**Current Controversy / Short Communication**

**Why a new ethical framework is needed to eliminate disability discrimination? A new learning from the pandemic.**

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**Abstract:**

Discrimination between disabled and non-disabled people is still an issue of unfairness. In this COVID-19 pandemic time this issue highlighted in a significant way. In the hospital, the disabled are faced today by triage questions like - do we (disables) have the right to get the ventilator first when there is limited ventilation support? Or, is their vulnerability could be the cause to treat them neglect? Or, due to their disability, does it mean that - he does not have a quality of life? There are lots of ethical dilemmas that we faced today and these are not solvable by the existing framework or policies. The existing paternalism, utilitarianism, or even ableism can not ensure us today to make people living with disabilities (PLWD) rights equal. It is now clear that the policy or the framework that we have, has a great gap based on ethical decision making. This paper focuses the emergency on ethics based - research, policy directions, and frameworks to eliminate the discrimination.

**Keyword:** Disability Ethics, Pandemic Ethics, COVID-19, Healthcare Policy, Disability Discrimination.

**Ethical Dilemmas:**

[1]

COVID-19 pandemic raises a myriad of ethical dilemmas. Among these dilemmas, Bramble 2020 mentioned 8 major ethical questions - (1) question on lockdown, (2) who is morally blame to COVID-19, (3) question about immunity passport, (4) Question on mask, (5) question on moral duties, (6) question on vaccine trial, (7) triage question & (8) question on living the life.1 From these important questions, number seven (7) is very relevant to think about the rights and facilities for pandemic healthcare. He asked if all of the life-saving resources (e.g - ventilator, ICU bed, etc) of the hospital have to run out, who should get their first use? If it could be the issue of disability then this problem faces a major challenge to eliminate discrimination. Now it is clear that this triage problem increases the disability discrimination instead of elimination and even if the solution is asked to the bioethicist - how would we be satisfied in this disability triage critics, they have no easy answer yet.2

[2]

Michael Hickson, a quadriplegic patient tested positive for COVID-19 in early June in Austin, Texas. He was admitted to the St. David’s South Austin Medical Center from a nursing home. Eventually, the hospital stopped treating him. Cause? The doctor said the man has no “quality of life”. A recorded conversation explains that - Doctor asked “will it (treatment) affect his quality, will it (treatment) improve his quality of life? And the answer is no”. The patient already died. The patient’s wife asked - Does it mean that he’s paralyzed with a brain injury, so he doesn’t have the quality of life? The doctor said - “Correct”.3 So, there is another ethical question on that perspective and that is - If someone is disabled (paralyzed), does it mean that - he does not have a quality of life?

[3]

In Nepal, A wheelchair user disable was died after he was suspected as COVID positive in the southern Chitwan district. When he was admitted into a local hospital, there were no wheelchair-friendly healthcare facilities which may cause his death as stated by the German public international broadcaster Deutsche Welle.4 The lack of adequate facilities makes them vulnerable and if it is, then could we say that this vulnerability is intentionally man-made?

[4]

As stated by the BBC, 22-year-old Ginny was a wheelchair needed girl who needed a supporter or assistant to conduct her daily life. If her assistant became COVID positive in any case, it would be a very complicated situation for her. She had a ventilated tracheotomy and she was very anxious due to the lockdown for “zero guidance” if her assistant became ill or isolated. As a people living with disability (PLWD), Ginny has 11 times more likely to die than her peers due to this COVID pandemic.5 What should we do to eliminate this discrimination here?

**Argumentation:**

There are more than 1 billion disabled people in the world. In only the UK two-third of COVID, deaths have occurred within the disabled community, stated by the BBC.5 We may notice now, in the civilized world people living with disability (PLWD) are faced with a lot of discrimination like the upper [1], [2], [3], and [4].

When a pandemic has a great risk and it is more dangerous, the inequalities in the healthcare sector acts as a mediator to enhance public health discrimination. People living with disabilities (PLWD) faced discrimination and some of them also faced unfairness by medical professionals.6 To achieve universal health coverage when it is important to maintain global health commitment, 80% of people living with disabilities (PLWD) from the low-income and middle-income countries faced a limited capacity to respond with the COVID-19. And in this way, the risk of increased mobility and mortality is growing up. According to a newly published paper in the lancet public health, Richard Armitage from the University of Nottingham, Stated that three issues make PLWD more vulnerable - (1) inequities to access public health messaging, (2) disruption of the physical distancing, and self-isolation, and (3) increasing risk of COVID-19, and the additional barrier to get healthcare facilities.7

The debate here makes a few dilemmas between people with chronic conditions and disabilities. The triage question is - who would particularly be vulnerable to get healthcare (ventilator) first? The COVID-19 pandemic has now untold suffering among all aspects of human lives. Disabled people are 42% more likely to have poor health and, therefore, they are extremely vulnerable to the virus. According to the WHO, people with disabilities have a high risk due to their difficulty to enter the hospital or clinics, difficulty to maintain social distance, problem to gather updated Infos, and for the problem to touch anything. So, how can we measure who will get healthcare first?

According to the Equity Act 2010, it is unfair to create discrimination with the people living with disabilities (PLWD). Though the disability rights movement, the disability discrimination legislation, and the UN convention on the rights of persons with disabilities change the perception of the disability, there is another perception between the difference of disability rights and human rights. And now the healthcare priority is seemingly an issue about rights. According to the UN convention, the disability right is not so specific an issue or different than the human right. They all are the citizens and have a similar right as human rights e.g- rehabilitation, healthcare, live into the community, and the right to have a say about their own healthcare facilities. Like every human being, people living with disabilities also need the same healthcare and treatments.8 So when the disability comes in front, why this question arises - who will get the healthcare (e.g ventilator) first? To eliminate these disparities the concept of the “medical model” or later the “social model” legitimate medical paternalism.8 But is it suitable to make this answer ethical?

On The other hand, for the fair distribution of all facilities, there is a problem to decide what we have to do? Based on the 40 years of philosophical and academic observation by the scholars now in the field of disability Reynolds, 2018, stated that the 3 core insights from disability theory - “assumptions about the quality of life, the problem of ableism, and the distinction between disability, disease, and illness”.9 When medical rationing and disability justice is an essential element, ableism is one of the major causes of discrimination, unfair costing, and affect to determine the good health of people with disabilities today.10 “This form of systemic oppression leads to people and society determining who is valuable or worthy based on people’s appearance and/or their ability to satisfactorily produce, excel and ‘behave,’ stated by Talila A. Lewis.11 So to make the proper framework, to decrease the devaluation of the peoples living with disabilities, “ableism” has a question mark and the question is - is it really working?

Thirdly among the three philosophical approaches (Utilitarianism, Liberalism & Communitarianism) utilitarianism is the most important public health discourse and a standard among the policymakers and the practitioners. According to Beauchamp and Childress Utilitarianism is one of the ethical theories also that help to make a final decision based on their ultimate ends and consequences and it is the best-known oft-ed used theories for the medical and nursing ethics.12 So, could it be confirmed to eliminate the discrimination of the public health issues of the disabilities?

All of these models or frameworks come across as a bit well done but the issue of arguing is why still discrimination is happen? Medical paternalism is like a tendency of a physician that determines patients' wishes or choices should not be honored. So it makes a patient surrogate-decision-maker and disvalues their autonomy.13 But according to Bassford, medical paternalism is only considered when utilitarian considerations apply and don't violate any personal rights.14 But unfortunately, Roger Severino, the director of the Office for Civil Rights at the U.S. Department of Health and Human Services warned that “Medical providers must not engage in “ruthless utilitarianism” in deciding who gets life-saving treatment for the coronavirus”.15 He claimed by the name of utilitarianism, disables and old people should not be put at the end of the line for healthcare facilities in this pandemic emergency.15 So if we think or judge paternalism or utilitarianism or anything other else is an appropriate medical or social model or framework to eliminate the discrimination, then how can we overcome from being ableism? As stated by Leah Smith -

*“Ableism is a set of beliefs or practices that devalue and discriminate against people with physical, intellectual, or psychiatric disabilities and often rests on the assumption that disabled people need to be ‘fixed’ in one form or the other. Ableism is intertwined in our culture, due to many limiting beliefs about what disability does or does not mean, how able-bodied people learn to treat people with disabilities and how we are often not included at the table for key decisions.”*16

Leah Smith says to de-root this ableism it is essential to set up and fix that there is always a seat at the table for both of you and those who are not like you, and it is also considered to judge our treating procedure when a person with disabilities once seated at the table. So, ableism raises the assumption that the able bodies are more superior than the non-able or abnormal bodies. Oppositely the other issue of injustice could occur if disabilities are over medicalized.8

**Conclusion:**

Though there are lots of frameworks still now even then the rising ethical problems in this paper can’t be solved by these existing frameworks and policies that we had. To eliminate the disparities we recommend further ethical based research, policy directions, and ethical framework to decrease the health inequalities for individuals with disabilities which will help to strengthen health and human services workforce capacity and ensure inclusive disability for the future pandemic and economy.

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