

EMBRACING MISFIT BODIES: A REFLECTION ON MY BROTHER'S DEMENTIA IN THE TIME OF COVID-19

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For Moy

When we fit harmoniously and properly into the world, we forget the truth of contingency because the world sustains us. When we experience misfitting and recognize that disjuncture for its political potential, we expose the relational component and the fragility of fitting. Any of us can fit here today and misfit there tomorrow.

– Rosemarie Garland-Thomson, “Misfitting”

2020 was a year of global crisis. During this time, like many others, I experienced crisis on a very personal level. For me this coincided with the beginning of the pandemic, when my older brother developed a kind of dementia. He is only 56 years old now and his disease came as a complete surprise. Thus, when almost the whole world became “uncanny” (Aho 2020), saturated with profound uncertainty, anxiety, and continuous loss, we too—all who love and care for my brother—were drowning in despair.

Havi Carel, Matthew Ratcliffe, and Tom Froese (2020) lucidly describe how the personal and the political have become interwoven during the pandemic. They argue that it is precisely the fact that COVID-19 has affected us globally that allows us to reflect on those aspects of experience that are common to most of us, while at the same time discerning those that are modified by and dependent on various social injustices—and, I would add, on personal and/or circumstantial afflictions. In their short reflection on the phenomenon of social distancing within the pandemic, Carel, Ratcliffe, and Froese emphasize the central role of phenomenology in attempting to understand and give sense to these diverse aspects of experience:

Phenomenology is concerned with aspects of experience that are so deeply rooted in our lives that we typically overlook them, seldom reflecting on

their nature . . . The fact that lives have been altered on a global scale further presents us with an opportunity to learn more about which aspects of human experience are invariant across backgrounds and cultures, and where differences lie. Health, racial, and social inequities, as well as different health-care systems, have been shown to give rise to profoundly different pandemic experiences, thus emphasising the importance of situational contexts. (87)

In this text, I briefly explore a few philosophical issues relating both to the spread of COVID-19 and to my brother's disease. I attempt to make sense of the experience of personal crisis in times of global crisis. I believe most of us went through different personal crises, in varying degrees of severity, while experiencing the global pandemic. This has forced us to constantly negotiate our "personal," "social," and "political" selves in myriad ways, making us understand that our pain was both private and shared.

UNCERTAINTY AND ANXIETY

Uncertainty, or a sense of chaos and resulting anxiety, was there from the beginning. During the first days of the pandemic, uncertainty was rampant; nobody knew what exactly was happening, what the dimensions of the phenomenon (COVID-19) were, how contagious the disease was, how it was transmitted, how severe or deadly its effects were, and how we might protect ourselves.¹ All the while, my brother exhibited increasingly unusual behavior, personality changes, and memory lapses. He was not himself—but in what sense, exactly? What was this strange condition? Where was this leading? Doctors were puzzled, and every other day a new diagnosis was suggested.

Existentialists are known for discussing the effects of chaos and uncertainty on the human condition, arguing that certainty and predictability provide an artificial structure to which we cling in order to avoid experiencing the emptiness and severe anxiety caused by (true) knowledge of the world's unpredictability, chaos, and lack of inherent meaning. Kevin Aho (2020) reflects on this Heideggerian understanding of the world as inherently "uncanny" and its relation to COVID times. In describing what was revealed to many of us during the pandemic, he draws on Martin Heidegger's idea of existence as always already estranged and uncomfortable—irremediably linked to anxiety. Thus, it is not that the pandemic *turned* our world into an unfamiliar one, but rather that the essential uncertainty

¹ Carel, Ratcliffe, and Froese (2020) refer to this as an experience of "global uncertainty," which they define as "the loss of a once prereflective trust or confidence relating to most things in our lives." They add: "This does not concern specific situations or places. Rather, it envelops one's experience of, and engagement with, the world as a whole. Various elements of pandemic experience are characterised by suspicion, uncertainty, and doubt. We may distrust the air we breathe and the surfaces we touch, while strangers suddenly seem unpredictable sources of potential danger" (88). In other words, during the pandemic we ceased to feel "at home" in the world, as Kevin Aho (2020) explains, wrapped up as we were in disconcerting, unfamiliar experiences of time and space.

and uncanniness of human existence was made crystal clear through the unsettledness of the pandemic times. In Aho's words:

[T]he more fundamental analysis, for Heidegger, involves exposing how the uncanny is not simply something we feel in times of existential breakdown or crisis; it is *who we are*; “[the uncanny] is the basic determination of [human existence] itself” . . . This means, in the most primordial sense, the comforting and familiar experience of *das Heimliche* was an illusion all along that we are not and never have been at-home in the world. (3; emphasis in the original)

Anxiety is thus a reasonable response to recognizing life as “open,” lacking a settled program, and intrinsically involving human freedom (Crowell 2020)—not an absolute freedom, but the possibility to choose given the circumstances, which are beyond our control. We are doomed to be free within a world that is hardly predictable. We cannot “opt out” of the pandemic (or my brother's rare condition)—we can only choose what role to play within it and how to give it meaning. Thus, recalling Heidegger, Mark Ralkowski (2020) explains:

Heidegger says famously that “real anxiety” is not about anything in particular . . . it is about our “being-in-the-world as such.” We are anxious over the fact that we must make something out of our finite lives, and that we must do so without any guidance from nature or the structure of the self . . . We can never *fully* justify our choices, and so our projects, commitments, and roles—in short, our identities and sense of meaning and purpose in life—are constantly vulnerable and undermined by anxiety, which “is always latent in being-in-the-world.” (41; emphasis in the original)

The pandemic exposed these elements of choice and freedom at both personal and national levels. Libertarian narratives (“mask requirements rob us of our freedom”) conflicted with narratives of social solidarity (“mask wearing in the service of the vulnerable”). Each of us was also forced to decide how to act and give meaning to our own day-to-day life under the pandemic.

Chaos also left its mark on the life of my brother and those around him; every day, his behavior and thinking became more erratic, and we never knew what tomorrow would bring. The violently rapid-onset cognitive decay he experienced—and his apparent unawareness of what was happening—made us feel we were losing him a little more every day. And yet, he was somehow still there. We had to choose how to approach him and the disease; mainly, we struggled to ascertain exactly how much agency to afford him, and to make decisions accordingly. Should we force him to do more, be more active, speak more (given that he could barely find words)? Should we just let him sleep, like he wanted? Should we let him go out walking alone? What about pandemic restrictions, doctors' opinions, and advice from others? Should we keep searching? Should we keep trying to treat him even

though it was unclear what was wrong? In short, we were constantly confronted, on both a global and a personal level, with the burden of freedom and forced to make decisions in the context of painful uncertainty.

“Existential anxiety”—even when caused by a global disaster—is always experienced as a personal affliction. I believe that each of us experienced the anxiety of the pandemic (and of other contemporaneous crises, as in my family’s case) very personally. This is why anxiety is connected to authenticity. For existentialists, anxiety is not necessarily destructive. In fact, it is usually the opposite; the crisis of our recognition of life’s absurdity—and the resulting anxiety—move us to find our own life path and to face the freedom we have within apparent chaos. Crisis and anxiety are also motors for creativity and change.² This is the meaning of the authentic Heideggerian “being-toward-death”—facing the absurdity of existence and yet choosing to make it our own, despite (or rather, because of) our anxiety:

What authentic being-toward-death does is *maintain* this anxiety, and so it is *anxiety about death* that brings us back from our falling and individualizes us. In doing so, it also shows us that while we can never give a full justification of our life or choices, because there is no human telos to follow, we can ensure that our lives are *our own*. (Ralkowski 2020, 41; emphasis in the original)

Thus, crisis frequently forces creativity and a change of perspective. The COVID-19 crisis has brought about technological and scientific innovations that were unimaginable a year ago. Those who could, joined forces to create new ways to live with the pandemic and overcome its havoc. For my part, I became a specialist in my brother’s (supposed) disease. The doctors hypothesized, tentatively, that it could be a very rare brain disease (autoimmune encephalitis). All year, I read every piece of scientific research I could find, seeking out interlocutors to discuss the findings. I discovered how it is possible for a layperson like myself to understand research from another field, to put the pieces together, and to imagine solutions. The story of the discovery (barely more than a decade ago) and treatment of this rare disease resembles the meteoric findings and research developments regarding COVID-19 (the vaccine being the ultimate example)—with the difference that COVID-19 is a massive threat to all humanity, not a rare condition afflicting just a few.

PRIVILEGE AND GRIEF

The discussion of anxiety, freedom, and choice must be contextualized within an understanding of privilege. The COVID-19 pandemic has affected the poor and marginalized in abysmally different ways than it has the wealthy (Carel, Ratcliffe, and

² On this—specifically in relation to the pandemic, Aho (2020) writes: “The pandemic, on this [Heideggerian] reading, has certainly unsettled our sense of being at-home, but this unsettling is at the

Froese 2020). So-called “choices” over how to experience the pandemic, how to live our daily lives, and what meanings to ascribe to relationships during this pandemic have all been dependent on our degree of privilege and/or vulnerability. Millions did not have the option to stay home or practice “social distancing”—and for too many, the odds were stacked fatally against them. Judith Butler (2009) explains why so many lives are never grieved in the context of war; certain lives are never mourned because they were never considered lives to begin with. They are ontologically superfluous:

In targeting populations, war seeks to manage and form populations, distinguishing those lives to be preserved from those whose lives are dispensable . . . Ungrievable lives are those that cannot be lost, and cannot be destroyed, because they already inhabit a lost and destroyed zone; they are, ontologically, and from the start, already lost and destroyed, which means that when they are destroyed in war, nothing is destroyed. To destroy them actively might even seem like a kind of redundancy, or a way of simply ratifying a prior truth . . . Thus, there are “subjects” who are not quite recognizable as subjects, and there are “lives” that are not quite—or, indeed, are never—recognized as lives. (190–91; 198–200; 418–19)

Many lives lost to COVID-19 were (and will be) ungrievable lives. They fall into the void of the abstract numbers that even now keep rising and accumulating daily—the interminable count of pandemic victims. Most of these people were marginalized even before the pandemic, and they continue to be nameless, mourned only as a group. If a life is only mourned as part of a collective, what does that imply about the recognition it is afforded by the living as the loss of a particular, concrete subjectivity? My brother’s disease and the possibility of his death (literal or metaphorical, i.e., the death of his self-consciousness, the person we knew) were in no way part of the ungrievable mass. Surrounded by a loving family with the material and emotional resources to care for him, he had the privilege of being attended by different doctors in several hospitals, and to have specialists attempt to decipher his rare disease. Like some of the “privileged” victims of COVID-19, he was not an anonymous number, becoming part of a statistic. He had a name, he was somebody: even if he was not too aware of it.

VULNERABILITY AND EMBODIMENT

Recognizing certain lives as ungrievable results, at least partially, from failing to recognize our common vulnerability, Butler argues. It means some of us have been blinded by our privilege (we are the “real” subjects, with meaningful lives, while others constitute a

same time freeing; it loosens our rigid hold on things, opening up a ‘room for free play’ (*Spielraum*) where we can let go of our fallen routines and envision new meanings and possibilities for living” (17).

“disposable crowd”), forgetting that we, too, are embodied subjects, vulnerable to sickness, loss, disability, and death. We have forgotten that we, too, are dependent on others (and on what they create for us and provide us with) for survival and flourishing:

We cannot talk about a body without knowing what supports that body and what its relation to that support—or lack of support—might be. In this way, *the body is less an entity than a relation*, and it cannot be fully dissociated from the infrastructural and environmental conditions of its living. Thus, the dependency of human and other creatures on infrastructural support exposes a *specific vulnerability* that we have when we are unsupported, when those infrastructural conditions characterizing our social, political, and economic lives start to decompose, or when we find ourselves radically unsupported under conditions of precarity or under explicit conditions of threat. (Butler 2016, 19; emphasis mine)

Much of recent feminist theory is devoted to vulnerability as an existential condition and the central role embodiment plays in this conception (Butler 2016; Murphy 2009; Mackenzie, Rogers, and Dodds 2014). The idea of the autonomous, neoliberal subject is strongly criticized as fraudulent, giving way instead to a notion of subjectivity as emerging from relations, interdependence, and vulnerability. These new elaborations often use a robust conception of the subject as profoundly embodied, linked to others through leaky boundaries that make it both vulnerable and strong—open to both violence and protection, precisely because of its connection to other embodied subjects (Butler 2016; Murphy 2009). But what happens when the possibility of connection through embodiment is obstructed? The pandemic isolated many of us—again, those of us who had the privilege of being able to stay home and to keep a “safe distance” from the bodies of others. Bodies became dangerous, and phenomenological conceptions of intertwined subjects, existing through their shared embodiment—touching and being enmeshed with each other—gave way to a pandemic-specific dystopian reality in which we all faced the loss of that very shared embodiment; we shared the realization of how isolated, discrete, and independent from other bodies we can be and, at times like these, are in fact required to be.³

And yet, paradoxically, the pandemic and the distance it forced between bodies provides a strong argument for the inevitability of connection: the ontological necessity for embodied subjects to exist interdependently, intertwined, touching each other, and materially supporting each other’s lives. After more than a year of “social distancing,” the embodied interdependence at the basis of our existence—the urgent, critical need we have

³ As presented, for instance, in my own writing on grotesque bodies as allegorical of Merleau-Ponty’s understanding of the intertwining that is characteristic of embodied existence (Cohen Shabot 2006). See also Carel, Ratcliffe, and Froese (2020) and Aho (2020) for a broader discussion of the phenomenological meaning of the experience of social distance during the pandemic—an experience that filled us with anxiety and uncertainty mainly by challenging our previous sense of “being-in-the-world” and “being-with-others,” as our known, secure patterns for moving through space and interacting with others through our bodies.

to be with, touch, and encounter others—is no longer remote and invisible, or obscured by the illusion of atomic subjectivity; it is palpable and manifest. Likewise, my brother, who until his disease was considered a productive, independent, working man, suddenly became a disabled person in need of constant assistance. As happened to many COVID-19 victims to varying degrees, my brother’s vulnerability, his dependence on others for survival, became an irrevocable fact. Thus, if vulnerability is essential to our existential condition, the pandemic—and sickness and disability in general—only serve to reveal the always-already present, undeniable existence of our common embodied vulnerability and our essential interdependence.

HOPE (BUT ONLY THROUGH “MISFITTING”)

I am writing these lines sitting in a café, in a country where, thanks to widespread vaccination, life has almost returned to the “old normal.” I know this is far from the case in the rest of the world, but it does seem that science is effecting change and that, sooner or later, the pandemic will come to an end in more and more places. And during the last month, a bold young neuroimmunologist finally discovered which autoantibody had been attacking my brother’s brain. Now we have a firm diagnosis (autoimmune encephalitis, after all), and his dementia may be treatable and at least partly reversible. In the face of these developments, both general and personal, I feel hopeful. Nevertheless, it is clear that, even in the best scenario, the future will be broken; the reality in which we live, though a much better one than last year, will have multiple cracks in it. In light of this, I want to end this text with Rosemarie Garland-Thomson’s concept of “misfitting,” as a hopeful option for thinking about embodied existence always-already in terms of disability and thereby challenging the idea of “healthy,” “normal,” “abled” subjects.

“Misfitting” is a way of understanding our embodied existence as permanently prone to disability, and disability always as relationally dependent on material and environmental conditions that either support or fail to support certain bodies: “disability emerges from a discrepant fit between the distinctive individuality of a particular body and the totality of a given environment that the body encounters” (Garland-Thomson 2020, 227). Thus, being “fit” means being privileged, and being afforded harmony with the environment. Garland-Thomson recognizes the obvious disadvantage of being a “misfit body,” and the oppression and marginalization such bodies face. However, like Heideggerian “anxiety,” Garland-Thomson’s “misfit” leaves the stagnation of “harmony” behind, offering instead the potential for creativity and change, for a “cracked” reality from which consciousness-raising, solidarity, and freedom may emerge:

While misfitting can lead to segregation, exclusion from the rights of citizenship, and alienation from a majority community, it can also foster intense awareness of social injustice and the formation of a community of misfits that can collaborate to achieve a more liberatory politics and

praxis. . . . Even the canonical protest practices of disability rights, such as wheelchair users throwing themselves out of chairs and crawling up the stairs of public buildings, act out a misfitting. . . . Misfitting . . . ignites a vivid recognition of our fleshliness and the contingencies of human embodiment. . . . Although *misfit* is associated with disability and arises from disability theory, its critical application extends beyond disability as a cultural category and social identity toward a universalizing of misfitting as a contingent and fundamental fact of human embodiment. (228–29; emphasis in the original)

In the face of this crisis, global and personal, I refuse to make my hope one for harmony, order, and control. I no longer expect life to “return to normal” or bodies to be (only, always) healthy and abled. I embrace “misfitting” in a sincere attempt to recognize the pervasiveness of sickness, disability, and absurdity, in hopes that others will accompany and support me, in mutual solidarity and empathy, in the effort not to fall, or fall apart, while holding each other’s broken pieces.

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