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DISABILITY STUDIES: A NEW RESEARCH AREA

Disability Studies in medical curriculum. Transforming medical practice and making it more human

Disability Studies nel curriculum di medicina. Trasformare la pratica medica per renderla più umana

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Disability Studies has surfaced as an interdisciplinary subject which can be taught and applied to any academic discipline which concerns the wellbeing of an individual. The modern medical techniques, adopted and practiced by the doctors, focus only organs and organ systems involved in disease process. These techniques are scattered, withered and non cohesive rather than being holistic. The perspective of looking at the patients or an individual is atomistic and analytic. There is a need in the health sciences to lay stress on the humane and social perspectives. Co-existence of disability studies with medicine can transform medical practice, leading to high quality healthcare. Unfortunately, a number of studies have confirmed the inadequacy of disability and rehabilitation training in the curricula of medical education. Disability studies emphasises on civil rights and self determination which shifts the focus from a prevention/treatment/remediation paradigm, to a social/cultural/political paradigm. Collaboration between university academics, persons with disability, and disability interest groups may help in ensuring medical students are adequately sensitised to issues about disability. The broad outcomes of teaching Disability Studies to medical students would be their having a basic understanding of disability as an equity issue.

Key words: Disability, doctors, healthcare, stigma, rehabilitation

I "Disability Studies" nella formazione medica si propongono di introdurre le Medical Humanities nella professione medica e contribuire ad eliminare la visione negativa e stereotipata che i medici hanno nei confronti delle persone con disabilità. A tal fine si mostra anche l'utilità della collaborazione tra ambito accademico, diversabili e gruppi che operano a favore dell'integrazione dell'handicap.

Parole chiave: *Disabilità, medici, sistema sanitario, stigma, riabilitazione*

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Introduction

Disability Studies emerged as an academic discipline after the emergence of disability as a human rights issue. Disability Studies regards disability as a social relationship characterized by discrimination and oppression rather than as a personal misfortune or individual inadequacy (Centre for women policy studies).

Though the subject matter has arisen from sociology, Disability Studies has surfaced as an interdisciplinary subject which can be taught and applied to any academic discipline which concerns the wellbeing of an individual.

The basic premise of Disability Studies is that people with disabilities (PWDs) are an element of society in a manner closer to ethnic, gender, and sexuality studies rather than individual "cases". It explores disability as a phenomenon reflecting and constituting identity formation by incorporating the "real-lived" experiences of people with disabilities (Kanter, 2011).

Disability studies emphasises on civil rights and self determination which shifts the focus from a prevention/treatment/remediation paradigm, to a social/cultural/political paradigm. There is no denial of the fact that impairments are present, nor there negation of the utility of intervention and treatment. But what the medical students are taught about disability is a sharp contrast to it. They are trained to focus on disability as a medical, physiological, anatomical, psychological and functional pathology that originates in the body or mind of the person. Disability Studies in Medical Education would embody values based on viewing the person with a disability not as a victim of pathology, but as one who is limited more by social attitudes and environmental barriers than any inherent "defect" or "deficiency" within the person that must be remedied (Kanter, 2011).

Narrator's personal experience

Since I, myself, am a person with disability, it has been my personal experience since my childhood that the medical practitioners sometimes exhibited a negative as well as a complacent attitude towards those whose disability is a chronic one. Having no other option but to go to the doctors for getting operated upon for various deformities or for getting assistive devices as a means of disability coping up management, I really had to sometimes to undergo greater amount of pain than my own disabling conditions.

Though I have really been benefitted from the medical treatment provided to me by the doctors, yet the scant attention was paid to the psychosocial aspects of chronic illness and disability which could have a negative impact on psyche of a girl who was growing up and felt embarrassed time and again as she was not considered a young women with all the human emotions but only as an 'interesting case study' who had a deformed body that needed to be engineered. This underestimation of patients' disability in hospital and ambulatory care setting can cause irreparable dent to the psychology of the patient.

I still remember, the day when I was prescribed a Milwaukee Brace that had to be attached with my full length bilateral callipers i.e. the leg braces after my scoliosis correction. For that I had to visit the rehabilitation department of one the most reputed hospitals my country, to give the measurements for the same prescribed orthotic device. I was a thirteen year old girl, then with all the other natural bodily changes that happen during teenage. Disappointingly the place had no proper system of taking such measurements as it had to be done in standing position while giving traction to my neck. Since I could not stand without support, my hands were tied with the pelmet of curtains with strings, with no clothes on my body, just like the criminals are tied to a post for interrogation purposes.

The discomfort of the whole procedure, the physical pain caused due to it and emotional trauma suffered because it almost snatched away all the mental equilibrium of girl entering into adolescence. Her confidence level, her body image, her innocence all completely razed to ground, shattered and thwarted.

Had the doctors or medical service providers acquired the knowledge, skills and attitudes required to provide effective service to persons with disability, I think I would not have been agonized so much and that too in the hands of medical professionals.

The education system must acknowledge the need of graduating doctors to have basic knowledge about disability and rehabilitation in addition to knowledge of diseases causing disabilities.

Need of disability studies in medical education

The majority of medical students work as general practitioners, where they come across the most frequent problems related to chronic diseases, trauma, and ageing. Students are acquainted with principles of diagnosis and treatment of these conditions during their studies in internal medicine, surgery, neurology, and orthopaedics. However, they also need to acquire competence in skills of managing those who are, as a result of these diseases and injuries, permanently or temporary disabled.

Disability Studies can train medical students in good practices in disclosing the diagnosis various disabilities like Down's syndrome, Cerebral Palsy, Autism or many other chronic /genetic disabilities to the parents. Parents of children with physical disability often express dissatisfaction with the way that disclosure is handled by the doctors (Sloper and Turner, 1993), (Quine and Rutter, 1994).

The non-medical participants show their dissatisfaction when they interact with healthcare practitioners. A parent of a child with disability reported:

"There are definitely challenges. I am a parent of a child with a disability and I always get a feeling that I am being

treated as if I don't know anything and they are the professionals and I am just the parent and I must do what they say. It's very often that they don't want to hear what the challenges are. I have to listen to what they are saying and there is no connection… always getting the feeling or the sense that my input is not valuable and I don't know what I am doing or saying. This is probably why I got so involved with the disability sector" (Amosun and Taukobong, 2010).

Because of the stereo typification in the society, even the doctors find it hard to consider a person with disability as a sexual being. If a person with disability goes to a clinic for getting treated for STI he is often preached about not engaging in 'such' activities. The medical professional would ask about how the person got this disease as he was a person with disability and is rather blamed for getting the disease. That negative attitude actually prevents people with disabilities from going to the clinics (Amosun and Taukobong, 2010).

So I think attitude is one of the issues that needs to be addressed which can be done only by introducing Disability Studies in the medical syllabi.

In many cases the sexualities of people with disabilities are forcibly prevented. "Ashley's Treatment" is one of such examples where the parents asked the doctors to give her high-dose estrogen therapy to stunt her growth, conduct a hysterectomy to eliminate the menstrual cycle and associated discomfort to Ashley, and perform breast bud removal to avoid the development of possible large breasts as Ashley had brain injury of an unknown origin which had caused her mental and motor facilities not to develop (Albertz and Lewiecki-Wilson, 2008). The doctors did what all was asked by the parents irrespective of the fact that it was against human rights.

Gynaecologists have the highest rate of inaccessible practices because their offices lack examination tables that can be raised and lowered or a lift for transfer out of a wheelchair. Patients in wheelchairs can be transferred from wheelchair to the examination table by an emergency medical technician only (Lagu et al., 2013).

For the people with disabilities doctors are the main and reliable source of all the information, who, according to everyone, have training, experience, and knowledge about their needs. But ironically doctors themselves do not about the certain conditions in detail which can arise out of the patient's interaction with his immediate environment. For instance, the condition of depression. A person with disability is prone to get frustrated and depressed because of his chronic pain, isolation or marginalization. Sometimes we find the medical professionals are not adept in dealing with certain kind of disabilities like intellectual disability. They feel uncomfortable in answering certain questions of the care givers and guardians because they themselves don't have the answers.

Thus the medical professionals need a comprehensive training which could help them become more sensitive to the needs of patients with disability and their clinics must have adaptive equipment such as scales that can weigh patients in wheelchairs or mammogram machines that don't require patients to stand for the X-ray. Disability Studies in medical curriculum would help the doctors in their commitment to a core tenet of professionalism i.e., increasing access and reducing barriers to equitable health care. Health care professionals need to acquire the knowledge that people with disabilities have lives outside of their health care needs – lives in which they may be very active and accomplished. The health care system needs to work on making the accommodations required for effective communication.

Another reason for including Disability Studies in Medical Education is that the doctors have to make disability assessment for issuance of Disability Certificate or grants on the basis of their disability. Disability Studies would train them in shedding the negative perceptions about disabilities and getting over the emotions which sometimes could play key role in disability assessment for health insurance claims.

From medical model to social model of disability

Disability Studies can assist medical model in understanding the kind of life which a person with disability lives. Medical model only focuses on organs and organ system and their impairment. The perspective of looking at an individual is atomistic and analytic. There is a need in the health sciences to lay stress on the humane and social perspectives. Human being rather than a human body has to be rehabilitated. A person with disability is just not a group of organ system and that too impaired one (Khetarpal and Singh, 2012).

It is not the body but the complete human being who has to be rehabilitated. According to the medical model the problem of disability is located within the individual, i.e. a person is disabled due to their individual impairments and therefore requires medical interventions to provide the person with the skills to adapt to society. Thus individuals are placed into medical categories for medical conveniences. Doctors distribute categorical labels which carry social stigma, and these doctors tend to be the adjudicators for resources to assist people with impairments. Some medical and other professionals are uncomfortable with disability, either because the condition cannot be "cured" and represents a persistent "failure" by the health professions, or because of the role those professions may have had in the aetiology (cause) of the condition / impairment (e.g. brain damage resulting from a badly handles birth process, Union of the Physically Impaired Against Segregation, 1976).

The Social Model believes that disability is a social construct that exists in a realm beyond language within a complex organisation of shared meanings, discourses and limitations, imposed by the environment at a particular time and place. In other words individuals with impairments are not disabled by their impairments but by the barriers whether environmental, economic and cultural, that exist in society do not take into account their needs.

Disability is largely a legal and social problem that needs a solution based on social principles. The diffuse and subjective nature of social problems is incompatible with conventional medical thinking. There is a need for an interdisciplinary approach in the holistic management of patients, as disability is a condition that stretches beyond medical limits. And Disability Studies stands for this interdisciplinary approach that should include the medical fraternity, the social services specialists, psychological service providers, the economists, industrialists, the spiritual leaders and educationists. It is only through an all-inclusive holistic approach that all psychosocial problems could be addressed (Tumbo, 2008).

Incorporation of disability studies in medical education

Medical Studies play a significant role in shaping the budding physicians' medical professionalism and medical values. The syllabi, the curriculum that is offered to them, in every way has a definite impact on their learning capabilities and how they would approach their potential patients.

Undergraduate medical education should enable students to acquire the competence necessary for practicing physicians. The majority of medical students will most probably work as general practitioners, where they can expect the most frequent problems to be those related to chronic diseases, trauma, and ageing. Students are acquainted with principles of diagnosis and treatment of these conditions during their studies in internal medicine, surgery, neurology, and orthopaedics. However, they also need to acquire competence in skills of managing those who are, as a result of these diseases and injuries, permanently or temporary disabled. It has been rightly said by someone, "It is not medicine, rehabilitation, special education, physical or occupational therapy and professions oriented toward the cure, prevention, or treatment of disabilities".

Though medical students are taught about disabilities, whether acquired, chronic or genetic, but the number of lectures and the scope of subject matter isn't sufficient enough in sensitizing them towards the practical problems faced by the people with disabilities (Kahtan et al., 1994). What is required is a patient centred approach rather than disease oriented studies for medical students. They need to learn about socioeconomic implications of a patient's disorder.

We find a worldwide patchiness of teaching disability and rehabilitation in the medical colleges. To be successful in doing that we would requires some innovative endeavours, mainly pertaining to experiential activities which would aim primarily at changing attitudes. These can be:

Use of videos and role-playing (Kahtan et al., 1994)

Simulation sessions (Grayson and Marini, 1996)

Direct involvement in the rehabilitation program of a specific patient

Visiting support services or persons with disability living in their homes (Crotty et al., 2000).

Apart from these when undergraduate medical students have lectures in Psychiatry and Neurology or Paediatrics they can have some module in learning from intellectual and mental disabilities. During their lectures in orthopaedics, they can learn about locomotor disabilities. Similarly structured teaching in ENT and Ophthalmology classes can increase their adequate knowledge about auditory and visual disabilities. Likewise in every subject they have some additional classes concerning various kinds of disabilities and how the patients cope up with them.

Conclusion

Thus the study of disability by all the students in general and medical students in particular matters because it forces us to interrogate ethical and political questions about the meaning of aesthetics and cultural representation, bodily identity, and dynamics of social inclusion and/or exclusion.

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