

A CRIP QUEER DIALOGUE ON SICKNESS

EDITORS' INTRODUCTION

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The idea for this special issue emerged through a winding (and queer) series of conversations. In February 2019, in the dead of winter, we drove to windy Quebec City together to present at a feminist philosophy conference organized by a friend and her colleagues. This was our first time presenting together and we wanted to reshuffle the expected presentation format and talk about what was really on our minds, together, in collaboration and dialogue. Our conversations at the time often revolved around our experiences living with (un)diagnosed mental illness.¹ When we checked-in with each other via text, sent virtual “spoons” (a token of energy, in crip parlance), and met for coffee, we talked about pain and unwellness, bad mental health days, medical appointments, changes in prescription medications, and the feeling of being not-at-home in our bodyminds.² We were—and remain—particularly interested in how these elements affected our research both conceptually, in terms of the ideas we are drawn toward, and practically, because being disabled, for

¹ We have both received various diagnoses of so-called “mental illness” and have had varying experiences obtaining such diagnoses. Many of these diagnoses are typical of those often received by white, female-coded patients in the psychiatric-industrial system today. While we do not explore these questions at length here, much excellent work discusses issues of Mad and disabled (dis)identification in ways that we find illuminating and comforting, including Johnson 2010; Price 2011; Samuels 2003; and Schalk 2013.

² Christine Miserandino coined the “spoon” metaphor in an essay titled “The Spoon Theory” (2003). Miserandino employs the metaphor to describe to a friend the energy-consuming effects of daily tasks when living with chronic illness. Spoons indicate the limited units of energy that disabled and chronically ill folks have available to go throughout the day. When spoons are running low, they need to be recharged (e.g., by resting, canceling plans, or receiving care).

Disability studies scholar Margaret Price introduced the notion of bodyminds in her 2015 article “The Bodymind Problem and the Possibilities of Pain.” Price’s use of this term rejects our tendency to think about bodies and minds in dualistic terms. Because it rejects this artificial, second-order distinction, in favor of our felt experience of our bodies, this notion is particularly ripe for a phenomenological analysis of experiences of illness, madness, and disability. The term has since been widely adopted by disabled communities and was recently employed in Sami Schalk’s excellent *Bodyminds Reimagined: (Dis)ability, Race, and Gender in Black Women’s Speculative Fiction* (2018).

each of us differently, means managing unexpected flare-ups of pain the day before an important deadline, losing a day in a psychiatric emergency room, feeling too ill to read and write, dealing with panic attacks at academic conferences, or not making it to the conference at all. In an early email about submitting a proposal for the Quebec City conference, Corinne observed how strange it was to write conceptually about realities that are also conspicuously felt and material for them: “I guess it’s also a point we’re trying to make in this presentation, but it’s still difficult.” Emily agreed: the past few months had been particularly challenging in concrete and everyday ways, and yet they “*could not but* write and think about madness.”

Our presentation that February explored how illness, which at the time felt like the appropriate vocabulary to describe what this special issue now calls sickness (more on this later), un/made traditional conceptions of subjectivity, temporality, spatiality, and embodiment. For this task, and given our philosophical trajectories and inheritances, phenomenology seemed like the obvious place to start. From its inception in Husserl’s *Logical Investigations* (1970), the field of phenomenology has developed a rich conceptual vocabulary and a rigorous methodology to describe human experience as it is *lived*, without prejudices or assumptions. Phenomenology’s focus on the transcendental structures of everyday experience reveals commonalities across our ways of accessing the world as a meaningful milieu. We argued in our presentation that phenomenology also offers us important tools to study the meaning and lived experience of illness beyond the narrow scope of a biomedical framework. Take, for example, phenomenology’s sustained interest in corporality. Corporality is an ostensibly “universal” feature of human experience and thus it functions historically within phenomenology as a springboard for the distillation of the meaning of our everyday lives. For Husserl (1989) and for Merleau-Ponty (2012), we must distinguish between our body as a neurobiological entity (*Körper*) and our body as it is experienced (*Leib*). The lived body, as Husserl explains it, determines our “near sphere” or “primordial core sphere” (1989, 149-150). Put another way, it is the “here” from which we encounter the world, our zero-point of orientation. Our lived body is our means of *having* a world and being-*in*-the-world. Phenomenology is borne by this originary relation of inhabitation and body-world reciprocity.

When it is employed to analyze particular human experiences, we view the *Körper/Leib* distinction as an invitation to re-orient philosophical analysis toward first-person accounts of illness, madness, and disability. From an ethical viewpoint, we must remain attentive to the contrasts between first-person accounts and biomedical assessments, priorities, and decisions, including normatively laden medical assessments of quality of life (Reynolds 2018; Stramondo 2020). The recorded disparities between patient experiences and medical etiology map onto urgent concerns about the place given to the voices and experiences of those immediately affected by illness, madness, and disability in medical discourse, and the perceived illegitimacy of their epistemic claims (Kidd and Carel 2017, 2018). Finally, a phenomenological approach also highlights the existential importance of meaning (or sense) in our lives, and its elision from most biomedical frameworks. Illness, madness, and disability transform how we orient ourselves in everyday lifeworlds; these experiences may

render alien and uncanny our understanding of ourselves and of others, thus shifting how we *make sense of things*. A phenomenological approach turns our attention toward the many orientations and *disorientations* that these experiences prompt, the moments of doubt, loss, joy, grief, pain, solidarity, and clarity that make up ill, Mad, and disabled lives.

Husserl and Merleau-Ponty's foundational phenomenological forays mainly pursued structures of experience that were not only common or shared, but also "universal." Yet, as our presentation in Quebec City highlighted, these claims to universality have since been contested. In particular, feminist phenomenologists have rejected putatively universal accounts of embodiment in favor of analyses considering how "oppression, power, and privilege may form the horizon wherein [. . .] experience is situated and historicized" (Al-Saji 2017, 143). Our everyday lifeworlds are shaped by social, political, cultural, affective, and historical circumstances that inflect what we are oriented toward and the "here" from which we encounter objects, others, and environments. A too-broad focus on universality threatens to reproduce harmful assumptions about what counts as *universal* and to erase minoritized identities from our analyses in the process. By revealing a richer breadth of embodiments and perspectives than those offered by earlier phenomenologists, feminist phenomenologists have produced important analyses of the multiply situated ways in which people of all genders encounter the world. The work of feminist, critical race, and queer phenomenologists reveals that our bodies are positioned along different axes of power that determine what counts as "normal." The long-standing privilege of the able-bodied, white, middle-class, cisgender male subject is slowly giving way. In its place, phenomenologists (and philosophers, more generally) are finding a rich variation of bodyminds whose lived situations and horizons greatly vary.

A second important lesson of feminist phenomenology is that we must pay closer attention to aspects of embodied life that have been cast as deviant, deficient, or flatly non-philosophical. In recent years, this provocation has led to analyses of such diverse phenomena as illness and psychopathology (Carel 2016; Fisher 2015; Lajoie 2019a; Wilkerson 2014), sexed embodiment and sexuality (Heinämaa 2010; Zeiler and Guntram 2014), pregnancy and childbirth (LaChance Adams and Burcher 2014; Heyes 2012; Oksala 2016; Young 2005), aging and death (Cuffari 2011, 2014; Weiss 2017), biomedicine and medicalization (Dolezal 2010; Wieseler 2018; Zeiler and Käll 2014), and disability (Diedrich 2001; Salamon 2012; St. Pierre 2015). These phenomena, in fact, are deeply philosophical: they provide a critical foil for the unexamined ideal of normate embodiment and reveal to us that the course of human experience is neither exclusively oriented, nor entirely or even primarily predictable, autonomous, and voluntary.³

As inheritors of this legacy of work, we continue to ask: why have early phenomenologists taken so long, or been so reluctant, to investigate disability, illness, and madness as inherently valuable forms of existence? Rather than employing these experiences as exemplary of breakdowns or deviations in the course of human life, how can we view them as

³ For details on the conception of normate, access Garland-Thomson (2017) and Reynolds (2019).

“complete forms of experience” (Merleau-Ponty 2012, 110) or points of departure for what Joel Michael Reynolds (2017) aptly terms a crip phenomenology? Why have these experiences so often been framed as mere limit cases for describing “normal” embodiment and consciousness? Lastly, and speaking more directly to the purpose of this special issue, how do “the complex textures of social life” transform the ways in which we feel ill, disabled, and Mad (Guenther 2013, xiii)? In particular, the impulse for this special issue grew from a certain uneasiness (or a *dis*-ease) with the lack of intersectional framing and interdisciplinary focus of most existing phenomenological research on illness and disability.⁴ While there exists much excellent work on gendered conceptions of health and ability, considerations of race, class, size, sexuality, and nationality are only rarely and cursorily addressed. Indeed, on closer inspection, and as others have pointed out, social positionality and lived realities of privilege and oppression are often bracketed out of phenomenological analyses of illness and disability (Wieseler 2017, 2018). To our knowledge, there has been no collection of work, special issue or philosophical volume dedicated to phenomenological examinations of illness, madness, and disability which centers issues of oppression, power, and privilege beyond the category of gender. And, while scholars outside of phenomenology have shown interest in cross-pollinations with phenomenology (e.g., Mad and disability scholars using phenomenology), phenomenologists themselves have been less likely to integrate and contribute to lively political, theoretical, and ethical debates emerging from Mad and disability scholarship and activism. Our concerns with these limitations are central to this special issue. Moving forward, we need phenomenological analyses that do not gloss over the crucial significance of structural injustice and oppression in our lives, but rather examine their role in shaping how illness, madness, and disability are lived, diagnosed, distributed, perceived, and produced. Phenomenology can become a germinal site for the study of such varied topics as care work and vulnerability, political agency and representation, access and inclusion, medical racism, and past and current histories of forced institutionalization, sterilization, and incarceration of disabled and Mad people. To embark on this task, however, a critical method is needed.

We understand the *critical* in critical phenomenology to mean at least two things. The first concerns the importance of interdisciplinary dialogue; the second addresses the methodological limitations of classical phenomenology. Regarding the latter, we view critical phenomenology as a growing project that gathers phenomenologists of various horizons around a developing set of scholarly orientations that also function as *dis*-orientations of the tradition. Critical phenomenology breathes new life into problems and questions that are familiar to the phenomenological tradition by taking them astray, away from straight and narrow paths. In this sense, we view critical phenomenology as a *queer* enterprise, in the sense given by Sara Ahmed (2006) to this term. By putting phenomenology to queer use and steering it in new directions, critical phenomenology also asks how phenomenology has been used such that, much like the phenomena it studies, it, too, has a tacit background

⁴ The political category of madness is more rarely taken up by phenomenologists, who tend to work with the notion of mental illness or mental disorder.

that has largely become taken-for-granted. For this reason, Lisa Guenther writes that the ways in which we *see* and *make* the world require “a sustained practice of critical reflection” (2019b, 12). We believe that this practice of reflection must examine both worldly phenomena and the ways in which the lifeworlds that contain them are instituted and maintained, including our own intellectual lifeworlds. Alongside Guenther, we hold that as a philosophical and a political practice, critical phenomenology must pursue the “illumination and transformation” of systems of domination (e.g., racism, capitalism, heteropatriarchy, ableism) that have long been normalized and naturalized as simply *the way things are*—thus receding to the background (2019b, 15). Rather than starting from the assumption that these systems are irrelevant to phenomenological analysis, a critical approach interrogates their role in the creation and maintenance of intellectual traditions, social worlds, and intercorporeal experiences.

This brings us to the question of interdisciplinarity. An important contribution of recent work in critical phenomenology has been its willingness to integrate insights from a variety of fields, including cultural sociology (Melançon 2014), critical prison studies (Guenther 2018; Pitts 2018), political theory (Ahmed 2019), human geography (Kinkaid 2020), aesthetics and visual studies (Al-Saji 2019; Ortega 2008, 2019), environmental studies (Christion 2019), queer and trans theory (Salamon 2010, 2018), critical whiteness studies (Ahmed 2007; Guenther 2019a), and decolonial theory (Whyte 2016). This interdisciplinary work showcases the unique value of the phenomenological toolkit at the same time as it refines our awareness of its limits and indicates avenues of potential growth. To this end, our aim with this special issue was to encourage interdisciplinary work that considered the contributions of Mad and disability scholarship, alongside other fields of critical inquiry, to the phenomenological study of illness, madness, and disability. As intellectual projects that are rooted in grassroots activism and social critique, these fields have the potential to sharpen phenomenology’s foundational methodological tools. In recent decades, Mad and disability scholars have produced some of the most important research on modern conceptions of health, sanity, and normalcy. These scholars study illness, madness, and disability not as individual tragedies, but as worldly experiences that have been systematically devalued and stigmatized. Recent work has also exposed the sexed, gendered, classed, and racial distribution of vulnerability and debility as a central feature of contemporary bio- and necropolitics (Ben-Moshe 2020; Erevelles 2014; Puar 2017; Tremain 2017). The insights developed by Mad and disability activists and scholars are momentous and they must be an integral part of future phenomenological conversations about sickness.

Our use of the term *sick* in this special issue is intentional and responds to the concerns we have outlined thus far. The notion of “sickness” became a focal point of our discussions after our presentation in Quebec City. We both used the notion colloquially, at the time, to discuss how our bodyminds felt out of synch with dominant expectations of sanity and productivity: sick as deviance from the norm and as a willful refusal to be well, if “being well” meant *falling in line*. Today, we use the notion of sickness conceptually and colloquially to draw connections between experiences of illness, madness, and disability within a critical phenomenological framework. This is not to say that these experiences are either mutually

exclusive or strictly synonymous: they are neither of these things. We also do not intend any of these notions to function as a placeholder for the others; caution is required as the rhetoric of similarity or dissemblance can inform a politics of sickness that further disenfranchises and oppresses marginalized peoples. When thinking and writing about these experiences, we must remain carefully attentive to the phenomenological and political particularities of illness, madness, and disability. With this caveat in mind, we choose to talk about sickness to honor the many coalitional alliances formed between Mad, disabled, and ill folks. Our use of the term “sickness” also challenges the ways in which illness and disability have been deployed within phenomenology mainly in isolation from critical examinations of ableist and sanist norms and normalizing labels of somatic and psychiatric normalcy.

In their 2019 *Symposium* article, “A Critical Phenomenology of Sickness,” Corinne suggests that sickness functions as a disruptive analytic for the traditional phenomenological dyad of illness and disease, which is widely employed in the literature (Carel 2016; Leder 1990; Svenaeus 2019).⁵ Most traditional phenomenological approaches to illness view the distinction between illness and disease as conceptually contiguous with, respectively, the body as it is experienced by ill patients and the body as a medical object of scrutiny. One is diseased, for example, when she is medically diagnosed with a “natural” dysfunction through empirical observation. Illness, on the other hand, captures what it is like and what it means to the ill person to live with disease (Lajoie 2019b, 50-51). In turning to the notion of “sickness,” we are not claiming that this phenomenological distinction is unhelpful or unimportant. However, the vocabulary of illness and disease alone does not highlight the intersubjective phenomenology of our social and material lives, including the ways in which experiences of bodily difference are framed by systems of power, exploitation, and oppression. Our use of “sick” refuses this depoliticization of experiences of illness, madness, and disability. Thus, the deeper point that follows from its terminological addition to the dyad of illness and disease is that being “sick” is a political experience in ableist, racist, sexist, sizeist, and classist social worlds. Similarly, Emily’s dissertation and current research ask how the ascription of agency, potential, or resistance to “sick” bodies is conditioned both by their lived experience and by the sociogenic roots and treatment of much disability, debility, and madness. We both believe that we must analyze the structures that sicken us and keep us sick, as well as their sustained normalization. Without this practice of critical reflection, we risk forgetting that sickness is neither a “natural” fact of the body, nor a “natural” feature of contemporary lifeworlds.

A final clarification is in order. Our concern with the social architecture of illness, madness, and disability is *not* meant to frame these experiences as social constructions (Douglas 2018). A critique of socially disabling and debilitating environments should never dislodge the recognition and analysis of the complex—and often understated—scope of pain, grief, and agony that sickness may prompt (Hedva 2016; Mollow 2014). Being sick

⁵ A notable exception to phenomenological tradition’s focus on illness and disease is Kevin and James Aho’s (2009) discussion of sickness. Although they make a different use of the notion of sickness, their discussion of deviance in relation to sickness bears some similarities with our approach.

can lead to existential insecurity and suffering, especially in the face of violent economies of care and vulnerability. To modify a brilliant formulation by Merri Lisa Johnson and Robert McRuer, “the sensory experience of [disability, illness and madness], what it feels and looks like [to be a ‘sick’ subject]” is intrinsically linked to and cannot be detached from “the body politics of [these experiences], how [they operate] as a cultural location of stigma and defiance, marginalization and collective organizing” (Johnson and McRuer 2014, 134). The intertwining of these elements is central to our use of “sick.”

The articles in this special issue follow illness, madness, and disability along distinct conceptual, methodological, and historical axes. By being brought together, they tell a story about sickness that is anchored in the complexity of ill, disabled, and Mad existence. In “Shifting the Weight of Inaccessibility: Access Intimacy as a Critical Phenomenological Ethos,” Desiree Valentine investigates the phenomenological implications of disability activist Mia Mingus’s concept of access intimacy. As Valentine explains it, Mingus’s conception of intimacy invites a reconsideration of dominant, rights-based frameworks for thinking about access and draws into focus the everyday forms of relating and belonging between disabled and non-disabled people that birth accessibility and inaccessibility. Access, then, is not simply about checklists and guidelines. It is a way of relating to and with others in transformative ways. Drawing on Kym Maclaren’s account of ontological intimacy as intercorporeal encroachment, Valentine asks how we can harness the transformative potential of this encroachment to promote the greater freedom, agency, and becoming of others.

Through an analysis of the phenomenology of containment, Kirsten Jacobson, too, offers insights into human becoming through an analysis of spatial and existential agency. In “Spatiality and Agency: A Phenomenology of Containment,” she examines forms of containment that are constitutive and nurturing, on the one hand, and forms of containment that oppress, hinder, or block the exercise of our freedom, on the other. As Jacobson observes, the world around us can be supportive of our growth and agency or it can be hostile and threatening. This claim is illustrated by her analysis of disabling physical containment—and engulfment—in modern prisons. Jacobson’s essay illustrates how our existential health can be compromised by environments that violate the relational and dynamic features of human agency.

Critical phenomenology can be particularly helpful for drawing links and connections between structures and apparatuses of power, pathologization, and distress. Sujaya Dhavantri’s “The Violent Origins of Psychic Trauma: Frantz Fanon’s Theory of Colonial Trauma and Catherine Malabou’s Concept of the New Wounded” forcefully asks us what happens when an event is so shocking that we shatter, considering specifically the event (and ongoing structures) of colonialism. Drawing on Frantz Fanon’s analyses of the “psychopathologies” of colonized peoples, Dhavantri argues that the wound is first, central to understanding the various disorders of colonialism, and second, a bridge to connecting psychic trauma with contemporary neuropsychiatric analyses of “cerebrality.” Dhavantri’s paper thus crosses through phenomenology, discussions of transformative experience, and the constructions and destructions of trauma.

Finally, the shorter musings in this special issue explore the themes of this special issue in a less conventionally academic, more exploratory and personal format. We provided the invited authors of the musings with the following prompts to reflect on: What does it feel and look like to be a “sick” subject? How can critical phenomenology engage with discussions around illness, madness, and disability? What are its possibilities and where are its limitations? Lastly, what is the role of first-person narratives in a phenomenological disability studies approach? The answers that Thomas Abrams, Anthony Vincent Fernandez, Lauren Guilmette, Shayda Kafai, and Joshua St. Pierre offer in their musings should also be read as provocations: they invite us to expand both our thinking about sickness and our ideas about what constitutes academic writing.

This special issue is timely for many reasons, with the most manifest of these also being the most unexpected and upsetting. When we first started thinking about a special issue on critical phenomenological approaches to illness, madness, and disability in early 2019, we could not anticipate the extent to which a global shift toward the unpredictability of crip time would define the course of this project. In the past few months, the COVID-19 pandemic has rapidly unraveled all of our agendas and exacerbated pre-existing social inequalities. It comes as no surprise that the health crisis has impacted most drastically low-income, undocumented, incarcerated, disabled, ill, Mad, and racialized persons (with these categories, of course, often overlapping). Among other alarming realities, the ongoing pandemic unmasks our dependency on and abuse of health-care workers (for example, in long term care facilities) and of other, much less publicly valued frontline “essential” workers.⁶ The pandemic has also thrown into sharp relief pre-existing racial and gendered inequities and class divides in higher education. It has exposed the deep-seated ableism of institutions willing to deploy material and financial resources that have long been denied to disabled students now that the able-bodied world is under threat. This pandemic sharply highlights who is made sick, kept sick, or denied suffering.

I, Corinne, am writing from a white middle-class position, as a femme-coded disabled queer with access to health insurance through my institutional affiliation in a large R-1 university. I am still able to afford psychiatric medication and therapy, which I need now more than ever, given how deeply distressing this crisis has been. I, Emily, am a white, lower-middle-class disabled queer femme. I live in Canada and have access to health coverage, but I am also enrolled in a doctoral program with limited funding for students past the fourth year—a crack in the system that existed before the virus and will continue to exist long after it, with no additional financial aid planned for graduate students in light of the current situation. The lockdown has affected my daily life in ways that exacerbate my madness, my repetitive strain injury, and my sense of isolation from academic community.

⁶ In both Canada and the United States, there has been considerable loss of life due to the coronavirus in long-term care facilities, exposing many additional health and safety issues. See Béland and Marier (2020) for an account of policy issues in addressing the vulnerability of seniors in long-term care facilities in Canada. See Hold, Ramos, and Mahmoud (2020) for a brief summary of the challenges that the coronavirus is posing to patient well-being and experience in the United States.

Neither of us has lost their income or health coverage and this has largely made possible our bringing this project to completion.

As provinces and states begin to reopen, ableist, racist, sexist, and classist frames of disposability determine the terms of deconfinement. Those whose lives have been made expendable during this crisis may never fully recover from it or survive it. While we have been talking about disabled, Mad, and ill life since the beginning of this introduction, we have only spoken indirectly of the deaths that routinely result from its sustained oppression. For those whose survival is an act of embodied resistance, the question of death is unavoidable. We are being asked today to expect and even welcome the “unavoidable” deaths of many in order to preserve the “well-being” of the economy and to uphold law and order. As we write this introduction, anti-racist protestors are restlessly occupying the streets to call for the disarming, defunding, and disbanding of the brutal police and social forces that murder Black lives and keep those alive in a constant state of near-death debility. We must ask ourselves: who gets sick when the economy gets healthy? How do political and health crises reinforce each other? How do societies decide who gets to be “sane” and who gets to be “healthy”? How can we develop liberatory ways of thinking about illness, madness, and disability, and dismantle the systems that make and keep some of us sick? Wherever it finds its readers, we hope that this special issue generates these and similar questions. There remains much to be said about what it means to be sick and how we can think and write about sickness in ways that nourish our bodyminds, our work, and our movements. We welcome future work around these questions with enthusiasm and curiosity. We hope that crip brilliance and solidarity will increasingly inform how we transform the world.

One last note. We lost many wonderful contributors to unexpected new duties and life shifts due to the COVID-19 pandemic. While they could not contribute to this special issue, we want to hold some space for them in this introduction. There will always be absences in the margins of scholarly projects; we look forward to reading their work through other pathways soon. Finally, we wish to extend our warmest and most sincere thanks to our generous reviewers, to the authors who have contributed their labor and ideas to this special issue, and to the editors of *Puncta*, for believing in the importance of this project and for giving it a home.

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