Pandemic Praxis

# Commentary on 'All Bodies': Indian perspective

Satendra Singh, MD

Deputy Editor-in-chief, RHiME and Associate Professor, Physiology,
University College of Medical Sciences and GTB Hospital, University of Delhi, India

Corresponding Author:
Dr. Satendra Singh
Department of Physiology, UCMS and GTB Hospital
Delhi 110095, India
Email: dr.satendra at gmail dot com

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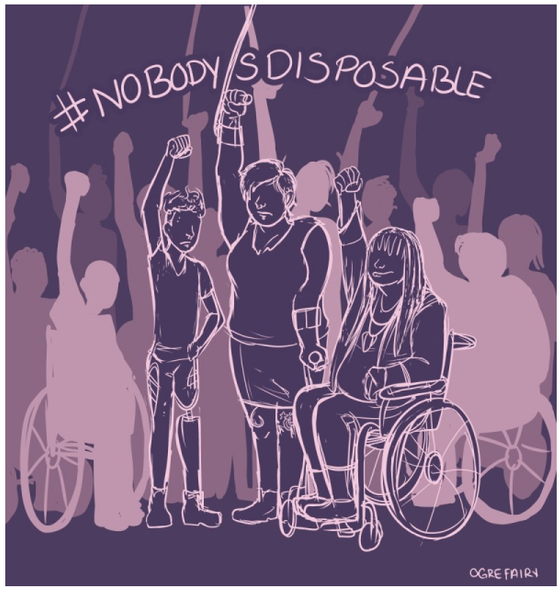
The commentary is in response to the graphic titled "All Bodies" which is accessible at http://rhime.in/ojs




Artist
Michaela Oteri @Ogrefairy
"All Bodies"

Source: Oteri M. All Bodies. RHiME. 2020;7:106-7.

## Unlocking Ubiquity

Absorbing the painting as a person with a disability in general and a doctor with a disability in particular, I can't ignore the disabled lives lost in the pandemic (from COVID-19 or non-virus causes exacerbated by pandemic). These people, to me, are the palest figures shown as trying to fade out of the frame. The three in front have visible disabilities as they clench their fists in solidarity while being supported by their assistive devices (a prosthesis, a crutch, and a wheelchair). The picture also embraces the much-neglected area of invisible disabilities and intersectionality. The message is loud and clear - all lives matter and nobody is disposable - be it

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disabled people, elderly, people of color, migrants, or transgender people.

*Crip Camp*, the Netflix documentary released during the lockdown, explained how a New York campground for people with disabilities inspired the American Disability Rights movement. For me, the defining moment in the documentary was when the protestors (some sitting in their wheelchairs and others leaning on crutches) abandoned their assistive devices and began climbing the 78 marble steps up the Capitol. It was the coming of age of an international disability rights movement. The sight of protestors against the backdrop of "Injustice anywhere is a threat to justice everywhere" gels equally well with this artwork: #NoBodyIsDisposable.

## Why 'One Size Fits All' Doesn't Work in a Pandemic

On 24 March 2020, to fight COVID-19, the Indian Government put in place a nationwide lockdown under the provisions of the Disaster Management Act, 2005. The National Disaster Management Guidelines (Hospital safety) describe how hospitals are to act during a National Disaster. The section on triage contains merely a single page guidance and utilizes the principle of "sickest first".[1] The guiding ethical principles of 'first-come, first-served' are clearly not suited for application to the COVID-19 pandemic; however, even the 'sickest first' or 'youngest first' should be used with great caution and only when it aligns with the principle of maximizing benefits.[2]

Beauchamp and Childress's bioethics framework is built on four moral principles: respect for autonomy, beneficence, nonmaleficence, and justice.[3] A deficiency of this structure is that little experimental proof exists showing that physicians utilize the four principles in ethical decision making.[4] Jonsen, Siegler, and Winslade bridged the gap by pioneering the "four-quadrant" approach and establishing the field of Clinical Medical Ethics.[5] However, these principles get strained in case of public health emergencies like COVID-19 which require the following: setting priority (identifying procedures to tackle medical emergencies), rationing (identifying protocols to support multi-agency and multi-disciplinary collaboration), and triage (identifying how limited resources will be allocated to support medical care).[6]

The National Preparedness Survey on COVID-19 by the Department of Administrative Reform and Public Grievance uncovered what we were fearing - there are insufficient ICU beds and ventilators.[7] On March 29, eleven Empowered Groups were constituted by the Ministry of Home Affairs for planning and ensuring the implementation of COVID-19 response activities. The Chairman of Empowered Group-3 admitted that India needed 75,000 ventilators and had only 19,000.

All of us struggle with the isolation of a quarantined life and with the uncertainties of a pandemic; however, many disabled people have always had to manage such isolation, irrespective of pandemics. Moreover, with the acute shortage of ventilators, now doctors have to make the dreaded decision of who lives and who dies. The disability sector is fearful that these decisions will be based on practitioners' traditional prejudices and biases, especially on the surmised quality of life and the imagined social worth of people with disabilities.

## Nothing About Us, Without Us

The reason discrimination against disabled people creeps easily into such medical decision-making is because of deficit-based perspectives (medical model of disability). It took doctors with disabilities, in partnership with activists and health professions educators, to frame disability competencies for health professions courses; the purpose was to tackle such stereotypes and promote the human rights model of disability.[8] It is unethical to use stereotypes about an individual's disability to ration care (some of the Crisis Standards of Care guidelines), like weighing a patient's "worth" based on the presence or absence of disabilities.[9] Even in this pandemic International treaties like the United Nations Convention on the

Rights of Persons with Disabilities and legislations like Americans with Disabilities Act, the Rights of Persons with Disabilities Act (Section 3.3; India), and Equality Act (UK) are applicable.

The voices of disabled people are being neglected in the response formulated to the COVID-19 Pandemic. The Disability-inclusive Disaster Risk Reduction (DiDRR) Guidelines from the Government of India explicitly states that if DiDRR is to function, people with disabilities and their organisations would have to be included in all decision-making that affects them (Section IV, Point 15, page 27).[10] However, none of the circulars released by the Government of India includes disabled contributors. Canada stands out in this regard as perhaps the only country to establish a COVID19 Disability Advisory Group by involving Disabled Peoples Organisation.[9]

Kirschner, in her commentary on the above artwork, laments the medical and bioethics communities for not showing solidarity in disability-inclusive COVID-19 response. Amidst growing protest by disability rights groups, the Office of Civil Rights in the US has released COVID guidance prohibiting discrimination based on disability.[9] In a recent article, I proposed a Disability Ethics framework in employing anti-discriminatory approaches to value disabled lives in triage.[11] The Bioethics Group of the Republic of San Marino has published similar guidance but we need the voices of disability ethicists.[9]

The NoBody Is Disposable Coalition in the United States is campaigning against discrimination in triage. In their open letter to medical professionals, they have an unusual signatory listed among organisations supporting the cause - this is the Doctors with Disabilities: Agents of Change from India.[12] Society often forgets that disabled people are not always patients but they may be health care providers too. There are many doctors and nurses with disabilities who are working at the frontline in this pandemic - we need look no further for evidence that the provisions that use of life expectancy and “life years” as the basis for allocating ventilators are discriminatory. The presence in hospitals of providers with disabilities shreds apart the false notion that we should rely on ‘comorbidities’ to assess ‘long term survival’.

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