Editorial

Embracing brokenness

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When we are born our sight and hearing are not fully developed - we cannot walk, nor can we talk. Towards the end of our lives too, we have diminished vision, reduced hearing and a limited ability to move meaningfully. At any time between these two stages of life we could face temporary disability brought about by factors like pregnancy, depression, or injury; looked at from this perspective, disability is part of our lives – it is as if we are only temporarily able-bodied.[1]

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Although disability is all-pervasive, it is very diverse in its manifestations – locomotor, visual, psychosocial and many other – that people who are currently 'able' do not understand the lived experience of persons with disabilities. There are misconceptions and stereotypes – and many myths are perpetuated by cinema and the media. Often, non-disabled persons portray disabled characters without understanding the disability.[2] Cinema tends to show people with disability as discontented, as wanting to end their lives being unable to bear the thought of burdening their loved ones.[3] Such portrayal, apart from being non-representative, seriously undermines the work of disability activists who are struggling to show the world that disability is not a burden; in fact, physical and attitudinal barriers cause greater impairment than the disability per se.[4]

There are many people who refuse to be burdened either by their disability or by society: Dr SH Advani, an oncologist, is a wheelchair user who pioneered bone marrow transplantation in India; Arunima Sinha, national level volleyball player, is the first woman in the world to conquer Mt. Everest on a prosthetic leg.[5] To truly abolish all barriers that burden persons with disabilities, we must bring about change. This journal contributes by publishing articles that address inclusiveness; in addition, the ABCDE paradigm, published earlier, uses the medical humanities to change attitudes and behavior and may help to foster a culture of inclusiveness in medical professionals.[6]

Honing appropriate Attitudes and Behavior

Attitudes develop through experience, education, and environment; psychologists believe that they can be modified and reinforced.[7] Attitudes often dictate behavior which is how one expresses oneself in action. As medical teachers, we should work actively to craft appropriate, analytical attitudes in the hope that they will influence medical students' behavior.

Making Communication meaningful

Medical professionals should be encouraged to connect and communicate with persons with disabilities. Exposure to the narrative experience of persons with disabilities could enhance understanding, and generate learning of the social and psychological constructs of disability. Literature suggests that the study of disability identity informs therapeutic practice by combating antipathy.[8]

Embracing Diversity

No two living entities are uniformly able or uniformly disabled. In that sense, each one of us, regardless of our ability or disability, happens to be unique and different; therefore it is erroneous to single out and to describe only persons with disabilities as "Differently Abled".[9] Sharing lived experiences of having a disability can activate disability identity and bring change.[10] This is how attitudinal barriers may be broken and we may embrace diversity.

Empathy, not pity; Ethical treatment, not glorification

Persons with disabilities in Bangladesh are being called 'Golden Citizens' and those in India are now called 'Divyang' which means those having divine body parts.[11] Such clichés or metaphors, if systemically incorporated into societal structures, could push persons with disabilities back several decades, trapping their "humanisation" in metaphysical concepts of disability.[11] By selling the idea that people without disabilities are "normal" and those with disabilities are divine, instead of encouraging assimilation, we could be promoting exclusion.

A language that demeans and isolates can never be ethically correct. Culture, language and social behaviour are not only interrelated, but are also interdependent.[12] Thus, the ethical use of disability language and cultural and linguistic competence is extremely important if everyone is to embrace diversity. Medicine has a tendency to call the disabled body a case – as Michael Foucault says, "it pathologizes the exceptional and normalizes the ordinary."[13] Overwhelmed by medical jargon, the person - the patient - remains obscured. This results in the objectification of the patient, the production

of insensitivity, and the decline of empathy.[14]

The medical model of disability positions the disabled subject as someone "broken", one who needs to be "fixed." On the contrary, the social model entails accepting disability identity.[9] We need to integrate these two models. There are stories unfolding in every doctor-patient interaction. In order to become humane health-care providers, we must try to listen to the stories - to embrace that brokenness so as to understand disability. It is our brokenness that bridges the gap between 'them' and 'us'.

Through the ABCDE paradigm - by changing attitudes and behavior, communicating effectively, respecting diversity and becoming empathetic and ethical - we can embrace brokenness. Embracing brokenness is embracing humanity with all its imperfections. As Parker Palmer says, 'Wholeness does not mean perfection; it means embracing brokenness as an integral part of life.'[15]

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