Disability ethics in the coronavirus crisis

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Abstract

The disability viewpoint is fundamental for understanding and advancing social justice for everyone in the population. Despite this fact, it is regularly dismissed by public health experts and policymakers. Understanding of disability rights is central in an all-inclusive COVID-19 preparedness. This paper attempts to explore disability ethics in understanding structural discrimination, equitable practices, respect for disability culture and ways to safeguard health care professionals with disabilities in the coronavirus pandemic. In crisis standards of care, resource allocations must not be solely based on a disabled person's subjective quality of life. Health professionals should avoid stereotypes about an individual's disability to ration care. Triage protocol committees and disaster risk reduction working groups should explicitly recruit people with disabilities and chronic illnesses in their response strategies. Disability ethics can reform medical rationing by removing prejudices and safeguarding fair protection of the interests of all patients, including those with a disability.

Keywords: Clinical ethics, coronavirus, COVID-19, disability studies, disabled persons, health equity, medical ethics, pandemics, resource allocation, social justice, standards of care/ethics*, triage

The outbreak of a novel coronavirus—first reported in Wuhan, China, on 31 December 2019—quickly erupted into a human crisis. In the past, respiratory outbreaks have been named without consideration of unintended negative impacts: like the "Swine Flu" and "Middle East Respiratory Syndrome". This resulted in the stigmatization of certain foods, communities or economic sectors. Similarly, the recent outbreak was referred to as the "Wuhan virus" or "China virus" on social media as well as by prominent leaders. A language that demeans can never be ethical.[1] This time, the World Health Organization (WHO) in February formally named the novel coronavirus COVID-19 to avoid stigmatizing a country or a particular group, and in March 2020, the COVID-19 outbreak was characterized a pandemic by the WHO.[2]

Family medicine ethics entails how family physicians routinely consider and assess concepts of better and worse in our everyday activities.[3] In a pandemic like COVID-19, the task of primary care teams becomes more challenging because of lockdown restrictions. The prominent bioethics institute Hastings Center has proposed 3 ethical duties for health care leaders as part of COVID-19 pandemic preparedness: (i) the duty to safeguard (supporting workers and protecting vulnerable populations), (ii) the duty to plan (managing uncertainty), and (iii) the duty to guide (contingency levels of care and crisis standards of care).[4] Using a disability rights prism and disability ethics framework, I discuss here how this pandemic affects the world's largest minority – people with chronic illnesses and disabilities.

Duty to safeguard (protecting vulnerable populations)

The disability viewpoint is fundamental for understanding and advancing social justice for everyone in the population; despite this fact, it is regularly dismissed by public health experts and policymakers. From the perspective of non-disabled people, the disabled community is considered a 'vulnerable' population, but this concept has been questioned by many disability studies scholars as it often overlooks relational and situational contexts.[5]

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Understanding of disability rights is central in an all-inclusive COVID-19 preparedness. The subsequent paragraph will delve on this issue.

Structural discrimination (ableism and ageism)

Tunzi and Ventres' four-step process for Family Medicine Ethics begins with identifying conflicts.[3] Each time a reporter introduces a tale about readiness by underlining that COVID-19 has generally impacted the older and the immunocompromised, it sends an unreasonable message that a few people's prosperity is more significant than that of every citizen, and it devalues the lives of the elderly and the disabled. Ageism is grounded in the possibility that one's age can be used as a proxy determination of skill and ability. It thus refers to prejudice and discrimination against older people. Similarly, Ableism is the assumption that all bodies and minds work in the same "normal" way.[6] This divide creates a false binary of normal and abnormal. This conflict is termed as structural discrimination. However, viruses don't discriminate based on ageism or ableism and everybody—whether it is a person with a disability or without one—can acquire this infection.

Equality and equity

Equity is providing everyone what they need to be healthy and informed. Equality is treating everyone the same and though it looks to adhere to the principle of fairness, it can only work if everyone has the same needs. This is certainly not true for disabled people as they have different needs specific to their disabilities. Many health care professionals (HCPs) say that they don't discriminate, yet much of the health education material and press briefings lack captioning or sign language interpreters, thus excluding the d/Deaf. The information barriers amplify such inequities for the disabled population,[7] which are bound to get exaggerated in the Global South which has 80% of people with disabilities out of which 70% live in rural areas.[8]

Equity appears unfair, but it actively moves everyone closer to 'flatten the curve' by providing a level playing field. The health advisories must be available in plain language (for intellectual disabled); in multiple formats, such as audio and large print (for visually impaired) and should also be available in an accessible format on the websites (communication disabilities). We need to engage in equitable practices to leave no one behind and provide health for all including rural areas.[9]

Disability culture

Ethics requires HCPs to be mindful of their patient's beliefs, values, and preferences. The WHO suggested social distancing as the policy to control the COVID-19 infection. There are additional considerations to implement this within the disability community. Most of the blind, deaf-blind, those affected by leprosy, limb deficiency, dependent on assistance cannot avoid touch. Those having spinal cord injuries and who depend extensively on caregivers struggle to practice self-isolation. HCPs need to understand such barriers and disabled people should work with family and caregivers to identify adaptations and embrace reasonable accommodations (see below). WHO has also come up with disability-inclusive COVID-19 considerations to mitigate these barriers.[10]

We need to understand the Deaf culture that many of the d/Deaf people can lip read but the opaque masks may hinder this communication which can be overcome by the use of transparent or clear masks. We need to ensure that all clinics, testing centres and hospitals providing quarantine facilities that are completely accessible for people with disabilities.

Moreover, the term 'social distancing' has a different connotation in a geographically diverse country like India which has had its share of grappling with untouchability amidst socially outcast Dalit communities and segregated people affected by leprosy in colonies and institutionalized people with intellectual disabilities. I advocate physical distancing over social distancing to mitigate the attitudinal barrier and to respect cultural preferences. We need to be socially connected and physically distant. A society is just and fair only when it does not vilify an impaired individual's 'reliance' through recognizing that everybody is interdependent.

Liberty and lockdown

Utilitarian principle (maximum benefit to maximum people) opens up a new challenge — that in circumstances, for example, a pandemic, a few people may legitimately be yielded for the benefit of the more noteworthy. It would profit society to acknowledge losses, the contention goes, to limit disturbance. The Rights of Persons with Disabilities Act (RPDA) 2016 includes three hematological disabilities – Thalassemia, Sickle cell disease, and Hemophilia. The lockdown, rather the *preventive detention,* has led to the cancellation of mass gatherings including blood donation drives. This has seriously affected thalassemia major patients who need one to three units of blood every month.

The principles of beneficence and non-maleficence may get strained for people with disabilities and chronic illnesses who depend entirely on caregivers. Lockdowns may mean that parents of children with intellectual disabilities and dual sensory impairments are no longer able to access allied healthcare for their children. Individuals with previous poor psychological wellness would require additional help during the quarantine. There seems to be a high pervasiveness of psychological distress in isolated health care workers.[11] Children and individuals with developmental disabilities (autism, down syndrome) struggle when their daily routines are disturbed. Caregivers are finding it difficult to get timely curfew e-passes and struggle to get clearances amidst jurisdiction disputes on borders.[12]

The government needs to ensure the implementation of service continuity. The meager financial pension assigned by the Ministry of Finance has yet to reach beneficiaries with disabilities plans. 'Doctors with Disabilities: Agents of Change' has urged the Ministry of Health and Social Justice to ensure targeted measures to be taken by the nine autonomous National Institutes on disabilities and the respective State Commissioners Disabilities who are the grievance redressal officer in this pandemic.[13]

Disability accommodations

The silver lining of this pandemic has been the acceptance of a long time demand by people with disabilities and chronic illness for telecommuting. Able-bodied people are now realizing that remote work is an accommodation, not a self-centered preference, and it adds to a diverse workforce inclusive of people with varied disabilities making reasonable accommodation the new normal.

Duty to safeguard (supporting health professionals with disabilities)

Disability identity

The American Medical Association avoids proposing an obligation however all things considered calls for doctors to "apply [their] knowledge and skills when needed though doing so may put [them] at risk".[14] As per the American Nurses Association, for instance, nurses are committed to giving care in specific conditions (crisis not noted), yet they likewise have obligations to themselves, in particular, to protect their uprightness and wellbeing.[15] The SARS outbreak in 2003 was quickly contained but as per WHO, 20 percent of all persons known to have been infected with SARS were health care workers.[16]

Quite often people forget that people with disabilities are not always patients, but they may be providers too. There are many doctors and nurses with disabilities who are working at the frontline in this pandemic with their perseverance and resilience and the face of significant risks to themselves.[17] Taking care of ourselves and our associates has never been more crucial; 'we should give ourselves authorization to change "the patient first" account to "the patient always…yet not always first'.[18] Justifying a duty to treat must be balanced with preserving one's own life which becomes more complicated in COVID-19.

Reciprocity

The society has to support those who assume disproportionate burdens to protect public health in a pandemic. States and policymakers are accountable for the reciprocal social obligations which include the provision of Personal Protective Equipment (PPE); guarantees of care for HCPs who become ill; and adequate insurance for HCPs who die in the line of duty. Surging global demand and especially panic buying and stockpiling has resulted in shortages of PPE globally, thereby affecting the current availability to HCPs. Possible ways to minimize the need for PPE is to consider restricting HCPs with mobility disabilities if they are not involved in direct patient care or are working in non-healthcare or pre/para clinical settings. They could instead be deployed in tele-health to evaluate suspected cases of COVID-19. The proper use of resource allocation becomes paramount in COVID-19 which necessitates a restricted workforce so that the remaining HCPs are self-quarantined until they have to take over the charge to relieve the first responders. Such rotations can preserve valuable PPEs.

Veracity (truth-telling) and autonomy

The pandemic preparedness needs to represent the population they serve. Under this wider principle, the incorporation of HCPs with disabilities could help advance the consideration of patients with disabilities and their nuanced needs.[19] They too commit to being completely forthright and open about their condition, capacities and constraints. While not obliged to unveil the details of the specific condition to everybody, an HCP with a disability should share sufficient information with the hospital so that the administration can provide necessary accommodations as per RPDA to meet the particular expert abilities.

The Department of Personnel and Training has issued a circular exempting employee with disabilities in essential services in the wake of COVID-19. I discourage blanket exemption as many want to serve and this option must be discussed with them in advance (respect for autonomy) while weighing between the duty to care versus duty to self-protect. However, HCPs with locomotor disabilities may be exempted while performing aerosol-generating procedures if their underlying medical conditions interfere with that. The work restriction and sick leave/commute leave policies for HCPs with disabilities should be non-punitive, flexible, and consistent with disability accommodations as per RPDA.

Duty to plan (Managing uncertainties) and the duty to guide (crisis standards of care)

As emerging infectious disease outbreaks transform into pandemics, the focus shifts from patient-centered care to public health care influenced by utilitarianism. Discrimination against people with disabilities creeps easily into such medical decision-making because of deficit-based perspectives (medical model of disability).[8] As an example, what medical literature perceives as 'hearing loss' is proudly embraced as 'Deaf gain' in Deaf culture.[20]

Resource allocations

It is unethical to use stereotypes about an individual's disability to ration care, like weighing a patient's "worth" based on the presence or absence of disabilities. Choices by establishments concerning whether an individual is a possibility for life-saving treatment ought to be founded on an individualized evaluation of the patient using the best available clinical evidence.

There have been moral issues with the utilization of the Quality-adjusted life years (QALYs) in triage protocols since they were first imagined.[21] Disability ethics identifies 3 essential moral protests: (i) that disability may not decrease personal satisfaction; (ii) that QALYs oppress individuals with disabilities; (iii) that QALYs neglect to represent contrasts between what patients with a similar condition value.

Pessimistic predispositions and off-base presumptions about the quality of life of an individual with a disability are inescapable in our society and can bring about the debasement of and disparate treatment of individuals with disabilities. Many HCPs fundamentally underestimate the value of existence with a disability. They regularly imagine individuals with disabilities to have low QALYs when most report a high caliber of life and level of joy, particularly when they have adequate support. This misperception has adversely impacted doctors' medical futility decisions to withhold or withdraw medical care.

Medical rationing

Discrimination based on disability was alleged in the four states of Washington, Alabama, Kansas and Tennessee in the US.[22] Reports suggest medical rationing programs are discriminating against people based on having an intellectual disability, advanced neuromuscular disease, cystic fibrosis, and traumatic brain injury. Accordingly, the U.S. Department of Health and Human Services' Office for Civil Rights in Action had given a release citing federal law that prohibits discrimination.[23]

Crisis standards of care

We must not forget that anti-discriminatory disability legislation (RPDA) applies to all medical healthcare decisions. Section 3 (3) of RPDA warns against discrimination based on disability. HCPs frequently think little of both the quality of life of individuals with disabilities and the prognosis in terms of the number of years yet to be lived by their patients who have disabilities.

Disability justice

An individual with a disability, similar to one who is non-disabled, need not have to demonstrate that they lead "commendable" lives or will "contribute" to society to get life-saving or life-continuing consideration. Disability ethics emphasizes the paramount value of each human life and their inherent dignity. Triage protocol committees and disaster risk reduction working groups should explicitly recruit people with disabilities and chronic illnesses in their response strategies. DeBruin *et al.* also suggest a similar practical social equity approach addressing both health disparities and access barriers, in consultation with at-risk communities to shape pandemic preparedness.[24]

Beginning in 1972, the pioneer ethicist Mark Siegler at the University of Chicago created, named, developed and led the new field of Clinical Medical Ethics and pioneered Clinical Ethics Consultations (CECs) to assist patients, families, physicians, and the health team.[25] In the Indian subcontinent, formal CECs are still missing in a majority of healthcare institutions.[26] Where present, the procedures typically do not reflect disability diversity, and the groups seldom include disability ethicists. Perhaps, this deficiency compelled the creation of Central and State Committees for Research for Disabilities under RPDA. These committees are over and above the Institutional Ethics Committees, and the legislation had made it mandatory that half the members should be from the five specified disability categories. Unfortunately, to date, neither the Centre nor states (with the sole exception of Delhi) has constituted such committees.[27]

In 2018, the Supreme Court of India, in its landmark decision recognized the right to die with dignity as part of the fundamental right to life and also gave legal recognition to advance directives.[28] If an individual with (or without) disability wishes to make an advance directive in this pandemic, it will have to be executed before a judicial magistrate of the first class which is impractical in the current scenario. Moreover, the three-tier process that the apex court has put in place before life-sustaining treatment can be withheld or withdrawn involves multiple boards which makes the end-of-life care process cumbersome.[28]

Conclusion

Pandemics are a period of greater uncertainties that require equally swift action to embed ethics in all the decision-making processes. The principle of solidarity justifies efforts to overcome health inequities by protecting the rights of the most marginalized. The emerging field of disability ethics can help policymakers in employing anti-discriminatory approaches to value disabled lives in triage. Disability identity (of HCPs with disabilities), disability culture of different categories of disabilities and understanding of disability competencies can make HCPs improve their understanding of the value of life with a disability. Disability ethics can reform medical rationing by removing prejudices and safeguarding fair protection of the interests of all patients, including those with a disability.

Key Messages

Disability ethics can help healthcare professionals in understanding ethical dilemmas pertaining to people with disabilities in Coronavirus pandemic. Triage policies should be non-discriminatory based on equity and justice. Reasonable accommodation is the new normal.

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