

The gender and sexual politics of the COVID-19 pandemic - Original Article

# When vulnerability got mainstream: Reading the pandemic through disability and illness

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#### **Abstract**

Since its outbreak, the COVID-19 pandemic has generated discourses and practices that directly refer to the semantic universe usually connected to disability and illness. Words such as 'pre-existing conditions', 'risk groups', 'accessibility', and 'vulnerability' have become everyday elements of official and informal communications across the globe. In this article, I explore the contradictions that arise from such uses through the lens of crip studies. In the first part, I observe how the idea of vulnerability became mainstream, moving from being usually attached to disability and illness to being depicted as a universal condition. Such a shift serves the double purpose of reinstating the predominance of able-bodiedness as the preferable normalcy and invisibilising the particular conditions of disabled and chronically ill people in the pandemic. In the second part, I discuss the perverse use of the expressions 'risk group' and 'underlying conditions' as biopolitical tools to reinforce already existing forms of oppression. The third part comprises a reflection on accessibility and the sudden advent of workingfrom-home. Finally, I reflect on confinement and interdependence as key concepts to draft a politics of transformation that moves from disability and chronic illness to include all experiences of intersectional oppression. As other markers of oppression, illness and disability can determine the possibilities of survival through the crisis, not only because they are linked to bodily fragility but also because of the systemic violence they are immersed in. The knowledge produced from a place of vulnerability can hence show interesting elements to better understand the challenges of this pandemic through an intersectional perspective.

#### **Keywords**

Disability, illness, intersectionality, pandemic, vulnerability

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## Introduction

Since its outbreak, the COVID-19 pandemic has generated discourses and practices that directly refer to the semantic universe usually connected to disability and illness. Words such as 'pre-existing conditions', 'risk groups', 'accessibility', and 'vulnerability' have become everyday elements of official and informal communications across the globe.

In this article, I explore the contradictions that arise from such uses through the lens of crip¹ studies (Kafer, 2013; McRuer, 2006). In the first part, I observe how the idea of vulnerability became mainstream, moving from being usually attached to disability and illness to being depicted as a universal condition. Such shift hides important nuances, to the extent to which it serves the double purpose of reinstating the predominance of ablebodiedness as the preferable normalcy and invisibilising the particular conditions of disabled and chronically ill people in the pandemic. In the second part, I discuss the perverse use of the expressions 'risk group' and 'underlying conditions' as biopolitical tools to reinstate already existing forms of oppression. The third part comprises a reflection on accessibility and the sudden advent of working-from-home (WFH). Finally, I reflect on confinement and interdependence as key concepts to draft a politics of transformation that moves from disability and chronic illness to include all experiences of intersectional oppression.

The combination of systemic ableism (reduced inclusion to services, lower income, and structural inaccessibility) and the life-threatening effects of COVID-19 expose ill and disabled people to increased risks through the pandemic. The knowledge produced through their experiences of vulnerability *before* and *during* the pandemic can lead to a more comprehensive understanding of what future lies ahead. The effort to read the current crisis through the lens of disability and illness is crucial, because 'how one understands disability in the present determines how one imagines disability in the future; one's assumption about the experience of disability create one's conception of a better future' (Kafer, 2013: 2).

In this article, I bring together a reflection on disabled *and* chronically ill people acknowledging their 'collective affinity' (Kafer, 2013), that is, their common experiences of being labelled and othered as minorities. Although there may be great differences between disabilities and chronic illnesses, and among the significance of them within different cultural contexts, I want here to propose a reflection that brings them together as experiences joined by common challenges posed by structural ableism. This perspective recognises that the ableist norm 'construes goodness in terms of health, constancy, energy, wholeness, and strength at the expense of actual bodies that do not conform to these specification' (McRuer and Wilkerson, 2003: 8). As such, ableism affects disabled and chronically ill people with similar pressures and opposes their experiences to the supposedly universal normalcy to which they are constantly compared.

# The contradiction of vulnerability

The first contradictory element that emerged during the pandemic is the use of vulnerability as a universal category, as opposed to a systematic erasure of the (specific) vulnerability experienced by disabled and chronically ill people. As exponential numbers of

people of all ages have been affected so far by the pandemic and healthcare systems face unprecedented pressures, it appears clear that the meanings ascribed to vulnerability have gone through several changes and have been used following political and cultural agendas.

The concept of vulnerability is at the centre of theoretical debates (Koivunen et al., 2018): from a phenomenological understanding of embodied subjects (Ahmed, 2006; Butler, 2004), to a more political nuance employed by critical theory (Berlant, 2011), vulnerability is also often considered in its relationships with technological progress and bio-ethics (Braidotti, 2006; Shildrick, 2012). In this article, I focus in particular on the notion of vulnerability employed in critical disability studies (Shildrick, 2012) and crip studies (Kafer, 2013; McRuer, 2018). In this perspective, vulnerability is understood as a political language for the destabilisation of the categories of 'normalcy' and 'ablebodiedness': the importance of embracing, rather than avoiding, the vulnerability that comes with the disabled and ill experience becomes an act of reivindication, of rebellion against a compulsory bodily normalcy. At the same time, in this understanding, recognising vulnerability means to accept pain, fatigue, and weakness as instruments of production of valid embodied knowledge (Kafer, 2013).

Crip studies point out that the opposition between normalcy and deviation is based on dichotomies that oppose concepts like able-bodiedness/disability, health/illness, male/female, and heterosexual/homosexual (McRuer, 2006). The dichotomies serve the purpose of evidencing the positive, the right, and the good identity or behaviour, as opposed to the deviant, the monstrous, and the deviant. Historically, we find numerous examples of how such opposition is used to attach moral values to White, healthy, able-bodied, heterosexual men – and, on the contrary, to label women, homosexuals, disabled, and ill people as deviant and morally fraught.

In the case of the dichotomy between able-bodiedness and disability, vulnerability is a key element: as an intrinsic feature of the experience of disability and illness, it is normatively linked to the dominant perspective that others them as fragile, unlucky, and tragic. Disabled and ill people are often portrayed as objects of cure and not subjects of care (Kafer, 2013): they are construed as passive, fragile, weak, and less worthy. Indeed, 'such an understanding of vulnerability as 'different from the norm' easily allows the norm to remain invisible and uncontested' (Koivunen et al., 2018: 5).

The rapid emergence of a threatening illness on a global scale generated a short circuit in this understanding and the emergence of different nuances to the same concept: 'as governments modelled scenarios, the tenuousness of the entire population's normative position became apparent, and everyone was part of the vulnerable population' (Goggin and Ellis, 2020: 170). Some hope emerged that the long-standing difficulties experienced by disabled and chronically ill people would be understood by a large majority of the population. In many networks and online communities, there were expressions of relief and even the hope this moment of worldwide difficulty overturn historical, systemic hierarchies of oppression. However, instead of representing a level to flatten social inequalities, the pandemic has functioned as an accelerator that enhances pre-existing disparities and hastens their effects. Those who already possessed key privileges related to class, age, race, gender, and ability can leverage them to access better conditions of confinement, fairer treatment in healthcare systems, and more decent working

conditions. On the contrary, those who at the beginning of the pandemic were already in a condition of vulnerability, such as disabled, LGBTQ+ (lesbian, gay, bisexual, transgender, queer, and others) people, sex workers, women, undocumented, and racialised people, suffer increased difficulties in shielding, accessing healthcare services, and applying the required safety measures.

Disabled and chronically ill people fall into this second category: in a context of supposedly general vulnerability, in which nobody is invulnerable (Butler, 2004), disability maintained its status as a 'special form of vulnerability', different from the ontological vulnerability of human beings (Scully, 2013). When vulnerability got mainstream, it did not entail an effort to learn from disability activism nor to integrate the embodied knowledge acquired through much suffering and struggles by disabled and chronically ill people. On the contrary, the threat of illness and the dreadful realisation that, in the end, able-bodiedness and health are very precarious privileges, triggered reactions that went in the opposite directions.

The debates that arose in the United Kingdom, United States, Italy, and other countries about the ethical codes adopted in intensive care units is a vivid example of the double standard of vulnerability that emerged. In times of emergency and scarcity of life-saving resources, such as ventilators, hospitals are obliged to follow guidelines that indicate what parameters to privilege in the choice of patients to follow first (Abrams and Abbott, 2020). In a moment in which media communication was already quite dramatic, newspapers and televisions provided great attention to such choices, highlighting how medical professionals were urged to choose the patients that had more chances to survive and have a positive outcome, namely patients with no pre-existing conditions or disabilities, and under a certain age (see, for example, Kuper et al., 2020). The presence of disabilities or chronic illnesses are judged as unfavourable not only for survival but also to have a liveable life: as Wong (2020) and Pulrang (2020) note, the choice about who is better equipped to have a liveable life, and, ultimately, what are the conditions that make life liveable, is determined by ableist assumptions. The ableist fantasy of a future in which 'all illnesses will be cured and disability will be eradicated' (Clare, 2017) takes the form of the biopolitics of choice over disabled lives. In this scenario, some vulnerabilities matter more and raise questions about structural inequalities and privileges (Koivunen et al., 2018).

# A shift in the meanings: 'risk group'

A second contradiction emerges from the reflection above: it points to the use of 'risk group' as a biopolitical discursive tool. During the 1980s, when AIDS spread fast in several Western countries, the use of the term 'risk group' exposed a specific set of practices, a deviant way of life, associated with sexual perversion and use of drugs: as Sontag (1991) affirms, 'to get AIDS is precisely to be revealed, in the majority of cases so far, as a member of a certain "risk group," a community of pariahs' (p. 110). The implicit suggestion that illness regarded only a certain group of people, easily detectable, served for years as a reassurance to the White, heterosexuals men of their immunity to the illness (as if Africa did not exist, Sontag notes). However, it also caused misinformation and potentially harmful communication that did not include, for example, women as

potentially exposed to the contagion. Only recently the notion of 'risk group' concerning HIV/AIDS has been substituted by 'risk behaviours', a shift that moves the focus from the person to the action, from a specific identifiable group to a plethora of different behaviours that can be enacted by anyone.

The refashioning of 'risk group' in the context of the COVID-19 pandemic suggests two reflections: one related to disability politics and the other to intersectional coalitions.

The World Health Organization (WHO) states that 'COVID-19 is often more severe in people who are older than 60 years or who have health conditions like lung or heart disease, diabetes or conditions that affect their immune systems' (WHO, 2020). The type of pre-existing conditions (or underlying conditions) mentioned refers to illnesses that can provoke severe symptoms in combination with COVID-19, or even death. The combination of 'risk group' and 'underlying conditions' is often used as a caveat for most of the severe cases and deaths. In particular in the first 6 months of the pandemic, when there was still a lot to discover about the illness, reports on televisions and newspapers insisted on accompanying the count of deaths with the expressions 'all of them had preexisting conditions' or 'all of them were over 65 years'. Abrams and Abbott (2020) point out three possible meanings of the expression 'risk group': a medical one, that indicates a simple condition faced by a person; a social (or normative) one, that establishes a division between 'normal' people and those with elements of bodily fragility; and a moral one, which links the person's conditions to desirable behaviour. In the context of the pandemic, the three levels are mixed and their differences blurred. Their use is a powerful reminder of ableist conceptions according to which some lives are more expendable than others, and consequently, some deaths are less relevant than others. Indeed, as the authors point out, 'the phrase 'underlying conditions' is more than simply a reference to an individual's medical history, but rather it obscures the conditions which led up to that death' (Abrams and Abbott, 2020: 171). Whenever institutional communication states that someone died because of COVID-19 but they had underlying conditions, the subtle message reinforces that able-bodiedness is the preferable and more relevant option. In a system of compulsory able-bodiedness (McRuer, 2006; Pieri, 2019), such message makes sense: it basically suggests that not all deaths are equally worth of attention because not all lives are equally worth. In a twisted, more subtle way, the use of 'risk groups' to determine a separation between hierarchical levels of worth and reassure the majority they are untouchable reprises the one seen during the HIV/AIDS epidemic in the 1980s.

However, the expressions 'risk groups' and 'pre-existing conditions' also cut out of the picture the fact that disabled and chronically ill people are always at risk: in non-pandemic times, they are exposed to worse healthcare treatment, lower incomes, and fewer opportunities of integration in social life (Goggin and Ellis, 2020). The pandemic is a magnifying lens on the structural medical ableism they suffer in the access to healthcare and the lack of preparedness of healthcare systems in communicating effectively with people with disabilities. As a result, the pre-existing conditions that disabled and chronically ill people have are conditions of structural inequality, that, inevitably, have a major impact on the new forms of inequality created by the pandemic: 'with people with disabilities entering the COVID-19 pandemic worse off than their non-disabled peers

[. . .] it is likely that people with disabilities are discounted and, as result, fairing comparatively worse than their non-disabled peers in the pandemic' (Sabatello et al., 2020: 189).

This reflection provides a cue to a second consideration about the intersectional politics of the pandemic and how they affect hierarchies of inequality. Although there are significant differences from country to country, research showed that there exist a vast array of social and economic elements that increase the risk of getting infected or having an unfavourable prognosis in the case of infection, such as conditions of housing; working conditions; class belonging; gender and sexual diversity; racial identification; and cultural capital. For example, racialised communities in the United States suffer higher rates of infection and higher percentages of mortality, a reflection of the structural inequality of the North-American society (CDC, 2020; Figueroa et al., 2021; Forester and O'Brien, 2020). It is particularly striking, in this regard, that the Black Lives Matter protests that took place in Minneapolis and the rest of the country, following the killing of George Floyd by a policeman, happened at the same time in which the pandemic was unveiling the terrifying differences between White and racialised communities in the access to healthcare. The result of researches conducted on LGBTQ+ people during the pandemic suggests that they suffer from strong social isolation and mental health distress (Barrientos et al., 2021). Moreover, politics of social distancing generally attend to the logics of cohabiting families and excluded or deliberately ignored the forms of queer sociality and intimacy that constitute the basis of care for many LGBTQI+ communities (Paceley et al., 2021). Finally, gender violence, in particular in domestic contexts, exposed thousands of women to situation of abuse: centres for the prevention and treatment of violence on women recorded unprecedented rates of contacts during confinement in several countries (WHO, 2021).

The use of expressions such as 'risk group' and 'underlying conditions', therefore, focused public attention on the clinical aspects of the pandemic. However, it also had the effect of invisibilising the social factors that determine higher risks for some and the hierarchies of privilege that construct access to equal healthcare. It distracted the focus from the socio-economics of the pandemic, unveiling a biopolitical regime in the meaning suggested by Foucault (1978): a regime of power of life that becomes a deadly form of power for entire populations.

# The promise of accessibility

The third contradiction stems from the measures related to confinement and the consequent advancements in accessibility measures. People with disabilities and chronic illness are not new to the idea of confinement: either living in institutions and care homes or their houses, they are often forced to limit public participation due to a multiplicity of factors (accessibility, economic factors, personal assistance). Flexible working schemes, adaptation to work-from-home conditions, remote meetings have been part of the disability advocates agenda for years. When the pandemic struck, such changes were put in place for companies, universities, and schools in a very short time. Such a large-scale switch had a bittersweet flavour. On one side, it created some form of improvement in the living and working conditions of many disabled and chronically ill people: after

being systematically excluded from working and social activities, they could all of a sudden enjoy even a vast choice of cultural and artistic events made accessible. However, on the other, the swift change proved that the possibility to provide more disability-friendly working environments and more accessible spaces had always been there: what was lacking was the collective intention to make them effective. Indeed, the rapidity of such a change towards a WFH mode can only be justified by the fact that it was driven by a capitalistic need of maintaining productivity, not the political will to make social life and work more accessible. The spectre of a global economic crisis and the fear of seeing entire companies shutting down pressured enterprises and institutions to look for feasible solutions that could maintain the levels of productivity going. However, it is important to be reminded that the very notion of disability was born as antithetic to productivity (McRuer, 2018) and that in the contemporary political economy, disabled people occupy a specific place of disposability. The 'neo-liberal ableism' (Goodley, 2014) opposes the needs for productivity to the special needs of disabled people and creates hierarchies of worth in which illness and disability are defined primarily as inabilities to work.

Since accessibility was a collateral benefit of the pandemic, created by the need of keeping a productive system based on structural ableism that was shattered, it is legitimate to question whether such benefits will not be integrated in a new way of thinking about work and leisure, in the long run. For example, we can learn to produce differently and work at the best of our possibilities through accessible ways intended as a collective good and not as individual needs. As we get accustomed to the idea that the pandemic is not going to disappear quickly, the project of accessibility must be integrated into any collective political project of transformation.

# From confinement to interdependence

Given that the politics of the pandemic reflect the hierarchies of oppression that preexisted, how can we crip them to create a meaningful change? What can we learn from the disability politics of the pandemic to benefit the intersectional struggles of oppressed minorities?

One possible way, I argue, comes ironically from another important word of these times: confinement. The term originates from the junction of two Latin terms: 'con' (shared) and 'finis' (borders, limits). In the original meaning, the act of confining does indicate not only a mere delimitation of space, but also the connection between that space and the contiguous one: it is at the same time an act of enclosure and the creation of a contact. Therefore, confinement recalls the idea of isolation but also the ability to be close to each other: to connect.

While contributing to curb the spread of the virus, the measures of confinement put in place in many countries accelerated other factors of systemic racial, homo-transphobic, sexist, ableist violence, as previously discussed. The context of the pandemic shatters the meanings ascribed to care and forces us to rethink what it means to take care, not only of the people we love but also to take care of our communities and our environment.

In disability research and activism, the question of what is 'care' and how we define it has been central to forge politics that recognise the right to autonomy and self-determination (Kafer, 2013). The concept of interdependence (Fine and Glendinning, 2005)

suggests that every person involved in any relationship of care is, at the same time, dependent and privileged in relation to the others. Overturning the asymmetry that depicts the disabled in a position of need versus a care-giver in a position of power, interdependence reminds us of the intersubjectivity that constitutes the core of our relationships. We are all interdependent and while the pandemics may unveil our vulnerability towards the threat of illness, economic insecurity, and social conflict, it also reminds us that we need others to survive and thrive. If disabled and chronically ill people and activists have known this for some time, this may be a new lesson for the able-bodied population. Indeed, under the light of interdependence, the words 'vulnerability', 'pre-existing conditions', 'confinement', and 'accessibility' expand to a semantic universe that goes beyond disability and illness as forms of subjugation and includes all the subjects that are oppressed by the biopolitics of the pandemic.

Interdependence is not about creating groups of risk and isolating them from the rest: it is about recognising that the meaning attached to the idea of risk groups stems from systems of oppression that categorise and privilege some of us. So, cripping the pandemic may entail also breaking down the barrier between groups of risk, with the responsibility that comes at play when different vulnerabilities come together. Radical forms of collective resistance are already emerging and will emerge as the pandemic evolves. In several cities, public baskets to leave and collect food fostered the redistribution of resources in a moment in which the homeless and the poor could not count on support<sup>2</sup>. In other contexts, the pandemic forced institutions and grassroots organisations to work side by side in reorganising childcare in a way compatible with the new needs of WFH that emerged. Interdependence is a collective value that cannot (yet) be contained or foreclosed by modes of regulation (McRuer, 2018).

# Conclusion: are we in it together?

In this article, I discussed some contradictions arising from the use of terms arisen during the pandemic of COVID-19. By discussing the use of 'vulnerability', 'risk group', 'underlying conditions', 'accessibility', and 'confinement', I explored how a vocabulary usually about disability and illness is being weaponised by use to the extended population. However, as the examples show, while they seem to shatter the dualism between health/illness or disability/able-bodiedness, the practices explored reinstate able-bodiedness as the compulsory and preferable option. Moreover, they reinforce the structures of inequalities and the intersectional disparity between those who already held privileges before the pandemic and those who were already unprivileged, and continue to be, in an even more harmful way.

The politics of disability in pandemic times tell us a lot about crip times (2018) and the conditions in which disabled and chronically ill people lived before 2020 and continue to live. If we consider crip temporalities, the pandemic is only one step of a longer process in which disability and illness have been subjugated by systemic forms of ableism. These times unveil the pervasiveness of ableism into the healthcare system, medical rationalism, and its entanglement with other forms of systematic oppression, such as racism, gender oppression, and LGBTQ+ phobia.

The analysis here conducted, however, also aims at pointing out possible directions to *crip* the pandemic, that is, to learn from the current context and to build coalitional politics of transformation through bodily vulnerability. In this sense, the pandemic represents a collective opportunity to rethink the way we work and the way we produce, the way we socialise, and the way we take care of others. In particular, the concept of interdependence is crucial in this context: it shows a different conceptualisation of disability, care, illness, and vulnerability and provides a lead for a political transformation that could involve all subjects oppressed.

In his reflections on interdependence, Eli Clare (2017) writes,

White Western culture goes to extraordinary lengths to deny the vital relationships between water and stone, plant and animal, human and nonhuman, as well as the utter reliance of human upon human. Within this culture of denial, when those of us don't currently need help dressing ourselves or going to the bathroom try to imagine interdependence, we fail. [. . .] Our fears reflect not the truth but the limits of our imagination. (p. 136)

Disability politics and the experiences embodied by disabled and chronically ill people through this pandemic offer an important insight into how oppression works and how we can, intersectionally, imagine things differently.

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#### Note

- 'Crip' comes from 'cripple', a term historically utilised as an insult to disabled people. In its
  original formulation, Robert McRuer (2006) coined 'crip theory' as a theoretical perspective to reclaim disability as a contestatory condition, in a similar way as 'queer' in 'queer
  theory' reclaims the abjection, the difference, the minorisation as political locations to produce radical change. Crip theory focuses on the deconstruction of ableism and compulsory
  able-bodiedness and on the ways they are entangled to other forms of oppression, in particular
  heteronormativity.
- See https://www.npr.org/2020/04/07/828021259/in-naples-pandemic-solidarity-baskets-help-feed-the-homeless?t=1638913666551. Accessed 30 October 2021.

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