing (Brayboy, 2005; Delgado Bernal, 1998; Minich, 2016; Smith, 1999).

At the same time, the concepts of “normative” and “radical” imply that QBIPOC (queer, Black, Indigenous, and people of color) and ill researchers are doing something new; in reality, how we live and how we research have always existed (Lorde, 1984). So, while naming our epistemologies and honoring the ways they inform our work may be a “radical” tradition, it is only radical because of academia’s positioning of white, colonizing, cisheteronormative, able-bodied ways of knowing as the norm. Academia, then, has thrived on the silencing of those who might be deemed “non-normative,” in part because this has enabled “normative” academics to be given the status of agents and researchers, and us to be given the status of objects and “the researched” (Smith, 1999). This understanding was the foundation for CIM.

CIM was further shaped by the premise that research as an industry operates under ableist values. Some examples of this include demands for specific measures of rigor in research that might require researchers to have able and healthy bodies (for example, expectations of quick and heavy data analysis processes assume that a researcher has healthy vision, no learning disabilities that may require accommodation, and access to free time); specific publishing timelines linked to academic promotion (these assume the researcher will not experience prolonged sick time, require FMLA, or have disabilities that limit their capacity to publish in brief windows); and expectations that researchers will be able to present their research in formal and often elite settings (these assume that researchers have normative languaging, processing, and mental health capacities). With these assumptions in mind, I previously outlined five affordances CIM offers to the researcher:

1. License to research from the body, meaning the research protocol and practice can be shaped by the researcher’s personal needs and capacities, and that the research design can refer to the researcher’s embodied experience and limitations as valid reasons for certain decision-making.
2. Knowledge that the researcher’s feelings about what works and doesn’t work in the research system are supported by the researcher’s local epistemologies.
3. Capacity to reject methods and practices that do not work for the researcher’s researching life, meaning that if practices considered a gold standard for a certain framework or methodology do not fit the researcher’s body or life needs, the researcher can use this as a valid reason to reject them.
4. A language of trauma, justice, and empathy that is deeply threaded through every element of the work, beginning with empathy for the self and spreading out into the research context and participants’ lives.
5. A deep valuing of people’s painful truths.

These tenets aim to relieve the ill researcher of the limitations of researching in a world that does not always make room for ill or “unruly” bodies, i.e. bodies that do not function or behave in ways that are considered normative or respectable. This has historically included ill bodies, disabled bodies, trans bodies, neurodivergent bodies, fat bodies, and so on. This framework is intended to include *all* researchers because of the assumption that the ableist and healthiest values (described in more detail above) of traditional research paradigms punish us all and strip us of our humanity.

The covid-19 age is challenging healthy and able-bodied researchers to join their ill and disabled colleagues in our explorations

of the limitations and creative affordances of illness on our research practices. This includes the increasing demands on researchers to consider deeply the health needs of the people they study (especially vulnerable populations, including poor, trans, incarcerated, young, or immunocompromised people). Given this, these questions, though not exhaustive, are starting points on how to center illness epistemologies in one's research:

- In what ways do I buy into traditional value systems of academia? For example, do I cite the “right” pieces that perform my knowledge? Do I work on signaling that I have “enough” knowledge about marginalized or “non-normative” groups without necessarily investing time or energy into learning about and from them?
- In what ways do I impose my class, ability, race, etc. experiences on my participants? For example, do I assume that if they are to get sick while participating in my study, they will have easy access to health care? Do I assume they will have access to technologies, free time, travel, vocabulary, and other needs required for participation?
- In what ways do the personal, professional, institutional ethics that guide this research agree or disagree with the ethics my participants' involvement might require? For example, has my Institutional Review Board approved the collection or presentation of data without the need for layered member-checking in case factors in participants' lives change post-collection? Have I decided that as long as my work meets IRB standards, I do not have to put further thought into the post-collection needs of participants?
- Have I made space in the research site for participants to communicate their access needs? Have I shared my access needs with colleagues and participants?
- In what ways would I desire more transparency in this context if I were a participant instead of a researcher? For example, if I were a third party with no stake in the research, would I believe that participants should ask for more protections, more access to data decision-making, and post-write-up approval? Am I relying on their lack of familiarity with research practices so that I do not have to hold myself accountable to their potential needs?
- In what ways can I make my research design and site plans more inclusive of those who currently cannot participate? What potential barriers might there be to participation, and how are these shaped by my worldview rather than by what is possible?
- Am I ready to be challenged about what I know? How can I approach my work with a goal of de-centering my ways of knowing? Do I regularly consider that my point of view might be wrong or incomplete? Do I regularly consider that my participants' life choices are at least as valid as mine?

I frame these questions as a starting point because the goal here should not be to “get through” the covid-19 age and return to our old ways of knowing and doing, but rather to engage a mindset that centers illness epistemologies even when able-bodied researchers are not affected by a global pandemic.

References:

Brayboy, B. M. J. (2005). Toward a tribal critical race theory in education. *The Urban Review*, 37(5), 425-446.

Delgado Bernal, D. (1998). Using a Chicana feminist epistemology in education research. *Harvard Education Review*, 68(4), 555-582.

Kim, J. B. (2017). Toward a crip-of-color critique: Thinking with Minich's “Enabling whom?” *Lateral*, 6(1).

Lorde, A. (1984). *Sister outsider: Essays and speeches*. Berkeley, CA: Crossing Press.

Minich, J. A. (2016). Enabling whom? Critical disability studies now. *Lateral*, 5(1).

Smith, L. T. (1999). On tricky ground: Researching the native in the age of uncertainty. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed., pp. 85-108). Thousand Oaks, CA: Sage Publications.

Melissa Kapadia (they/she) is a lecturer in the Penn Critical Writing Program, organizer with the Radical Asian American Womxn's Collective, and community educator in Philadelphia.

[Report accessibility issues and request help](#)

Copyright 2021 The University of Pennsylvania Graduate School of Education's Online Urban Education Journal

Source URL: <https://urbanedjournal.gse.upenn.edu/archive/volume-18-issue-1-fall-2020/illness-methodology-and-beyond-covid-era>