

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 fairness and justice. In this COVID-19 pandemic time, this issue highlighted in a significant way. In hospital, the disabled persons to face today issues while triage like whether they have the right to get the ventilator first when there is limited ventilation support or their vulnerability could be the cause for being neglect or they do not have to have a quality of life. There are lots of ethical dilemmas that we face today and these are not solvable overnight by the existing framework or policies. The existing paternalism, utilitarianism, or even ableism can not ensure making people living with disabilities (PLWD) rights equal. It is very clear that the professional expertise, policy or framework have so many loop holes that we are still struggling to take steps to effective and ethical decision making. This paper focuses the emergency of ethics based research, policy directions, and frameworks to eliminate those discriminations.

Keywords: Disability Ethics, Pandemic Ethics, COVID-19, Healthcare Policy, People Living with Disabilities (PLWD), Disability Discrimination.

Introduction: The World Bank reported that one billion (15% of the world's population), experience some form of disability where 110 million to 190 million people experience significant Disabilities¹. If we think there are two categories of people on this earth - disabled and non-disabled, do we wrong to categories human beings? Or, if we think that how could we decide “who’s life is worth living” among them, do we wrong? We will see some real-life examples of those circumstances in this paper below. If we start our practice depending on these answers how could we maintain all the healthcare principles &

ethics like autonomy, nonmaleficence, beneficence, and justice?

The 3 ethical duties in this corona crisis for the healthcare leaders, proposed by the eminent bioethics institute Hasting Center, are - i) the duty to safeguard; iii) the duty to plan and iii) the duty to guide². When we have a lot of problems and dilemmas on our existing ethical frameworks and policies, then how could we maintain our duties to manage the principles? If we skip to give the concern on that point and treat the disabled as normal people, then it creates unfairness. Because a normal person can use the stairs, but the wheelchair-needed disable person can’t. On the other hand, if

we think they are different from the able-bodied people, then equality, equity & rights are questioned. This issue also creates a false binary to think about which one is normal and which one is abnormal². On the other hand when a senior disabled patient and a junior disabled patient come at the same time for the same treatment, who should get the priority? The issue of ableism (discrimination in favor of able-bodied people) and ageism (discrimination on the basis of age) creates a conflict on these points termed as structural discrimination².

If we are so strict to follow the duties and legislature that we have the concept of utilitarianism and deontology raises a myriad of ethical dilemmas which again make questions on the basic moral principles. If the policies and frameworks only considered the able-bodied then it is to deny the statement of the 2030 Agenda for Sustainable Development, where it is clearly stated that the “disability cannot be a reason or criteria for lack of access to development, programming and realization of human rights”¹.

Besides this utility and duty-based ethics (utilitarianism & deontology), there is another issue about medical paternalism that could hamper the doctor-patient relationship. Instead of getting the solution, it is defined as a problem indeed. According to the Encyclopedia of Applied Ethics (2012) “Paternalism is a problem, however, when interference with clients goes beyond what is absolutely necessary or is used as camouflage for actions that are motivated by other interests”³.

Today, It is very clear that the professional expertise, policy, or framework have so many loopholes that we are still struggling to take steps to effective and ethical decision making. This paper focuses on the emergency of ethics based research, policy directions, and frameworks to eliminate these discriminations. Our aim is to understand why we need to develop our existing ethical framework and infrastructure and focus on the emergency of ethics based research, policy directions, and frameworks to eliminate these disparities.

Methodology: This is a current controversy or short communication-based paper related to the COVID-19 pandemic crisis. It is not a biostatistical based study but an ethical based case study and investigation. It does not collect any data from the patients or any other respondents, and that's why informed consent is not necessarily important for this account. In this article, two patients' names are mentioned directly as “Michael Hickson” and “22-year-old Ginny” in the case section number [2] and [4] below, where their info's we just collected from the authentic press/media reports that we already cited in our article. We did not use any scale but we make arguments based on the very established bioethical theories like - utilitarianism, paternalism, and ableism. To make the citations & bibliography we use Mendeley software.

Ethical Dilemmas:

[Case 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 life⁴. 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 yet⁵.

[Case 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"⁶. 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?

[Case 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 Welle⁷. The lack of adequate facilities makes them vulnerable and if it is, then could we say that this vulnerability is intentionally man-made?

[Case 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 pandemic⁸. What should we do to eliminate this discrimination here?

[Case 5]: Study says people with intellectual and developmental disabilities (IDD) has a high risk of sever outcomes from COVID-19⁹. According to FAIR Health study, people with intellectual disabilities and developmental disorders are 3 times more likely to die if they have COVID-19, compared with others. It does not end, people with related conditions like down syndrome and other chromosomal anomalies and congenital conditions like microcephaly have also the risk. Director of medical ethics at the New York University Grossman School of Medicine, Arthur Caplan commented "There is no

question....These people are high risk and must be given priority for vaccination”¹⁰. But Who here? And Who cares? When, We have a gap into our guidelines and policy making for immunization¹¹. This is the point to raise the question - how could we distribute vaccines for the greatest good for the greatest number?

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 BBC⁸. Now it is very common and we all know by heart that washing hands frequently and maintaining 6 feet of physical distance prevents SARS-CoV-2 contamination, but is it disable friendly? Hand washing and physical distancing are not always possible or sometimes impossible for the peoples living with disabilities¹². When we need to take immediate response for an immediate situation we are not ready to create disable friendly policy and infrastructure compared to the non-disabled. 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], [4] and [5] cases.

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 professionals¹³. 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. In a recently published paper in the *Lancet Public Health*, Richard Armitage from 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 facilities¹⁴.

The debate also have raised a few dilemmas between people with chronic conditions and disabilities. A burning question about the triage process is who particularly will be treated as more vulnerable to get emergency healthcare (e.g. ventilator) first and why. 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 information, and for the problem to touch anything¹⁵. Hence, it is difficult and sensitive to measure who will get the healthcare first.

According to the Equality Act 2010, it is unfair to create discrimination with the people living with disabilities (PLWD)¹⁶. 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 treatments¹⁷. 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 paternalism¹⁷. But is it suitable to make this answer ethical?

On the other hand, for the fair distribution of all facilities, there are still several dilemmas to decide what we should do in terms of best interest of the patient, scarce hospital resources and most perceived benefit of the society. Based on the 40 years of philosophical and academic observations by the scholars in the field of disability, Reynolds 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”¹⁸. 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 today¹⁹. “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”. as stated by Talila A. Lewis²⁰. 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 whether it is 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-used theories for the medical and nursing ethics²¹. So, could it be confirmed to eliminate the discrimination of the public health issues of the disabilities?

All of these models or frameworks have proved their effectiveness in different settings and context; however, the issue of argument is based on the fact that still discrimination is happening in situ. 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 autonomy²². However, according to Bassford, “ medical paternalism is only considered when utilitarian considerations apply and don't violate any personal rights”²³. 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”²⁴. 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 emergency²⁴. Hence, 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”²⁵.

Leah Smith says that 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. Therefore, 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 medicalized¹⁷.

Conclusion: Though there are lots of frameworks are available to date, the rising ethical issues as discussed in this paper can not be solved. To eliminate the disparities, we recommend further ethics based research, policy directions, and ethical framework to decrease the health inequalities for individuals with disabilities, which will also help to

strengthen health and human service, its workforce capacity and ensure inclusive environment for people living with disability for future pandemic and economy of the country.

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