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Health Humanities: Social Dimensions of Illness and Disability

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Abstract:

Disability studies has generated several "models" such as the medical model, social model, and critical disability studies. These models have created an intense debate in terms of socio-cultural and political justice. In this paper, I would like to illustrate an understanding of the social model with respect to illness and disability. It shows how disablism, impairment, and illness are social constructions based on the notions of deviancy. It explores what types of illnesses are seen as disabilities globally. Further, it outlines how the social model addresses the limitations of the medical model.

Keywords: *Disability, Illness, Social Model, Impairment*

Introduction

In his essay, "The Social Model of Disability," Tom Shakespeare outlines how the social model of disability differs from the over-medicalized and individualistic accounts of disability. The social model challenges the concept of "divine punishment, karma or moral failing . . . [and] biological deficit" and focuses on "social oppression, cultural discourse, and environmental barriers" (2013:214). It makes a structural analysis of social exclusion. This model was developed by *the Union of Physically Impaired Against Segregation* (UPIAS), which is a small group of disabled people inspired by Marxism. The members of the group aimed to replace the segregations with opportunities for people with disabilities to fully participate in society.

The “sociology of disability,” which is different from “equality and diversity studies,” brings the tools of gender, ‘race’, sexuality, age and social class in understanding disability. The sociology of disability focuses on disablism and impairment effects and does not consider disability as an exclusive area of medical sciences. Carol Thomas observes that the sociological perspectives used in disability studies are significant to medical sociology in the present time. She has explored this notion in her book, *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology* (2007), in detail, and brings in a constant debate between disability and illness. In *New Directions in the Sociology of Chronic and Disabling Conditions* (2010), Graham Scambler and Sasha Scambler refer to the “transitional phase” of chronic illness which partly resulted from the debates of medical sociology and disability studies (cited in Tomas 2012:210). The central focus of Thomas in the sociology of disability is the importance of disablism which she defines in her essay, “Medical sociology and disability theory” (2010) as:

Disablism: refers to the social imposition of avoidable restrictions on the life activities, aspirations and psycho-emotional well-being of people categorised as ‘impaired’ by those deemed ‘normal’. Disablism is social-relational in character and constitutes a form of social oppression in contemporary society – alongside sexism, racism, ageism, and homophobia. As well as enacted in person-to-person interactions, disablism may manifest itself in institutionalised and other socio-structural forms. (cited in 2012:211)

Like disablism, impairment effects as:

Impairment effects: the direct and unavoidable impacts that ‘impairments’ (physical, sensory, intellectual, emotional) have on individuals’ embodied functioning in the social world. Impairments and impairment effects are always bio-social and culturally constructed in character, and may occur at any stage in the life course. (cited in 2012:211)

Thomas argues that "the medical sociologists specializing in chronic illness are actually bound up with the sociology of impairment effects" (2012:211) when it comes to coping with the disease and chronic illness symptoms. The impairment effects are important in common people's lives but are secondary to disabled people. The primary social needs become crucial for disabled people. Such social needs are access to education, performing duties/jobs, accessing health care, bringing up a child, looking after an ill parent, getting into public places, etc. So, disablism is crucial for disabled people than impairment effect.

How do we define illness and categorize illness? And how could we associate illness with a disability? The exploration of the social dimensions of illness (i.e. socially constructed illness) is a part of medical sociology. Peter Conrad and Kristin K. Barker focus on three aspects of illness: the cultural

meaning of illness, the social construction of illness experience, and medical knowledge as a social construction. Social constructionism focuses on the cultural and historical aspects of illness. A social constructionist approach differentiates between diseases (the biological condition) and illness (the social meaning of the condition). The experiences and meaning of illness are shaped and enforced by socially and culturally created systems. Illness is a social formulation/conceptualization and has no medical justification.

WHO: Mental Illness and Disability

Mental illnesses crucially lead to significant disability around the world. In “Disability Research in India,” H. Chandrashekar *et al* note that “nearly 31% of the world’s disability is accounted by mental disorders. It was found that five of the ten leading causes of disability worldwide are in the category of mental illnesses: major depression, alcohol dependence, schizophrenia, bipolar affective disorder and obsessive-compulsive disorder” (2010, 281). In *Mental Health: New Understanding, New Hope*, WHO has also included depressive disorders, substance use disorders, mental retardation, Alzheimer’s disease, epilepsy, schizophrenia, and disorders of childhood and adolescence under disability studies (21). WHO further says that depression causes the highest percentage, which is 12%, of all disability of disabilities (26). In *Mental Health Aspects of Women’s Reproductive Health* (2009), WHO observes that compared to men, women undergo depression frequently and the ratio is higher in women of reproductive age in developing countries that appear “with unexplained physical symptoms, such as tiredness, aches and pains, dizziness, palpitations and sleep problems” (1).

Mental illness causes different types of disability when compared to physical illness because they look physically strong but lack motivation and self-care. Any disclosure of mental illness hampers social functioning because of stigma and discrimination. Consequences of stigma and discrimination result in exploitation, deprivation of the social sphere, exclusion from the public space, amplifying illness, and barring care and treatment. In *Advocacy for Mental Health* (2003), WHO says that stigma is something that forces a person to have “a deeply compromised social standing, a mark of shame or discredit” (11). WHO argues that stigma makes other people fail to understand the people with serious mental disorders “feel uncomfortable about the persons affected and act in a negative way towards them” (11). Such kinds of responses exacerbate illness symptoms and disability in persons with mental illness. In *Advocacy for Mental Health*, WHO further provides an extensive list of general misconceptions about how people with mental disorders are seen and thought to be: “lazy, unpredictable, unintelligent, unreliable, worthless, irresponsible, stupid, untreatable, unsafe to be with, without conscience, violent, incompetent to marry and raise children, out of control, unable to work, always in need of supervision, increasingly unwell throughout life, possessed by demons, in need of hospitalization, [and] recipients of divine punishment” (11). WHO believes that the consequences and effects of stigma go deeper in the lives of people with serious mental illness, some of which are unwillingness to seek help, isolation from old friends, difficulty in making new friends, dent in self-esteem and self-confidence, deprivation of jobs and other

government schemes, social isolation of the concerned families, lack of resources, and the like. To combat such problems, the disability paradigm is extended towards an understanding of the misperceptions and consequences of mental disorders. In *Mental Health Legislation and Human Rights* (2003), WHO clearly states, “An increasing awareness of disability caused by and related to mental disorders has led to a move away from an illness paradigm and towards a disability paradigm for understanding the social consequences of mental disorders” (16). The disability paradigm protects the rights of mentally affected people and opens further legislative opportunities. However, it does not intend to vanish the boundaries of illness and disability completely. Despite culture and society being repressive conditions for disability and illness, it is important to maintain the differences between both to have space for medical interventions, social accommodation and empowerment. WHO reports suggests that disability and illness are largely socio-political and cultural problems that need broader understanding, humanistic vision and compassionate thoughts along with medical facilitation. The problem occurs when society perceives mental illness as “learning disability,” “mentally handicapped,” “mental retardation” or “intellectual disability” and suppresses their rights. Compared to speaking, reading is not an evolutionary and universal skill.

Social Dimensions of Illness and Disability:

The medical model portrays illness and disability as an individual deficit to be cured, but the social model considers disability as a social, cultural and historical phenomenon. The social model does not consider impairment and disability as the same. Impairment is "individual and private" and disability is "structural and public". Doctors and medical professionals try to provide a remedy for impairment. It is necessary to understand that impairment is individual specific and disability is a culturally and historically specific phenomenon. The social model is different from the medical or individual model. The social model defines "disability as a social creation—a relationship between people with impairment and a disabling society," and the medical model defines disability as an "individual deficit" (Shakespeare 2013, 216). According to Mike Oliver, the medical/individual model deems disability as "personal tragedy" while the social model stresses the "externally imposed restriction" (cited in 2013, 216). Tom Shakespeare clearly explains that the medical model's focus is on "medical prevention, cure or rehabilitation" and the social model mandates "barrier removal, anti-discrimination legislation, independent living and other responses to social oppression" (2013 216).

In *Profession of Medicine* (1970), Eliot Freidson discusses how the consequences of illnesses depend on what is socially “acceptable” or “desirable,” and are *independent* of any biological effects:

[W]hen a physician diagnoses a human's condition as an illness, he [*sic*] changes the man's [*sic*] behaviour by diagnosis; a social state is added to a biophysiological state by assigning the meaning of illness to disease. It is in this sense that the physicians create illness . . . and that illness is

. . . analytically and empirically distinct from mere disease.
(cited in Conrad & Barker 2010, 67).

Michel Foucault study of the social construction of illness incorporates his notion of "power/knowledge". He says that experts produce knowledge about "normality" and "abnormality" which is not objective but a mechanism of power in modern societies. Illness is not a neutral issue. It is experienced socially and culturally. It has both "biomedical and experiential dimensions" (Conrad & Barker 2010, 69). In *Illness as Metaphor*, Susan Sontag says that illnesses have metaphorical connotations, which generally carry negative, stigmatized, repressive or evil metaphorical meanings. Cancers, leprosy, mental illness, epilepsy, HIV/AIDS, etc do not have "acceptable" or "positive" metaphors. Apart from the metaphorical meanings, there are culturally given meanings of illness. Hence, some are seen as stigmatized, some as disability, and some have other terms. What it suggests is that illnesses have a social basis, rather than purely biological reasons. In this regard, Peter Conrad and Kristin K. Barker argue that "cultural meanings have an impact on the way the illness is experienced, how the illness is depicted, [and what is] the social response to the illness, and what policies are created concerning the illness" (Conrad & Barker 2010, 69). Disability, like illness, also embodies social and cultural meanings, which generate not from the physical impairments but everyday social interactions. Hence, one needs to distinguish impairment (i.e., the attribute of the individual) from disability (i.e., the social experience and culturally given meaning of impairment). It is now clear that illnesses have cultural meanings which are not reducible to biology. Such cultural meaning creates a further burden to the concerned individuals on account of the associated stigma and negative meanings. An understanding of illness needs to focus on the patient's perspective of illness, the patient's experiences of illness, and the patient's experiences in general and the illness experience. A patient may not have a negative perspective about an illness but what s/he goes through in society provides her/him a very different experience. Additionally, a patient is not always in the role of a patient, s/he could also have the roles of son, parents, profession, friend, etc. In other words, s/he has very little time to have the role of a patient. Hence, a study of illness needs comprehensive understanding. Peter Conrad says,

[A] sociology of illness experience must consider people's everyday lives living with and despite illness. It needs to be based on systematically collected and analyzed data from a sufficient number and variety of people with an illness. Such a perspective necessarily focuses on the meaning of illness, the social organization of the sufferer's world, and strategies used in adaptation. (cited in 2010, 71).

The patients struggle to understand their experiences of illness and make the sense of illness "within the context of their personal and social relationships, employment status, health insurance coverage, religious and cultural beliefs, and the like" (2010, 72). A person suffering from acute illness faces "an erosion of self" (a "biographical disruption"), and requires to reconstruct the pre-illness life and identity. Some patients end up creating a new illness identity (e.g., cancer survivor) (2010, 72). The consequences of illness

identities are debatable: it can be seen as "improved well-being" and "self-empowerment," and it can also "negatively impact" the life of the individual (2010, 73).

In this way, it challenges the notion of illness as a medical phenomenon in popular understanding. Researchers like Eliot Freidson and Irving Kenneth Zola revealed that medicine is an institution of social control and medical knowledge is socially constructed. Peter Conrad and Kristin K. Barker observe that "medical knowledge sometimes reflects and reproduces existing forms of social inequality. Rather than being value-neutral, some medical knowledge, implicitly or explicitly, shores up the interests of those groups in power" (2010, 73). There is no denying that medical knowledge promotes gender, class, racial-ethnic and the like inequalities. It shows, illness is embedded with cultural meanings which regulate how society responds to those afflicted with illness; and illness is also socially constructed at an experiential level that shapes one's life and identity.


Often people with mental illness and disabilities are seen as socially deviant. The root of the social deviance paradigm goes to Durkheim's categorization of socially *normal* and *abnormal*. The notion of social deviance was further established by Talcott Parson's observation on illness and medicine in his *The Social System* (1951). Parson says that social deviance is represented by the ill people who cannot perform social roles (for example, duties, jobs, mothering, nurturing, soldiering, etc) which are necessary for the social organism. He suggests that medicine can help to cure or repair such threats of social deviance.

Opposite to the "social dimension" is the medical model of disability which perceive disability as a problem of the person, directly caused by disease, trauma or any health issues which requires treatment or fixation to cure the problem. It is supposed that the social model is preferred over the medical model. But the social model also has some shortcomings within its structure as the social model vehemently disowns the medical model that impairment is not an issue but the truth is that it affects the lives of people with disabilities. The concept of a world in which people with impairments are free of environmental barriers cannot be functionalized because disability cannot be treated as a homogeneous category like some people cannot see, some cannot speak or hear so their requirements are different. Social practices and medicine intertwine to discriminate against people with disabilities. As in "The Birth of Social Medicine" (2000), Michel Foucault says that "humanity did not remain immune to medicalization" (134). Foucault further believes, "Modern medicine is a social medicine whose basis is a certain technology of social body; medicine is a social practice, and only one of its aspects is individualistic and valorizes the relations between the doctor and the patient" (136). Similarly, in "The Politics of Health in the Eighteenth Century" (1980), Foucault says "The doctor becomes the great advisor and expert, if not in the art of governing, at least in that of observing, correcting and improving the social 'body' and maintaining it in a permanent state of health" (177). In this way, the medical model did both discriminate against and help people with disabilities and illnesses.

In short, an understanding of illness and disability from social dimensions broadens the domain of disability studies. However, it does not mean that the social dimension is flawless – as it underestimates impairment as part of many disabled people's lived experiences.

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