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The Color of Breath

Coreen McGuire, Jane Macnaughton, and Havi Carel

### Breath under the Skin

Pulse oximeters are technological devices that measure oxygen saturation in the blood using a small infrared light beam. Through measuring the rate of light absorption, they record a proxy measure of oxygen levels in the blood. Normally, if your blood oxygen levels were measurably low, you would know it. You would experience corresponding physical symptoms, such as shortness of breath or dizziness. And yet the Covid-19 pandemic has generated significant reports of “happy” or “silent” hypoxia: the previously little-known phenomenon of people with dangerously low blood oxygen levels who nonetheless function without shortness of breath.<sup>1</sup>

These cases highlight a central theme emergent from the Life of Breath project: that there is often a mismatch between objective and subjective measures of health, also known as symptom discordance. A person with low oxygen levels in their blood may present with no discomfort, while another with reasonable levels might complain of severe breathlessness.<sup>2</sup> Symptom discordance also demonstrates the complexity of the sensation of breathlessness and underlines that the way we perceive breathlessness is constructed partly through physiological data but also through our individual context, personal experience, expectations, and individual psychologies.<sup>3</sup>

The recent uptake of oximeter use has helped to illuminate deeper problems with the ways we attempt to measure breathlessness through technologies. One of the most critical is that the infrared light is less effective on dark skin.<sup>4</sup> The oximeter tends to overestimate oxygen saturation levels in non-white individuals, with the error degree increasing in correlation with the skin’s darkness.<sup>5</sup> This is a pointed metaphor for how the pandemic has laid bare the racial and socioeconomic inequities that have tracked morbidity rates—and has shown simultaneously how systemic racism causes literal suffocation. George Floyd’s cry of “I can’t breathe” echoed Eric Garner’s identical plea in 2014, both of which so vividly express the devaluation of black lives in the United States. This rallying cry for the Black Lives Matter movement has been amplified by both the global growth of the BLM protests and the breathlessness caused by Covid-19, disproportionately affecting black people and other ethnic minorities.<sup>6</sup>

Breath has long functioned as a metaphor.<sup>7</sup> Now breathlessness is especially potent as a metaphor for the need for freedom from oppression. This is potently captured in Achille Mbembe's essay "The Universal Right to Breathe," in which he argues for breath as a key force for unification in a post-Covid-19 world.<sup>8</sup> Noting the malign influence of capitalism which has "constrained entire segments of the world population, entire races, to a difficult, panting breath and life of oppression," he insists that to survive this "constriction" we need to "conceive of breathing beyond its purely biological aspect, and instead as that which we hold in common, that which, by definition, eludes all calculation": the universal right to breathe.

### Skin-Deep

This universality is not acknowledged in clinical contexts, certainly. How we understand breath medically is subject to measurement and calculation—and this calculation undermines the universal in both obvious and subtle ways. Ingrained racial bias is not just skin-deep. It is embedded in the technologies *behind* technologies: that is, in the data itself. The *New England Journal of Medicine* recently published a list of race-adjusted algorithms to highlight the growing concerns with their uses given the "mounting evidence that race is not a reliable proxy for genetic difference."<sup>9</sup> Medical historians Lundy Braun and Coreen McGuire have shown how spirometric technology has historically been wielded to deepen and reinforce racial differences. Braun's *Breathing Race into the Machine* revealed that the practice of "correcting" for race in spirometry, the study of lung function, promoted scientific acceptance of difference between racial groups, without due concern to the racial categories employed to organize this data in the first place, or to the way that social conditions and living conditions affect lung function.<sup>10</sup> McGuire's *Measuring Difference, Numbering Normal* developed this analysis by demonstrating the use of variable and inconsistent reference classes in spirometry with regard to women and miners. Considering the way women were grouped in data sets (or not), McGuire showed how difference in lung function between men and women was established, and explored the varying extent to which such differences were attributed to biological or societal causes. Similarly, analyzing the efforts to define normal lung function for miners revealed how abnormal lung function was attributed to the essential nature of the miner's body, showing the

impact of politics on the classification of respiratory disability. Considering these historical interactions demonstrates how data can be used to reveal or conceal the social and environmental determinants of health. Understanding this has never been more urgent.

When data first emerged from the countries initially affected by Covid-19, we started seeing patterns—such as men being more susceptible to the disease than women. In Britain, data is disaggregated to reflect racial differences so the extent to which Covid-19 was unduly impacting those categorized as “BAME (black and minority ethnic) populations” became quickly visible.<sup>11</sup>

The patterns suggested by this data have been implemented in workplace safety questionnaires that ask individuals to calculate their “Covid age” according to their sex, age, ethnicity, and various comorbidities before they return to work.<sup>12</sup> Though this data is obviously valuable, such initiatives are based on the premise that risk to health originates in the individual rather than in their ways of living as a member of a particular group—ways of living which might include increased exposure to air pollution, decreased access to quality education, greater levels of poverty and stress, and increased levels of discrimination from health professionals. Historian Tina Sikka has recently questioned this premise in her analysis of race science and body mass index measurement. She explains that, “it is not that BMI fails to account for body types based on race that is the problem; rather, it is the material impact racialization has on health outcomes.”<sup>13</sup> In other words: we are not tracking race, we are tracking racism; not tracking sex, but tracking sexism; not tracking personal vulnerability, but tracking social and economic failings. We cannot change “personal vulnerability” factors, but we can change social and economic inequalities.

Placing blame for health at the level of the individual allows the most powerful to avoid taking collective responsibility. In terms of this pandemic, that responsibility means reckoning with the structural, governmental, and environmental factors that have placed Britain and the U.S. with the highest Covid-19 morbidity and mortality rates in the world. Now that these risk factors are becoming better understood, the question is: what policy changes will we see—indeed *demand*—as a response?

I (Still) Can't Breathe

The pandemic has exposed the already fragile pressure points within our communities. All children were affected by school closures, but children with disabilities and special educational needs were affected more, as were children from lower socioeconomic backgrounds. All families felt the pressures of lockdown, but families struggling with domestic violence felt it more. Everyone felt anxious and worried, but those with underlying health conditions felt more so, as did those with mental health problems. We all suffered from isolation and extended time at home, but those with limited access to outdoor space suffered more. Health inequities are fundamentally intertwined with social and economic inequalities: the pandemic is a palimpsest giving an accentuated impression of the “normal” inequalities we lived with before Covid-19.

Seeing these contours so clearly and having the costs of inequality so bluntly spelled out is an urgent call to use this moment as an opportunity for change. To start, we need further research into why Covid-19 affects some groups more than others and—crucially—how these effects can be mitigated. This includes studying the effects of acute and long-term breathlessness, the topic of our research in the Life of Breath project. What we have found is that there is a need for specialized breathlessness services (such as the pioneering Breathlessness Intervention Service in Cambridge, U.K.). There is a need for better training and interventions for end-of-life breathlessness. And there is a need to improve our understanding of the rift between objective measurements of lung function and the subjective experience of breathlessness.<sup>14</sup>

All these calls should be amplified by a program that recognizes and seeks out individual and first-person testimonies, respects difference, and is alert to the dangers of health inequities. The need to return to individual experience—to the stories, testimonies, and narratives of individual people—is a core message from Covid-19 reporting and news coverage. By investing so much meaning in quantification, we lose the stories of the individual people and families whose lives have been violently impacted by the pandemic. As our work with the Life of Breath has shown, these can be recovered through a phenomenological framework that promotes these principles and provides a useful tool with which to capture, study, and articulate the varied experiences of breathlessness.<sup>15</sup>

The pathogens associated with Covid-19 are airborne; there is little that individuals can do to escape them. As Ed Yong concluded in his recent *Atlantic* article, the etymology of the word pandemic is inherently revealing of this fact (*pan* meaning all, *demos* meaning people).<sup>16</sup> We share in this experience just as we share the

air, including its pollutants and its pathogens. Still, we all experience the sharedness of breathing differently. We need to embrace both the collective nature of co-breathing and the unique and deeply subjective way in which we each experience our own breathing. Intertwined and expansive, open and vulnerable, breathing is what keeps us alive—as well as being what may ultimately kill us.

#### NOTES

1. Couzin-Frankel, “Mystery of the Pandemic’s,” 455.
2. Jones, “Health Status Measurement.”
3. Faull, Hayen, and Pattinson, “Breathlessness and the Body.”
4. Bickler, Feiner, and Severinghaus, “Effects of Skin Pigmentation.”
5. Moran-Thomas, “How a Popular Medical Device.”
6. Macnaughton and Carel, “Five Breathtaking Years.”
7. See Rose, “Introduction.”
8. Mbembe, “Universal Right to Breathe.”
9. Vyas, Eisenstein, and Jones, “Hidden in Plain Sight,” 874.
10. Braun, *Breathing Race into the Machine*; McGuire, *Measuring Difference*.
11. Williamson et al., “OpenSAFELY.”
12. Coggon et al., “Assessment of Workers’ Personal Vulnerability.”
13. Sikka, “BMI, Race, and Bodies.”
14. See Carel, “Breathlessness.”
15. Carel, “Phenomenology as a Resource for Patients”; see also Carel, *Phenomenology of Illness*.
16. Yong, “How the Pandemic Defeated America.”

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