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Sickening Responsibility: Thoughts on Care Work from a Chronically Ill Scholar Activist

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Abstract

What does it mean to focus practices of responsibility around sick/unwellness during pandemic times? Using a disability justice framework and drawing from my experiences as a chronically ill / sick person, in this article, I argue that responsibility takes on different meanings when examined through a critical framework that recognizes sickness as an ordinary aspect of life under interlocking systems of power, such as capitalism, White supremacy, ableism/sanism, and cisheteropatriarchy. In particular, I contend that beginning conversations about responsibility from the assumption of sickness –that everyone is either sick or has the potential to become sick and that sick people are always impacted by individuals' actions –generates space for relational transformation towards more meaningful, substantive practices of responsibility. Moreover, because of the ways that pandemic times have disproportionately harmed chronically ill, sick, and immunocompromised peoples, I assert that sickening responsibility is both an urgent task for social justice activists and organizers and one which has the capacity to support the life of individuals and communities in the midst of great uncertainty, fear, suffering, and loss. The purpose of this paper is to intervene in and expand conversations about responsibility that so often marginalize and exclude disabled/crip folks, and sick people especially.



For many sick, chronically ill, and immunocompromised people, the Coronavirus pandemic has not constituted a break from our “normal” lives and experiences so much as it has led to an amplification of realities that were already present for us. The world around us had surely changed, in ways both good and bad, and there are emergent and worsened dangers to be sure, but lots of sick² people were already existing in “crisis mode” prior to the official pronouncement of the pandemic times. Many of us were already afraid of leaving our houses or going to crowded places because of the potential harm other people could cause to our bodyminds. Many of us were already taking safety precautions like social distancing and wearing masks because of how often we have witnessed other people act irresponsibly or unkindly towards us. And many of us were already strategically thinking about ways to care for each other in the midst of collective unwellness – for example, by building interdependent networks or “care webs” that help to ensure all our needs are dependably being met (Piepzna-Samarasinha 2018). The pandemic times have most certainly thrown a wrench into sick people’s lives, especially for those of us who are simultaneously disadvantaged or oppressed in relation to other axes of power (e.g., race, class, gender), yet many of us and the people practicing solidarity with us have been finding creative ways to generate access for much longer than the pandemic times have been going on.

That said, the social, political, economic, and relational shifts brought about by the pandemic times as well as the heightened possibilities of violence and harm make it urgent for sick folks and our relatives³ to collectively think about what responsibility means in this moment and as we keep moving forward. I define responsibility as a commitment to build just and equitable relationships and to always act from the understanding that everything we do affects our own well-being in addition to the well-being of people around us. Because our actions have consequences, practicing responsibility means doing what we can to minimize the harm we cause and to contribute to a society in which all peoples are supported in leading meaningful, worthwhile lives. This definition of responsibility is meant to align with the disability justice framework, which values intersectionality, interdependence, cross-disability solidarity, collective access, and collective liberation (Sins Invalid 2016; Lewis, 2019; Mingus 2018). In contrast, irresponsibility both emerges from and leads to suffering, inequity, and injustice; it is the very foundation of systems of power and oppression that disability justice defines itself against. In this article, I use the lens of sickness during the pandemic to think critically about what an anti-ableist, disability justice-centered approach to responsibility could look like. The guiding concept that I examine and develop throughout this paper is the idea of *sickening responsibility*, which broadly speaking describes a process of redefining or recentering responsibility around a generative practice of solidarity with sick folks. For the purposes of this paper, solidarity “in contrast to charity and philanthropy... is a form of reciprocity rooted in the acknowledgment that our lives are intertwined” (Taylor and Hunt-Hendrix 2019).

² For the purposes of this essay, I will use “sick” as an umbrella term that encapsulates sick, chronically ill, and immunocompromised folks as well as any other related identities. I recognize that many people do not identify with this term and that it is not perfect in its representation, yet it is the term that best fits my need in making the arguments of this paper.

³ I use the term “relatives” to describe anyone that sick people are in relationship with rather than just biological associations. People become relatives to one another as a result of building kinship networks that allow for deeper and more meaningful expression of interdependence. My use of “relatives” here is informed by Alison Kafer’s work (2019) on crip kinship as well as Mia Mingus’ writing on intimacy between disabled people (2017).

What does it mean to focus practices of responsibility around sick/unwellness during pandemic times? Using a disability justice framework and drawing from my experiences as a chronically ill / sick person, I argue that responsibility takes on different meanings when examined through a critical framework that recognizes sickness as an ordinary aspect of life under interlocking systems of power, such as capitalism, White supremacy, ableism/sanism, and cisheteropatriarchy (Barlow 2018; Cvetkovich 2012; hedva 2016; Helm-Hernandez 2013; Page 2013). In particular, I contend that beginning conversations about responsibility from the assumption that everyone is either sick or has the potential to become sick and that sick people are always impacted by individuals' actions – generates space for relational transformation towards more meaningful, substantive practices of responsibility. Moreover, because of the ways that pandemic times have disproportionately harmed chronically ill, sick, and immunocompromised peoples, I assert that sickening responsibility is both an urgent task for social justice activists and organizers and one which has the capacity to support the life of individuals and communities in the midst of great uncertainty, fear, suffering, and loss. The purpose of this paper is to intervene in and expand conversations about responsibility that so often marginalize and exclude disabled/crip folks, and sick people especially.

Sickening Responsibility in the Search for Disability Justice

Similar to other forms of disability⁴, sickness and chronic illness are socially, politically, and historically constructed in relation to intersecting systems of power and oppression. Even though they are located within individual bodyminds, the representations and meanings assigned to sickness, the communities of people most impacted by sickness, and sick people's access to social and material resources are all mediated by violent systems and structures (hedva 2016; Mingus 2015; Piepza-Samarasinha 2018; Wendell 2017). For instance, capitalism has organized Western society in such a way that poor and houseless people are *more* likely to become sick (e.g., because of food scarcity, lack of safe and stable housing, and worker exploitation) at the same time that they have *lessened* access to quality healthcare and healthy environments. Similarly, White supremacy functions to protect White wealth, health, and power through perpetual enactments of hatred, violence, and terror against Black, Indigenous, and people of color (Barlow 2018; Levins Morales 1998), and through the historical trauma of segregation, slavery, and settler colonialism (Goodkind et al. 2012). These enactments range from the routine state violence against Black and Brown bodies, to the exploitation of people of color through manipulative medical testing, to the tendency to position landfills and hazardous waste sites near communities of color – all of which lead to inequitable experiences of sickness and disease across racial lines.

Accordingly, sickness is as much a structural or political production as an internal reality, which means that substantively attending to the needs and experiences of sick folks requires a combination of social and medical interventions – activists and doctors alike. Medicine alone cannot remedy the imbalances in power and the neglected responsibilities between people underlying the many health crises affecting marginalized and oppressed peoples. And, overlooking the social dimensions of unwellness to focus exclusively on the medical has contributed greatly to the erasure and marginalization of oppressed people's experiences and needs. Ana Clarissa Rojas Durazo (2006) defines medicalization as the process that occurs when “institutionalized, ‘mainstream’ or western medicine reconstitutes social problems as ‘diseases’ or individual pathologies in need of medical intervention.” The danger of medicalization (and the related process of pathologization) is that we start to focus on what is “wrong” with individual people rather than how social realities are negatively impacting their health. We stop talking about how systems of power and oppression cause irresponsibility between people in a multitude of forms, such as intimate violence, food injustice, economic exploitation, and so

⁴ Describing sickness as a disability is an intentional choice that frames my arguments throughout this paper. There are notable differences between sickness and other kinds of disability, and holding them together creates a tension that, due to the constraints of this paper, I cannot fully explore here. For an extended account of this tension, see Wendell (2017).

on. Medicalization is insufficient for understanding sick people's experiences, and it cannot lead to a more responsible society.

The ongoing Coronavirus pandemic has demonstrated the urgency of attending to both medical and social interventions: even as vaccinations are becoming widely available, and even as people have been made widely aware of safety guidelines, many continue to act irresponsibly by not wearing masks in public, by refusing to social distance, and by choosing not to get vaccinated. While some may argue that it is their choice to do these things and that they should be supported in whatever decisions they make, their actions affect more than just themselves. And it is exploited and oppressed peoples who have been and continue to be most impacted by these kinds of social irresponsibility. I think here of how capitalism has remained operational during the pandemic and how many workers – particularly minimum wage, working class people – have been expected to put their bodies and health at risk for the sake of someone else's profit or gain in a spectacular display of exploitation, which is one of the five faces of oppression described by Young (2011). For many, social distancing and isolation have been luxuries too expensive to afford, which is another example of how Western society is structured around health inequity.

Recognizing that sickness is systemic and structural at the same time as it is internal and personal starts the work of *sickening responsibility*, by which I mean reframing the concept of responsibility through an anti-ableist perspective centering solidarity with sick, chronically ill, and immunocompromised people. Sickening responsibility means acknowledging that all people will experience sickness in their lifetimes, but that interlocking systems of power and oppression influence how and how often different groups of people are exposed to sickness as well as their access to restorative and/or life-sustaining resources. Genuinely making this acknowledgment changes the meaning and practices of responsibility to include actions that counteract the harm sick people experience in a capitalist, White supremacist, xenophobic, cisheteropatriarchal, ableist, and otherwise oppressive society. If we explain responsibility as acting in ways that promote *interdependence* and reduce harm through the dismantling of inequity and injustice, then it must include a commitment first to dis-inhabit systems and structures that contribute to our collective unwellness – whether of ourselves, other living beings, or of the land – and second to listen to and honor the lived experiences / needs of sick peoples. In this essay, interdependence refers to the recognition that the “liberation of all living systems and the land [is] integral to the liberation of our own communities” (Sins Invalid 2016, 18). In other words, all living beings are inherently connected, so rather than pursuing the colonial, White supremacist, patriarchal, and capitalist falsehood of independence, seeking interdependence encourages us to prioritize responsibility towards one another in order to promote equity, justice, and togetherness.

The dual reality of sickness that makes it necessary for us to generate access is that it is at once internal and external: sickness is an experience positioned within individual's bodyminds, yet the environments and social contexts in which bodyminds are situated have the power to subject people to sickness and /or to impact their experiences of being unwell (Clare 2017; Hedva 2016). This dual reality leads to a split meaning of responsibility, which is partly internal and partly external. Internal responsibility involves listening to our bodyminds and doing what we can to build our lives in ways that honor our lived experiences and needs as they evolve over time. This might involve ensuring we get adequate rest, that we eat nutritious meals, and finding ways to enter into relationships with other people that help us to love ourselves (Taylor and Duguay 2016). The external responsibility of sickness that all people share entails collectively, collaboratively building worlds in which all people have a full and unhindered capacity to be responsible to ourselves and others. In other words, fulfilling the external or social responsibility for sickness means contributing to social structures and systems that enable people to practice internal responsibility – because they have reasonable access to safe, stable housing, healthy food and clean water, consensual and competent healthcare, and other access needs that they may have. This paper primarily focuses on the external responsibility of sickness in order to offer tangible pathways to practicing solidarity with sick folks.

Part of this work of sickening responsibility is letting go of assumptions that sickness is about morality, that sickness is a mark of wickedness or wrongness, that sick people somehow deserve to be punished (Clare 2017). Moral attributions are especially dangerous and harmful when sickness has been correlated, empirically or in the popular imagination, with oppressed peoples. Sickening responsibility must include actions that intervene in these kinds of associations, for it urges us to shift away from oppressive individualism that leads to individual blame and towards a critical consciousness of systemic and structural realities. For instance, how many times has HIV/AIDS been weaponized against queer folks in support of heteronormative political agenda or belief systems? How many medical personnel have refused to help queer folks because they see HIV/AIDS as a sign sent from above to punish sinners or an otherwise deserved condition resulting from tainted morality? In the early years of the HIV/AIDS crisis, the Reagan administration's negligent and bigoted policies resulted in the suffering and death of numerous infected people and incited radical resistance from the queer left (Hobson 2016). Though it may be true that the illness ultimately took their lives, the systemic hatred of and structural violence against queer and trans people – especially queer and trans people of color – contributed to a social landscape in which the HIV/AIDS crisis was able to fester and to ravage entire communities of oppressed people, many of whom were multiply oppressed or marginalized.

Connecting sickness to the supposed morality of individuals is a sinister way that systems of oppression operate to obscure themselves from critique and therefore limit resistance to their reproduction, which is another way of saying that it empowers and enables dominant groups to continue acting from their positions of social and material advantage. This reproduction of power is one of the primary dangers of medicalization (Durazo 2006). For example, “obesity” discourses are in and of themselves problematic for several reasons, the first of which is that they make moral judgements about the health and well-being of fat people, especially poor and fat people of color, typically without recognition that bodies are diverse in their forms and needs and without acknowledging that food injustice is structured into Western society (Finley 2014; Stewart 2018). As with many other socially constructed diseases, the logics underlying “obesity” discourses are based in Eurocentric value systems which normalize and promote Whiteness, maleness, and able-bodiedness (Strings 2019). Moreover, these logics are medicalized and pathologized, meaning that they have oftentimes been neglectful of the social and political realities impacting people's lives. For example, if people are working multiple jobs just to get by, then they likely do not have time to cook home meals for themselves, and fast food is cheaper anyway. Worker exploitation contributes to a society in which health is made into a luxury reserved for the wealthy. Medicalization and pathologization are methods for shifting attention away from inequity and injustice toward individual people's decisions – that is, for taking attention away from the need for external or collective responsibility through victim-blaming.

Disrupting moral attributions and individualism is especially urgent during pandemic times because of the ways COVID-19 had been made shameful and used to punish people. Shame leads to secrecy and silence, both of which, in this case, underlie failures in responsibility that can lead to worsened harms (BCRW 2019; brown 2019; hooks 2000; Russo 2018). Consider how much different the pandemic might be in the United States if people felt safe and supported in naming their experiences with COVID-19 – if we could communicate openly about our experiences without being shamed and/or disciplined for doing so? What opportunities might that generate for us to show up for one another in different, more meaningful ways? Moving beyond shame, I believe, has the potential to get folks into alternative habits of togetherness that are more just, more kind, and more responsible. For one thing, it might open up vital space for people to have critical conversations about power and oppression as they contribute to the well-being and unwellness of our bodyminds. johanna hedva (2016) explains that sickness is a normative outcome of capitalism (and other systems of power) because practices of caring and caretaking go against expectations of productivity and independence. Shame is bound up in this equation because White supremacist, cisheteropatriarchal, ableist, capitalist social structures pressure us to feel bad about ourselves whenever we cannot successfully overcome “weaknesses” or need assistance from other people. Sickening responsibility inverts the source of this shame by starting with an understanding of interdependence – or with the understanding that people always need one another because that's the only way we can survive and lead meaningful lives (Mingus 2017).

Moving away from morality towards sickened responsibility also allows for us to think more critically about how people became infected due to their own irresponsibilities as well as how people were exposed because they were set up by social inequities and injustice, that is, because of society's normalized and routine irresponsibility towards them. Describing someone as acting irresponsibly is different from a moral attribution because the former is about how people's behaviors affect themselves and their relatives (i.e., those they are in relationship with) while the latter is a criticism of an individual's character or spirit. Responsibility calls for changes in behavior that make continued relationships possible, but moral attributions negatively assert that kind and loving relationships can only happen if people stop being who they are. As a sick person, the few relationships that I am able to build are cherished parts of my life, and I do everything I can to preserve them. When my relatives do wrong by me, or I do wrong by them, approaching the situation from a generative mindset of responsibility gives us room to do the work required to restore or repair our connection (Benaway 2019). Moreover, rather than focusing on what's "wrong" with us as individual people, we are able to think / talk about how our own identities and positionalities within an oppressive society affected the relationship and were connected to our irresponsibility. Accordingly, the change we request of one another can be centered around taking accountability for ourselves rather than determining if we are "good" or "bad" people.

In terms of reimagining accessibility and solidarity with sick people during the Coronavirus pandemic, there is a lot of space for growth when applying the concept of responsibility. In particular, it can help us to distinguish between situations where individual or group actions are the primary source of harm and those where harm is more a consequence of oppressive systems. Much of the time, a combination of individual action and oppressive systems is at play, and so responsibility helps to illuminate multiple opportunities for intervention. Because responsibility is attentive to relational change instead of moral judgements, it opens up space to imagine how we can use our relationships to promote equity and social justice within our chosen families and communities. For instance, there are easy questions about what we can do to reduce the spread of illness and how we can better follow safety guidelines. At the same time, there are harder questions to ask about what we can do to practice responsibility / solidarity with folks around us, especially those who have been systemically or structurally set up to be vulnerable during the pandemic. If our relatives are unable to follow isolation and social distancing guidelines, if they are routinely at risk of exposure yet unable to reduce that risk (e.g., due to worker exploitation or their living conditions), then what are we doing to protect them and help ensure their needs are getting met?

Building on this thought, I want to return to the questions of vaccinations and where they fit into this concept of sickening responsibility. From my perspective as a chronically ill and immunocompromised person, and as someone with multiple sick relatives who are particularly vulnerable to COVID-19, the simple act of getting vaccinated, particularly for able-bodied and able-minded people, is a fundamental, vital part of being responsible to ourselves and to others with whom we are in contact. Vaccines pose limited risk to most people, yet COVID-19 has well-demonstrated its capacity to end lives. Not all of the time, but much of the time, reluctance to get vaccinated seems to me to come from a causal ignorance of others' fear and suffering, especially for people who occupy dominant social positions like cisgender, heterosexual white men. People will often choose not to get vaccinated because they value their comfort more than other people's continued existence – because they see the lives of sick people through a lens of disposability, especially sick people who are multiply marginalized and/or oppressed (Kukla 2021). Much of the resistance to vaccination also rises from ableism and neuronormativity, which have been crucial aspects of the growing anti-vaccination or "anti-vaxxer" movement (Crowe 2020). So, disability is doubly present here as people are devaluing disabled, particularly sick, people's lives at the same time as they are utilizing the "threat" of becoming disabled to rationalize their irresponsibility and to extend that irresponsibility outward.

Of course, some people's resistance to vaccination comes from a legitimate fear of what might happen to them. For example, many people are afraid that vaccines will affect their reproductive ability. While this belief is problematic (e.g., because it privileges the *potential* life of a child above the lives of

real sick people), I can understand where people are coming from, especially considering the historical androcentrism, heteronormativity, coloniality, and Whiteness of Western medicine. There are also some people who refuse vaccination for religious and cultural reasons, or because they have medical trauma and/or a legitimate distrust of the “medical industrial complex” (Mingus 2015). The ways in which the medical industrial complex has violated and betrayed people, especially people of color, women, and queer and trans folks, is reason enough to treat vaccines with skepticism, to say the least. Part of the power of thinking through sickened responsibility is that rather than just discarding or “canceling” unvaccinated people, we can imagine and figure out alternative methods for solidarity and care.

We can ask of them, “If you won’t get vaccinated, then how else are you practicing responsibility and solidarity with sick peoples? Are you staying home? Are you wearing masks? (How) are you organizing for universal healthcare, housing, food, etc.? (How) are you involved in movements for worker’s rights or living wages? (How) are you supporting movements against environmental racism, pollutants, and other causes of sickness? And, if you aren’t doing these things, then how are you practicing responsibility to sick folks?” Vaccination is a single action, an important action, but far from all that an individual can do. Moreover, sickened responsibility is a means of talking back to the medical industrial complex and demanding more from the people and institutions who claim to provide healthcare. The legitimate fear and distrust that many people have for the COVID vaccine is indicative of much broader problems that need to be addressed. How are medical professionals demonstrating a substantive commitment to social justice, collective access, and collective liberation? How are they working to transform ongoing histories of systemic oppression and harm that have rendered so many communities distrustful of them? Where are the doctors at Black Lives Matter protests? How are they showing up for affordable housing or universal healthcare? What are they doing to say, “We recognize our history, and we are working to become better”?

Because responsibility is not a single pathway or set route, it requires ongoing conversation and actions that move us in multiple directions. Just because someone will not get vaccinated, whether or not they have a genuine explanation for their decision, does not mean that they are excused from pursuing other avenues for being responsible. It is when they decline to explore these other paths that their complicity in ableism and the multiple other systems of oppression with which ableism intersects becomes apparent. And, people who do get vaccinated should not be exempt from finding other ways to practice responsibility and solidarity: it’s not as easy as just checking off a box because responsibility and solidarity are *relational processes* – they are ongoing and never completed for as long as people remain in relationship with one another (Price 2011, 2021). Vaccinations are a point of entry from which a continuous dedication to equitable and just action can grow, from which people can begin or further the process of figuring out what exactly it looks like to show up for one another in substantive, liberated ways. These points of entry are cherished and invaluable, but they have to be kept up so we don’t get stuck in the doorway to a better future.

From Crisis Response to Pandemic Remedies

Sickening responsibility means acknowledging that sickness is as much a structural and political reality as an internal or private experience and, accordingly, that our actions and relationships have important consequences for the (un)wellness of other living beings. This acknowledgement is particularly crucial during pandemic times considering just how many people are struggling for their own survival against not only a life-endangering illness, but also the converging, destructive forces of oppression that have augmented the pandemic’s reach. Many sick, chronically ill, and immunocompromised peoples cannot leave our homes without great fear of the harm that will befall our bodyminds. For many, going outside into public spaces could quite literally kill us. As I stated above, this learned fear comes partially from the knowledge of how many people are continuing to act irresponsibly toward one another in spite of the staggering infection count and mortifying death toll. The world was unsafe for sick folks prior to this most current pandemic, and so the emergence of COVID-19 has forced many of us into greater isolation. Social distancing and isolation, accompanied by notable shifts in professional, familial, and intimate relationships, has also contributed to heightened

rates of violence against disabled people as well as emergent barriers to resources and support (Author 2021; Katz 2020).

Throughout the pandemic times, many people, perhaps the majority of people, have been existing in a prolonged *crisis response*. A crisis response is the body's natural reaction when trauma is occurring or feels dangerously close by; it describes the defensive procedures we undergo when our internal alarms have been sounded. Crisis response is a vital, evolutionary mechanism that has enabled human survival in the face of a multitude of harms because it gets us through life-and-death moments. However, crisis is another socially constructed and politicized term: it can refer to natural disasters like floods or fires, but it can also emerge as a result of the way that systems and structures of power *un-prepare* people for harms that could have been prevented or greatly lessened. Inequities arising from structural violence render a society in which numerous people do not have access to vital resources, like food or shelter, and are, therefore, ordinarily responding to one crisis or another (Berlant 2011). Pandemic times have evoked a crisis response among many people in the United States because our White supremacist cisheteropatriarchal ableist and capitalist society is not set up to promote collective access or to ensure that people's needs can be reliably met (Piepzna-Samarasinha 2018; Sins Invalid 2016). To the contrary, a great many people in the U.S. live perpetually on the verge of hunger, houselessness, sickness, and financial collapse. So, when the pandemic times began, there was great uncertainty and fear about how people would survive. The absence of a meaningful social safety net is a foundation of crisis, and it is a big part of the reason why the pandemic has gone on for so long and been so impactful.

A *pandemic remedy* is different from crisis response. Etymologically speaking, "remedy" is derived from the Latin word *remedium*, which means "that which restores health" or "that which is healing." And so a pandemic remedy describes spaces, tools, or resources for healing amidst the outbreak of widespread unwellness and vulnerability to sickness. Unlike crisis response, which is about staying alive, pandemic remedies extend beyond mere survival to include the restoration of body, mind, and/or spirit. I do not use healing here to refer to "cure," which is an ableist concept from the medical industrial complex (Clare 1999, 2017; Mingus 2015; Piepzna-Samarasinha 2018). Rather, I use healing to describe a consensual practice of care-taking through which people cooperatively respond to the sources of suffering in their/our lives by creatively organizing for alternative systems, structures, institutions, etc. that promote love, kindness, compassion, and interdependence. Accordingly, a remedy then is not something that just "fixes" individual people, but instead should be understood as holistic – as something that seeks to restore and honor wholeness by intervening in the denial of people's humanity, agency, or continued life. Put another way, remedies move people beyond crisis by transforming the socio-political conditions that cause them to be targets of irresponsibility. In terms of the pandemic, remedies create space for relational change towards the reclamation of responsibility and solidarity between living beings.

Crisis response means acting in the moment by responding to individual needs as those needs arise – putting out fires whenever the smoke becomes visible. Pandemic remedies, on the other hand, require acting from an understanding that most of us are all differently living in crisis mode right now, and so we need more than just "in-the-moment" responsiveness. Instead, we must collectively work to create networks and systems through which we can better anticipate and listen to people's needs and ensure that those needs are being met consistently through mutual aid and community building (Spade 2020). For instance, the pandemic has been a time of heightened intimate violence, especially against disabled folks. People are simultaneously experiencing more frequent acts of violence as well as changing relational dynamics that can make it more difficult to reduce harm or stay safe (Author 2021). Sick folks, who were already disproportionately vulnerable to intimate violence prior to the pandemic, may now be struggling even more to care for ourselves, which means that those of us in abusive relationships are often even more dependent on our partners than before. A crisis response here would mean waiting until violence takes place – until some kind of severe harm has manifested. A pandemic remedy, on the other hand, would entail working with our relatives to ensure that they always have options for escaping or reducing the violence enacted against them. Further, we can work with our

relatives to collectively learn alternatives to relational violence, whether that be tools for de-escalation, spaces for taking accountability without shame or judgement, or groups that promote more gentle, compassionate, and responsible visions of masculinity (Dixon and Piepzna-Samarasinha 2020; Mingus 2019).

Attention to temporality further differentiates crisis response from pandemic remedies, given that the former is inherently temporary (i.e., only lasts until the crisis is abated) whereas the latter should have long-term implications. Returning to the previous example, we might consider the difference between offering someone emergency shelter when they flee from or leave a violent relationship and working to build communities wherein decent housing is accessible and affordable. Emergency shelter depends on the generosity of those providing it and comes with an expectation of being reasonably short-lived. Organizing for affordable and accessible housing, on the other hand, helps to ensure that people have alternative places to go whenever the need arises and that they are not dependent on the generosity of other people. Having resources for housing can be especially important for sick folks who are isolated from our relatives or who do not have a community of supporters. Accordingly, activism and mutual aid calling for rent moratoriums, working against evictions, and organizing for affordable housing can all be looked at through the lens of solidarity with sick people who have experienced intimate violence, and especially so during a pandemic when great numbers of people are struggling to make ends meet.

As another example of temporal differences that is especially relevant to the pandemic, I think of the accessibility options for remote work/learning that have become common during the last year and a half. The transition to remote work/learning constituted a crisis response because it was undertaken with haste and in an overwhelming moment of uncertainty. People were so pressed to go remote when they could that the access needs of marginalized and oppressed people were often disregarded (Pettit 2020). And a lot of folks were expected to perform additional labor without compensation – such as many teachers who had to create materials for remote/online learning in a matter of weeks. Yet, how different might the transition to remote work/learning have been if employers and schools had already done the work of figuring out how to implement these alternative pathways? Disabled, and especially sick, folks have been requesting accommodations for remote work/learning for a long time now, so I can only wonder how much smoother the transition could have been if employers and schools had been more invested in doing the collaborative work of building accessibility. Now that many places are reopening for in-person work/learning, I fear accessibility options will quickly be taken away because the crisis response is nearing its end. But, what if we kept these options in place and embraced a diversity of methods for togetherness that were not dependent on any one mode of interaction? How much more collectively resilient could we become, and what kinds of beneficial shifts could that lead to in terms of practicing responsibility and solidarity with sick people?

As I talk here about the differences between crisis response and pandemic remedies, I find it beneficial to connect to *spoon theory*, which emerged as a non-academic, community-based term among sick folks (Miserandino 2003). Spoon theory is a common way for sick, chronically ill, and immunocompromised folks, often referred to as “spoonies,” to explain the embodied / enminded impacts of our disabilities from one day to the next. Simply put, this metaphorical theory asserts that each of us begins our day with a certain number of spoons. Each spoon represents the energy available to us to complete the various tasks we need to get done throughout the day. Different tasks might require different numbers of spoons – for instance, we might need more spoons to drive to work than we do to get ready in the morning, or vice versa depending on our specific bodyminds, capacities, and needs. Some days we might start off with more spoons and some days we might start with less, such as when our symptoms are flaring up or if we were exhausted the day before. More able-bodied and able-minded people have a different relationship to spoons than crip folks – they often do not have to consider their spoon count or really worry about what happens if they run out. Spoonies, however, often know that we have a limited number of spoons, and we may have to be strategic in how we spend them because not doing so can be detrimental to our health and mental well-being.

Much of the time, sick peoples' spoons are swiftly depleted as an outcome of living in an ableist society that views us as burdensome, less-than-fully human, and at times even altogether disposable. Sick people are often forced into situations where we have to account for ourselves – situations where we have to “prove,” for instance, that we are deserving of medicine (especially true for people with chronic pain), or in which receiving meaningful care depends on us routinely performing vulnerability (Mingus 2017). Accordingly, there are many important connections between spoon theory and responsibility, the most notable being that the experience of irresponsibility is spoon stealing. Or, put another way, oppression, marginalization, and harmful treatment are exhausting realities that force people to become “resilient” for their/our own survival (Ahmed 2013). If irresponsibility steals spoons, then building equitable and just relationships depends, in part, on an intentional redistribution of spoons in defiance of systems and structures of dominance. I argue that practicing responsibility and solidarity with sick people requires that all people learn to act with an awareness of their/our spoons and how those spoons are indicative of their/our positionalities relative to one another. Responsibility means organizing society in such a way that people can reliably expect to have enough spoons to get through their day without suffering or misery because we are all invested in a generative practice of spoon sharing.

Spoon theory has some important implications for redefining crisis response and pandemic remedies. In this metaphor, crisis might be described as a spoon shortage, as being caught up in a situation where our spoons are consistently too few for the tasks we need to get done from one day to the next. Crisis response, accordingly, would involve dealing with the spoon shortage as it becomes a problem – for example, by going to people and aiding them when their spoons are spent, which has been predictably occurring all throughout these pandemic times. Remedy, which can happen simultaneously with crisis response, would require substantively addressing the underlying sources of the spoon shortage, or the sociopolitical and relational irresponsibilities that lead people to become so depleted in the first place. For example, a remedy might ask how current social arrangements are putting pressure on sick people to overspend our spoons because space is not being made for our access needs. From this questioning, a remedy would then encourage us to consider options and implement changes, in conversation with the most impacted sick people, to better and more consistently meet those unmet access needs. Many of our spoons are spent dealing with enabled people who have not intentionally moved into a practice of solidarity with us, so doing this kind of transformative, relational work could go a long way towards reducing the politically produced suffering and harm present in our lives.

Conclusion

Responsibility, as I have been using it in this essay, describes a commitment to act in ways that promote justice and center interdependence. Within this commitment is an acceptance that all people need both to receive and to give care because care is the foundation of anti-oppressive relationships. For disabled and especially sick folks, care has oftentimes been a source of harm against us, particularly where it is non-consensual or where the people providing it expect vulnerability from us in return (Mingus 2017). Too much of the time, care becomes ensnared in the logics of dominance that simultaneously impact most other parts of our lives. That said, care work is vital to the work of social justice, and I understand disability justice in particular as advancing a vision of liberatory care that serves as a basis for freedom from intersecting systems of oppression (Piepzna-Samarasinha 2018; Sins Invalid 2016). For spoonies, this liberatory vision of care might be described as a method of sharing spoons for collective survival. In this definition, care work does not include things which cause unnecessary exhaustion or harm, for those things are rooted in irresponsibility. Rather care brings rest and restoration, frees up spoons for other things, and serves as a basis for right relationships.

The task of sickening responsibility requires finding ways to act from this liberatory vision of care that are simultaneously grounded in the lived experiences and needs of sick people. Responsibility is about justice and interdependence, and these concepts must purposefully center sick folks because we have oftentimes been neglected and not recognized as a group of people who have historically been targets of normalized irresponsibility. Particularly during a transnational pandemic, throughout which a great many

of us have been remarkably vulnerable to harm, it is vital for us to collaboratively imagine worlds against ableism, worlds beyond ableism wherein we can peacefully co-exist and substantively show up for one another.

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