**Personal Perspective:**

**Title: Ableism in Healthcare**

**Abstract**:

Healthcare is, by and large, considered a benevolent and humane field of care. However, the perception on benevolence can imply a patriarchal and avuncular approach to the interests of the patient. While this is an important part of the therapeutic relationship, it can also contribute to ableism in health care practice and research.

In this personal perspective, the authors draw upon their personal experiences as providers and consumers of healthcare and experiences with the identity of disability to draw attention to the wide ranging application of ableism in healthcare. This ranges from the ableist nature of the clinical consultation, to medical equipment that is built for the abled, to assumptions about the quality of life of persons living with a disability. Ableism through healthcare is influenced by and feeds back into the societal perception of the disabled as “defective” people. These biases also reach then, into health education, medical training, policy making and legislation.

Based upon these experiences of ableism, we provide recommendations and suggestions on how healthcare can diversify, empower and destigmatise the discourse around disability and ableism. We advocate for incorporation of persons with disability and a respect for their lived experiences in healthcare delivery and public health policies as a part of the health for all movement.

**Manuscript:**

**Medicine and Concepts of Disability:**

The realm of medicine is considered a benevolent and humane terrain where all human lives are valued equally without any bias or discrimination. Human equality is one of the key ideals of medicine. Medical ethics, in practice and research are founded on the ideals beneficence, non-maleficence, respect for autonomy and justice. The therapeutic relationship between doctor and patient is recommended to be based upon client centered principles of empathy, authenticity and non-contingent positive regard.

However, healthcare professionals come from the community and they too are vulnerable to societal prejudices and biases that dominate understandings about groups of people perceived to be “the others” or an “outgroup” or “outlier”.

Galli et al, in 2015, noted that irrespective of their personal goals, ideologies, intentions and normative expectations, even medical professionals have hidden and concealed biases that affect the treatment processes and outcomes. [1] Society associates disability with vulnerability and low competence and thus treat the members of this group differently. As a result, disabled people continue to experience discrimination and devaluation based on their disabilities. [2]

Campbell, in 2001, defined ableism as “a network of beliefs, processes and practices that produces a particular kind of self and body that is projected as the perfect species –typical and therefore essential and fully human. Disability then, is cast as a diminished state of being human.” [3]

This early medical model of disability reduced disability to a set of individual deficits. It acted to rationalize a paternalistic view in medicine. However, this model is now being increasingly substituted by a “social model” which sheds light on structural issues like the societal barriers and biases that surround the notion of disability and lead to exclusion of the people with disabilities.

**Ableism in Health Care:**

For years, the healthcare sector appeared bound by the chains of predominant ableism among other problems of inequality such as - poverty, casteism and racism. In India, an economically deprived individual with a disability is seen with sympathy rather than empathy. This view delivers care but also deprives the person with disability of agency and autonomy. Further, ableism is associated with subtle tones of privilege. In the healthcare, an economically underprivileged person with a long-term disability is often be considered as a “bed blocker” or a drain on resources which may be better used for the acutely ill.

A classic example of ableism in infrastructure is that of a patient on a wheelchair. They enter the consulting room of a physician and they need to use a weighing machine, but cannot. Most weighing machines are not designed to accommodate a person with locomotor disability. There are many such structural barriers limiting independence and inclusion in society, too. Is it too much to ask for? Why is disability still seen as a source of stigma in India and rather than a part of one’s identity to be accepted, assimilated and appreciated, much like our other abilities.

**Ableism in Health Education:**

Education is advocated to solve several societal ails. However, education may not be enough in the absence of compassion, respect and understanding for the lived experience of persons with disability. Even parents from higher socio economic strata often think of their children with disabilities as projects to be “fixed” or “cured” rather than to be raised with self-respect and compassion. We may do better to understand that disability is not a problem to be “healed by” or “prayed over” by a “baba” but an identity and marker of resilience to take pride in.

These social mores influence healthcare’s outlook on health, ableism and disability – contributing to the belief that a person with disability will always, somehow, be less then whole and able. Initiatives to improve health knowledge, education and practices in society delivered within this ableist framework of healthcare talk about helping the person with disability and advocate inclusivity, which is commendable. However, an emphasis on equality and respect for identity, autonomy and agency is often overlooked.

**Ableism in Health Technology:**

Health care technology is an important component of progress in care. Telemedicine provides an important interface between doctors and patients, even in remote area. Mobile phone applications help us monitor and regulate our healthcare and reach out to healthcare professionals. However, this form of progress too, is far from inclusive. Digital medicine has played an important part of our response to the novel coronavirus pandemic. Yes, recorded advisories during calls, text messages, mobile phone based applications (such as Arogya Setu), masks and social physical distancing place persons with visual and hearing impairment at a disadvantage and place a barrier to health information and care seeking.

**Ableism in Health Insurance:**

Another significant challenge for persons with disability is applying for insurance. No retail healthcare policy in India offers coverage for congenital defects. The experience of persons with non-congential disability who seek health insurance coverage too is usually discriminatory and humiliating. They are asked to prove both the nature of their disability and that they will not be a liability to the insurance company – an odd paradox.

**Relationship to perceived Quality of Life:**

Healthcare also assumes that persons with disabilities have a lower quality of life than those without disability. This influences the treatment plan and objectives. The field of medicine consist of a majority of clinicians who are non-disabled. This is associated with the risk of bias, with many clinicians mischaracterize the quality of life of people with disabilities. [4] While disability is often associated with distress, it may not always be so. Many persons with disability often lead as rich and fulfilling a life as those without a disability. People with disability have the right to be engaged in a collaborative discussion about their expectations from treatment, rather than have their treatment needs assumed.

For instance, a person diagnosed with a physical disability might be told by their physician or a specialist that they must prepare themselves with a life characterized by tremendous pain, loss and impairment of everyday functionality. This information is not necessarily wrong. However, it does both the clinician and patient a disservice by focusing only on the negatives. Such sort of an assumption is debilitating for an individual. Even for those with a good prognosis, the emphasis is often on ordeals of transition in abilities while overlooking the possibility of creation of new and different abilities and skill sets, which can lead to newer forms of growth.

**Internalization and Systematization of Ableism:**

Disability activists and scholars often argue that internalization of prejudicial and discriminatory beliefs prevalent in the society play a greater role in decreasing the quality of life rather than their functional and physical impairments. [5] This has parallels in the social appraisal theory in psychological science, where it is the appraisal of the event, rather than the event itself, which determines the stress and trauma the individual is subject to.

From inaccessible infrastructure and communication to exclusionary employment policies, society harbours stigmatizing attitudes towards the disabled which lead to their systemic exclusion and oppression. The recent proposal to modify some sections of the Rights of Persons with Disabilities Act (2016) in India, which was withdrawn after widespread civil protests is an example of this.

Jeffrey Martin has noted a similar and pertinent conundrum while carrying out research pertaining to Health Related Quality Of Life (HRQL). [6] A number of measures of quality of life confound health and function, giving rise to a widely held ableist notion that people with disabilities or functional impairments do not have very health and fulfilling lives.

**Need to cure or fix:**

Such erroneous judgments about the quality of life encountered by people with disabilities can result in treatment options for people with disabilities being either limited, or altogether eliminated. Central to such clinical (mis) judgements is the basic “ableist conflation”. As Joel Reynolds, a disability scholar points out, this conflation merely reduces disability to suffering, pain, disadvantage and morbidities. [7]

Health practitioners often view disability as a malady or a disease which needs to be “cured.” This stereotype can be particularly very damaging and insensitive. A pragmatic instance of this can be seen when a person who uses a wheelchair goes to the physician to get a common cold treated. The physician often assumes that they want some “remedy” for their disability, based on a visual appraisal, even before the consultation has begun. The person may be truly comfortable with their identity and just want the cold treated, but have to face the challenge of explanation. Such assumptions may affect the rapport that the person forms with the physician.

**Acceptance and Empowerment of Identity:**

Many people do not experience a lot of pain and suffering as a consequence of their disability and not everyone with a disability has a disease or an illness any longer. One can be disabled as well as a completely healthy individual. It is not an anomaly to be a healthy person with disability. With growing awareness, several people believe that their disabled identities are meant to be celebrated and accepted. People are evolving and getting increasingly comfortable with their disabilities. They may not wish for a change in identity. Such diverse experiences are evocative of social dimensions of disability and its multifaceted nature than merely being a “fact” of a person’s physicality.

**How can health care change the dialogue around disability?**

Healthcare practitioners may do well to recognize persons with disabilities as autonomous individuals who have control and authority over their life and who are entitled to make their own decisions independently. They can acknowledge persons with disabilities as experts in their own lives and experiences in the community. Medical professionals are important as potential allies and advocates. They can serve to amplify the voices of persons with disabilities. Many times, claims and opinions of the people with disability are not taken seriously or are dismissed in public policy making. [8] This marginalization is worsened in contexts where a non-disabled individual with no lived experiences of a disability is placed in the position of expertise such as a welfare board. Representation in decision making and administration is an important step towards inclusivity. The Mental Health Care Act has recognized this by emphasizing the requirement for two persons with mental illness or their caregivers to be part of the Mental Health Review Board.

The field of medicine can also help propagate the ideas of disability humility. This refers to learning about the culture, histories and experiences of disabilities. It also involves recognizing that one’s knowledge and understanding of disability maybe incomplete in the absence of lived experience. A deficit of this recognition may often influence judgments and actions.

Medical practitioners are also accountable for a better and more empathetic communication with and about their patients with disability. Instilling the spirit of disability humility among the practitioners can enhance the quality of interactions that the practitioners have with their patients with disability. It can enable healthcare professionals to see the situation from the perspective of their patients with disability. [9]

Also, healthcare professionals are requested to realize the impetus of holding direct communications with their patients with disability instead of interacting with their caregivers, parents, family members or other proxies. They can look for better and sensitive approaches to interact with the patients with sensory impairments, intellectual disabilities rather than forsake communication.

Having an experience in relating to people with mental health conditions is another, often neglected, priority. Research shows that failure to communicate in appropriate formats affects the therapeutic alliance, adherence to treatment, prognosis and outcomes.

Terminology/Jargon are both pertinent and sensitive. It can be guided by the choices and preferences of persons from the disabled community. Some might prefer to be known as a “disabled individual” thus identifying with their disability and conveying that they are considered disabled by the society. Others may prefer to be called person with disability, suggesting that disability forms just a fraction of their identity and that they are people first. However, no one usually prefers to be identified by their medical condition. For instance, referring to a person as “the quadriplegic” or the “cerebral palsy” is dehumanizing. Just as a survivor of sexual violence would not wish to be defined forever on the basis of their trauma alone, so too, every person with disability would wish to be seen as a person, rather than a disability. The essence lies in respecting the wishes and choices of the individual and recognize and reflect on our tendency to make assumptions that are often arbitrary.

Home visits to patients with disabilities can be inculcated as an important clinical practice in rehabilitation education. It can help medical students and professionals understand the context and the environment of the disabled people and acknowledge their capabilities. Positive results have been attained when paediatric residents have spent more time with families of children with disabilities. Additionally, participating in circles or disability peer groups enables the medical trainees and practitioners to understand the perspectives of the people with disability and the social milieu in which they live and grow. [10]

Learning alongside a peer who is disabled can be enriching for both the able and the person with disability. There can be initiatives to encourage more people with disabilities to join the health care services. A study by French reported out that irrespective of the hurdles they face, many disabled healthcare practitioners believed that they had an added advantage in the opportunity to improve their ability to empathize. They also found it improved the quality of rapport between the clinician and the client, since a lived experience was communicated across the therapeutic alliance. [11]

Medical education would benefit from greater inclusivity and welcoming of diversity. Opportunities work best when they are both accessible and empowering. It needs to be recognized that students and professionals with disabilities may have some special needs during training including improved access to multi-story teaching centres and multi-modal education strategies.

Healthcare professionals with disability have expressed distress at a reluctance to include them as frontline workers during the COVID-19 pandemic, even when fit and able to deliver essential care, due to a tendency to be appraised on the basis of their disability alone, rather than skill sets. Facilities for quarantine and isolation of those exposed often do not take into consideration disabilities – such as a doctor with locomotor disability being asked to quarantine on the third floor of a hospital building without access to an elevator, as was reported recently.

**Conclusion:**

Ableism clouds perspectives and sets ideals of “should’ve been” and “could’ve been”, similar to the “musterbation” delineated by Rational Emotive Behaviour Therapy (REBT). It sets limitations on human abilities. However, society would benefit from the realization that a construct as diverse as skill sets and abilities cannot be divided or fathomed into discrete categories. Abilities can be conceptualized, instead, as lying on a spectrum. Ableism not only harms the disabled but also establishes standards of worth for the able as well. Communication, respect and inclusivity benefits all of us and helps us all grow together. This, while the world is struggling to address the largest healthcare crisis seen in recent years (the long term implications of which are to be seen), is more important than ever before.

**Footnote:**

The first author is a mental health student and a person with disability. The second author is a mental health professional. Both are advocates against ableism and the perspective is influenced by these views.

**References:**

1. Galli G, Lenggenhager B, Scivoletto G, et al. ‘Don’t look at my wheelchair!’ The plasticity of longlasting prejudice. Med Educ 2015;49:1239–47.

2. Janz, Heidi. Ableism: the undiagnosed malady afflicting medicine. Canadian Medical Association Journal. 191. E478-E479. (10.1503/cmaj.180903.

3. Campbell FK. Inciting legal fictions: disability’s date with ontology and the ableist body of the law. Griffith Law Rev 2001;10:42–62.

4. Kothari S, Kirschner KL. Abandoning the golden rule: the problem with “putting ourselves in the patient’s place”. Top Stroke Rehabil 2006;13: 68–73.

5. World Health Organization; World Bank. World Report on Disability. Geneva, Switzerland: World Health Organization; 2011. https://www.unicef.org/spanish/protection/World\_report\_on\_disability\_eng.pdf.

6. Martin JJ. People with disabilities and quality of life: the role of physical activity. In: Mitchell L, editor. Physical disabilities: perspectives, risk factors, and quality of Life. New York: Nova Science Publishers;2017:1–15.

7. Reynolds JM “I’d rather be dead than disabled” — the ableist conflation and the meanings of disability”. Rev Comm 2017;17:149–63.

8. Smith DL. Disparities in patient-physician communication for persons with a disability from the 2006 Medical Expenditure Panel Survey (MEPS). Disabil Health J. 2009;2(4):206-215.

9. Reynolds, Joel. . Three Things Clinicians Should Know About Disability [AMA Journal of Ethics]. 2018; 1181-1187. 10.1001/amajethics.2018.1181.

10. Shakespeare, Tom & Lezzoni, Lisa & Groce, Nora. The art of medicine Disability and the training of health professionals. Lancet. 2009; 374. 1815-6. 10.1016/S0140-6736(09)62050-X.

11. .French, S. and Swain, J. The relationship between disabled people and health and welfare professionals, in Albrecht, G. L., Seelman, K. D. and Bury, M. (eds) Handbook of Disability Studies, Thousand Oaks: Sage. 2001