Workshop Submission

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As an ethnographer of data, I am interested in the question of what it takes to count and be counted i.e., specifically, who comes to count as disabled in urban India, and under what circumstances. This interest has taken many forms over the last few years, starting with the question of what categories of people are considered disabled under the Indian census, a project that was scrapped during my initial months of fieldwork due to the Citizenship Amendment Act protests and the subsequent postponement of the census. Switching the shape of my project quickly, right before the onset of the COVID-19 pandemic in India in March 2020 and the resultant lockdown, I focused instead on the process of being certified as disabled, first through the disability certificate and the unique disability ID (UDID) card. Across these objects of study, my interest in disability and data were motivated by curiosity about what it meant for disability to be widely written about as 'undercounted,'[1] often by a factor of 10 or more.

I began my fieldwork by following various kinds of disability numbers, trying to place where they'd come from and to understand why they were thought of as lower estimates. However, a few months into the start of my fieldwork, on March 24, 2020, Prime Minister Narendra Modi announced a 21-day nationwide lockdown to prevent the spread of COVID-19, allowing citizens across the country less than four hours to prepare to shelter in place for the duration of this lockdown. Later extended until May 31, the lockdown shut down all access to public transport, halted food and medical supply chains nationwide, and disrupted healthcare services. After it was lifted, although much of the country began to resume "normal" life in fits and spurts, I first began to question whether my project could continue as planned. Although I had intended on conducting ethnographic fieldwork at two different government offices, I could no longer think of continuing to do so in person – in this sense, my field site continued to exist, but as a disabled researcher with numerous disabled participants, the site was no longer accessible to me.

Further, as the ripple effects of initial disruptions in healthcare services due to the lockdown continued to be felt by numerous disabled communities that I was working with, calculating the risks of an in-person ethnography was horrifying. Although I knew that my affiliation with a global North university meant that I would have access to healthcare in many more ways than my participants would, working across different field sites (i.e., for instance, between a government office and a smaller disabled peoples' organization) would mean a level of exposure that both my participants and I were not comfortable with. As a result, I moved my project entirely online, studying what I could of my original set of questions through a range of social media platforms. Therefore, although there was no longer an opportunity for me to hang out at government offices, for instance, I could still attend Facebook lives, read tweets, and

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[1] This description of people with disabilities/disability itself as undercounted appears widely across reports by international organizations, newspaper articles, social media posts and journal articles.

attend public and semi-private consultations. Additionally, although I would no longer be conducting semi-structured and unstructured in-person interviews, I was able to continue to speak with several of my initial research participants virtually.

Navigating interviews virtually in the early months of the pandemic meant negotiating different access needs that my participants had. In numerous instances, the sudden lockdown had caused breadwinners to lose their source of income, because of which accessing the internet was more than my participants could afford. Thus, even as my participants searched for work in the backdrop, when we were able to keep talking, these interviews were conducted over the phone. In other cases, being house bound during the lockdown meant that participants no longer had access to their own private spaces in the ways that they would previously have had, as a result of which interviews were conducted entirely over WhatsApp (messages, or voice notes). Following Ahlin and Li's (2019) understanding of the field site not a singular location, but rather as a series of networked events made possible through ICTs allowed me to reconceptualize what it meant to do fieldwork in Delhi during the lockdown – although I no longer had access to some of the sites that I had laid out in research proposal, I was able to approach the idea of a site differently, instead assembling the site through digital events.

However, in April and May 2021, the worst of a severe COVID wave swept across India. Delhi, my fieldwork home, was one of the epicenters of this devastating surge. Even when this wave might seem – given everything else that has happened between now and then – like a distant memory, I am struggling a little to describe the magnitude of these waves[2]. Instead, I will attend briefly to what I can allow myself to remember: the politics of numbers in counting death. Although thousands of deaths were counted across the country daily, so many of us who lived through this wave expressed doubt, in-person and online, that the numbers we experienced in everyday life were far different (and lower) than the numbers we'd seen reported. A couple of months after the end of the wave, for instance, NPR reported that India's pandemic death toll was estimated at about 4 million (i.e., 10 times the official death count alone)[3].

These questions about bodies being made into numbers across "multiple scales of counting" (Nelson 2015, 2) dovetailed with my research on who comes to be officially counted as disabled in India, another area where the state's efforts to count were being widely questioned. From my vantage as a disabled researcher interested in whom the state considers disabled, the question of counting the pandemic's dead was inseparable from the question of *who* was most likely to die. Owing to sociopolitical conditions prior to and during the pandemic, disabled people have been rendered more vulnerable and less likely to receive adequate care than their non-disabled counterparts (see for example the summary in Shakespeare, Ndagire and Seketi 2021). Against this backdrop, in Delhi, somewhere I'd considered a home even before fieldwork,

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[2] Dastidar (2021)

[3] The NPR piece (Pathak, Freyer and Silver 2021) provides an estimate of the total number of deaths that had occurred in India since the beginning of the pandemic in March 2020, although the wave in 2021 was the most severe. Other sources (see for example Kaur 2022) also provide an estimate of undercounting since March 2020, rather than for the wave alone.

I was still at ethnographer on borrowed time, needing to do fieldwork for a certain number of months before I could go back to writing my dissertation.

Given everything that was happening with the severity of the COVID wave, I didn't quite know what it meant to do ethnographic research – to follow the field, to attend to the realities it made room for – during this time. Right before the wave began, my research participants and I had just started to meet in person after more than a year of "hanging out" online, excited for what the then-drop in COVID-19 numbers might mean for our work together. But as the number of positive cases started to rise rapidly, I noticed a larger rupture—not merely a disruption in fieldwork plans, which had already occurred at the start of the COVID-19 pandemic, but more so a constant, grief-filled question of whether and how to continue research. Already skeptical of how my research would translate into "real-world" results, Arvind, a research participant who had been house-bound without access to necessary medical care during the March 2020 lockdown asked me only half-jokingly at the start of the wave: "And now that the numbers are rising, what do you think your research on undercounting will do? Will it convince the government to care about disabled people?"

To answer the many questions that I raised above, I thought with chronic illness methodology. Melissa Kapadia writes of this methodology as one that does not seek to lay out "ways of doing" (2016, 58 – 29): instead, "it locates the act of researching, the methods and practices of the work, and the beliefs and value systems of the research within the researcher herself. In this way, chronic illness methodology is not a methodology at all but an embodied practice shaped[4] by the researcher's lived experience" (Kapadia 2016, 59). In later writing at the start of the pandemic, Kapadia also notes that chronic illness methodology can be understood as "[…] the application of ill lenses and ways of knowing to the practice of research." Kapadia (2020) further notes that "researching while ill [is] not simply a practice rooted in necessity for ill researchers, but an important framework that shape[s] the work itself." Importantly, they describe the practice of chronic illness methodology as being shaped by the following tenets: "(a) license to research from the body (b) knowledge that the researcher's feelings about what work and don't work in the research system are supported by the researcher's personal and local epistemologies (c) capacity to reject methods and practices that do not work for the researcher's researching life (d) 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 and (e) a deep valuing of peoples' individual painful truths" (2016, 59 - 63).

Chronic illness methodology's emphasis on doing in ways that work for both the research and their research participants allowed for me to work through questions that arose alongside an uncertain and ever-changing field situation. To be clear, the methodology did not provide directives or answers, at least not in the ways that I had learnt to look for them pre-pandemic, and certainly not to questions like: What do I do during fieldwork if I am not sure there will even be anything going on at my field site? Should I be typing up my field notes at the end of each

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[4]

day, memo-ing at the end of each week? Instead, it allowed me to negotiate the unpredictability of illness as a composite – my illnesses, those that my participants had and were worried about having, and the severity of a mass disabling event with no defined beginning or end – in ways that felt most respectful to my participants and to the intentions of my project.

Methodologically, on numerous occasions, this meant that I studied a question through a form or medium different than I could have anticipated in my research plan: for instance, at the very beginning of 2020, I had several in-person meetings with research participants to think through their use of social media platforms for local and national advocacy around disability and identification. As the pandemic began, our time together was virtual, but often focused on strategizing around the possibilities for in-person advocacy with the government. It also meant that sometimes, when interviews that had begun in person were halted by illness, they were continued through voice notes on WhatsApp.

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