

Beyond the Medicalization of Disability: A Review

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Abstract

This article aims to outline the ethical perspectives on disability discourse in medicine and nursing elucidating the necessity for a more multifaceted approach to disability and patients with disability within medical and nursing curricula. While advancements in medical engineering and pharmacology have enhanced independence and quality of life for people with disabilities, the approach to disability often results in arbitrary assumptions about disability as a concept and the objectification of people with disabilities in clinical settings. This article attempts to advocate for a more inclusive approach in medical and nursing education that incorporates an interdisciplinary understanding of disability and respect for personal experience of disability. It proposes an ethical framework that challenges contemporary views on the concept of disability and associated disability terminology in healthcare and medical education and promotes a holistic approach to the treatment of individuals with disability respectful of their experience of disability.

Keywords: disability, medical model, personalism, health-care curriculum

Introduction

Medicine and disability in context

Over the past four decades, there have been notable advancements in the inclusion and emancipation of individuals with disabilities in society. This, besides the political activism of people with disability, has been made possible by several practical advances in different fields. Advances in medical engineering, like the production of prostheses and wheelchairs, enable people with disability increased independence and mobility whereas medical and pharmacological treatment interventions grant better health and longevity improving people with disability's quality of life and well-being.

Yet, modern medicine, especially in the global West brings with its high-tech innovation practice a particular framework towards patient care and an objectifying view concerned with the cure of individuals (1). Inevitable challenges, prejudices, and misconceptions occur when it comes to understanding the concept of disability and the experience of disability itself. This is particularly present in the liberal ethical discourses of prenatal medicine suggesting the prevention or elimination of those with certain genetic malformations and cognitive and physical deformities (2,3). Moreover, the growing confusion of disability with an illness or a pathologic condition is present among medical staff and students (4,5), and the lack of experience with disability or encounters with a person with disability outside of clinical medicine and rehabilitation therapy is all too common (6,7). This could be one of the reasons many people with disabilities feel marginalised, disvalued or depersonalized within the context of clinical medicine (8,9,10).

All this entails that disability in some way is a challenge to medicine, medical and nursing education and the healthcare system as a whole. In what way can a multidisciplinary approach to disability remedy such a situation or contribute to a better understanding of disability? What necessary knowledge should a physician or nurse gain for a more holistic treatment of patients with a disability? Where

is the line between the medical approach and the medicalization of disability? The recent literature in medical and nursing education has called for the implementation of a "disability-conscious" approach to education within the field of health professions inviting for the integration of disability studies, social models of disability, and the principles of disability justice into medical training (11,12).

Concerning this, the present article aims to offer an ethical, more comprehensive and balanced approach to disability and use of disability terminology which will go beyond the objectification of people with disability, surpassing one-sided views about disability and helping to combat social inequalities for people with disability in the clinical context. In the first part, the article critically assesses the assumption of the medicalization of disability. The second part presents the major views of disability and the multifaceted approach to disability definition. The article concludes by suggesting a more inclusive and holistic approach to disability within medical and nursing education, emphasizing the value of the personalist approach to disability as a unique criterion in medical decision-making.

Medicalization of disability

The history of disability outlines several approaches, treatments, ways of comprehending, and ways of using language to describe people with disability and give the meaning of disability (13). Disability was for a long time and in some societies even today understood as a supernatural phenomenon, a punishment, an individual pathology, a personal tragedy or a reason for a political and charity action (14,15). Very often due to their cognitive or physical impairment and non-typical behaviour and body looks, they have been labelled with stereotyping images and terms or have been stigmatised, institutionalised, and excluded (16,17). One of the most impactful frameworks of disability in the context of medicine is a view that associates' disability with a medical condition, illness or a lack of ability. Within the contours of this article, such

approaches will be considered under the *umbrella* of the medicalisation of disability as it is not merely a medical model which medicalizes disability, but several practices and particular socio-cultural worldviews projected into a framework of medical education. This is a ground to justify the implication that the medicalisation of disability in such a perspective does not only include the framework of the medical model of disability. It also includes associated terminology, the vulnerablizing images and socio-cultural prejudices towards disabled person embodiment, and the distinction between the normal-pathological, disabled-abled binaries, as well as objectifying attitudes towards patients with disability. The next paragraph attempts to clarify such terminologies and approaches.

The medical model of disability

The medical model within the history of disability has been a dominant framework of ideas and knowledge that shaped and impacted certain perceptions and attitudes towards disability. The critical disability studies bioethicist Rosemarie Garland-Thomson claims that very often thinking about disabilities is overdetermined in our medical subjectivity which often means particular logic and practices (18). The primary characteristic of such logic implies medical reasoning about disability, that it is the treatment of disease (i.e. biological physical impairment) and includes the inspection of causes, signs and symptoms. As such, it goes by different names, like the individual model, biomedical pathology, or functional paradigm (19). The medical model reduces disability to either a medical category (an illness which requires cure and fixing), a problem of the individual (a deficiency or a tragedy which requires pity and help), or a functional deficiency (pathology which requires treatment). Accordingly, a person with a disability is considered a patient, a victim of tragic destiny or an ill or sick individual. This means that disability was perceived as an illness or pathology attributed to genetic and biological factors that give rise

to specific bodily malformations. In other words, the burden of disability is put on an individual as a functional limitation (20) and the person's experience of disability was not of interest at this stage of treatment. The research surrounding the medical model of disability reflects the inhumane treatment that disabled individuals have endured throughout history, particularly in hospitals, rehabilitation centres, and other institutions (21,22). Such approaches often included the depersonalisation of disabled persons. In this sense, the disabled person is not seen as a person with dignity and possibility but is imprisoned to functional deficiency – seen as an individual with a vulnerable and handicapped physicality, as a patient or as an individual with a tragic condition. Besides the medical model being largely applied in clinical medical practice towards disabled individuals, it impacted the wider socio-cultural view towards disabled people present also in contemporary culture such as ableism, charity model, rehabilitation model, socio-cultural prejudices about disability, etc. This view has been often accompanied by a particular power of language and disabling images of one's embodiment.

Language and vulnerable corporeality

The power of language

In line with the medical model, the medicalization of disability was also accompanied by the use of specific language and stereotyping perceptions which consequently associated disability with tragic images, and people with disabled bodies with a vulnerable or abnormal corporeality.

The use of certain language and particular terminology serves the mainstream culture not only to demonstrate the asserted value we ascribe to others but also to convey a particular context in which certain expressions are used (23). Therefore, the use of disability terminology in a clinical, but also in a broader socio-cultural context, deserves attention as terminology and the politics of language for disability in a certain context demonstrate the perception of the person

with disability and related construct for comprehending disability. It also illustrates the mentality connotations that come with the use of specific disability terminology. A significant number of terms for disability in the related context, including medical manuals, have been conceptualized according to biological or intellectual etiology (24). These include “crippled”, “idiot”, “mental patient”, “lunatic”, “freak”, “weak-minded person”, “mentally retarded”, or “handicapped person”. Additionally, due to their non-typical bodily appearances, individuals with disabilities were perceived as unreasonable, deformed, dysfunctional, and crippled. Terms such as loss, abnormality, restriction, or lack of ability go hand in hand with such a view. Other frequent images connected with disability on a social scale include wheelchair users, sickness, helplessness, cure, neediness, status of dependency and vulnerability, etc. These stereotyping images are not only a result of particular terminology and language but also related perceptions that disability as an illness is a medical condition and a person with a disability is a carrier of genetic malformation or a patient with an abnormal body appearance (25).

Vulnerable corporeality

Henry Stiker in his work on *History of Disability* asserts that the connection with the disabled body is not the same as with a sick body as often there is no healing. The person in a wheelchair or with physical impairment using prosthesis devices is a visible fact (26). Furthermore, the history of disability has been characterized by the utilization of the term ‘vulnerability’. Due to their dependency status, perceived neediness, atypical functioning, and physical and intellectual disadvantage, disabled people have historically been marked as vulnerable (27,28.). Due to this, stereotyping images of people with disability frequently include the deployment of the term *vulnerable body*. In its initial formulation, the concept of vulnerable body is ascribed to people with disabilities due to their bodily appearance and non-typical, or beyond normal, bodily functionality. In the context of clinical medicine,

the body of a person with a disability was considered outside the contours of the *bell curve* (29), or what has been measured as normal and typical. The complete personhood has been reduced to bodily functionality and form because it has been associated with images of a non-typical, broken, or vulnerable corporeality. The philosopher Susan Wendell, who embodies the experience of disability, claims that rejected or negative body images refer to those aspects of bodily life (e.g., disability), physical appearance (e.g., deviations from the cultural ideals of the body), and bodily experience (e.g., forms of bodily suffering) that cannot be controlled and that are deviating from the norm (30). In other words, having a disability means a departure from a certain calculus of the norm and non-compliance with a standardized bodily look. Besides the vulnerability being associated with a person with disability’s bodily appearance, there is a set of social vulnerabilities which pertains to the identification of a person with disability on a broader socio-cultural scale. Such attitudes in addition to the natural form of vulnerability, contribute to the increase of vulnerablizing attitudes towards people with disability and give rise to social and emotional isolation, loneliness, poverty, and exclusion. Put differently, on account of their status as being dependent on others, their atypical functioning, and their physical appearances, disability (31) has been perceived as a condition that vulnerablizes disabled people on a socio-cultural scale in addition to their natural ontological vulnerability (32,33).

The perception from a history of medicalization, including medical models, exploitive language, and views on disabled bodies as presented in a discussion above, has shaped the responses and attitudes of not merely the medical practitioners but also the public health and medical and nursing education, as well as the mentality of an ordinary person towards disabled. These perceptions have also had a broader impact on the definitions of disability and the professional and mainstream discourse surrounding disability (34). Yet, the medicalization of disability has been

the subject of considerable criticism. This creates the emergence of other views and perceptions of disability initiating a more broad, comprehensive, and non-objective picture of disability. The next section attempts to outline such views.

Going beyond the medicalization of disability – a multifaceted definition of disability

Social Model

The *Union of the Physically Impaired Against Segregation*, UPIAS (35) occurred as a response and reaction to the prevailing formula of seeing disability as merely a physical condition and a person's limitation. The UPIAS traces the roots of a social model of disability whose conceptual framework differs from a medical model and sees disability as a problem of society and a social barrier. Contrary to the medical model, the social model rationale is oriented towards people's experiences of disability and is critical of the medicalization of disability and the socio-cultural prejudices towards disabled people (36). Within this approach, the problem of disability is not located in an individual. Rather, the reduction of opportunities for disabled people is because of social and environmental barriers and attitudes such as exclusion, limited workplaces and transportation, as well as limited health care benefits (37).

The key insight of the social model is that it makes a distinction between disability and impairment. Disability, on the one hand, is a problem of society and a social construction regarding the disabled because society as a whole tends to stigmatize, judge, and exclude disabled people (38) by limiting spaces and stereotyping attitudes towards them. An impairment, on the other hand, is the physical disadvantage or restriction of activity due to a physical condition such as lacking a limb or having a defective limb, organ, or mechanism of the body (39).

Such an approach is helpful as it not only broadens the perception of disability from an objective towards a more subjective setting

but includes people with disability to speak about their experience of disability in their own voice. Besides this, the social model has been highly impactful on societal changes, such as the inclusion of disabled people through political action and the distribution of human rights, but also into a broader setting of medical education such as the emergence of an inclusive medicine approach. However, the creation of rights and the constant battle against oppression turned disability into a political identity and created a new pride of being disabled. Related to this is the problem of over-emphasized social barriers and the fights for independence, autonomy, rights, and choice, eclipsing the importance of dependency, common belonging, charity, and the human need for the other person as universally accepted human values. Moreover, such a critique addressed the limitation of the social model and the strict separation between impairment and disability as unrealistic (40), which is why a new approach to a more comprehensive disability approach was required.

The bio-psycho-social model within disability definition

This overview of the conceptualizations of disability illuminates the transitions between the medical and social models. The discussion also outlines limitations in these approaches to disability which led to the emergence of the bio-psycho-social model as a new paradigm integrated into the WHO's 2011 definition of disability. According to this model, *disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's personal, environmental and contextual factors* (41). With its "workable compromise" between the medical and social models, the bio-psycho-social model was a ground for reassessing the definition of disability apart from a strict distinction between impairment and disability or, in other words, the medical and social model. It offers a comprehensive perspective on disability that encompasses social and psychological functioning, environmental

factors, personal attributes, and contextual influences. This approach, in contrast to disability definitions, now employs a more elaborated definition locating disability beyond strict categorization, and instead looking at it as a human condition dependent on internal (biological, psychological) and external (social, environmental, cultural) factors.

With constant elaborations and the emergence of disability bioethics, the 2011 World report on disability evidenced a notable transformation in its disability definition. These definitions have been subject to multiple changes, which have been influenced by disability policy, different human rights movements, shifts in the economy and society, improvements in psychology and health sciences, etc. (42). Defining disability has also been a matter of interpretation among different academic disciplines (disability studies, the study of disability, medical sociology, social policy, law, etc.) whereas, the experiences of disability from disabled people themselves have provided a unique way of understanding disability as an embodied experience.

Thus, according to bio-psycho-social model, disability is an interaction between a person's environment, participation and activities, bodily functions, and personal features. This can be evidenced in the 2011 World report on disability where disability is a complex, dynamic, multidimensional, and contested condition of human life. This is to say that the WHO definition integrates bio-psycho-social aspects, indicating that disability is not merely a physical condition or societal barrier. Rather, disability is an umbrella term, a more integrative and applied concept that includes biological, psychological, social, and environmental perspectives.

According to recent (1st March 2023) data from WHO, an estimated 1.3 billion people – or 16% of the global population (1 in 6 persons) – experience a significant disability today. Besides disabilities being complex and sometimes difficult to define, the present and universally adopted terminology distinguishes between people with (physical)

impairment and intellectual disability. Every other arbitrary terminology such as people with special needs, mentally retarded or handicapped should be avoided.

Moreover, the current approach to disability distinguishes between different types of disabilities: physical disability, intellectual disability, developmental disability, and nonvisible disabilities. Because it is a multidimensional concept influenced by culture, defining disability remains a complex task as often the notion does not demonstrate a univocal definition. Sometimes, disability can mean many things and at the same time nothing at all. (43). Disability in a medical context is still lacking epistemic reliability. However, it is important to emphasize that the present disability terminology places a person before his/her difficulty. This means that to indicate something as disability one should be reminded to use a person's first language before indicating a person's impairment (44). This for instance includes usage such as person with intellectual disability, *a person* with physical impairment, a person with hearing impairment, *a person* with vision impairment, etc.

Conclusions

The objective of this paper was to equip healthcare providers with the knowledge and skills to deliver more inclusive and empathetic care to patients with disability by recognising disability as an integral aspect of a patient's identity, rather than merely as *a concept* or a medical condition to be managed. This necessitates a comprehensive revision of evolving medical and nursing curricula (45) to incorporate training conducted by disabled individuals, thereby ensuring that healthcare professionals are adequately prepared to address the distinctive needs of disabled patients effectively. A significant number of scholars specialising in the field of disability studies have highlighted the absence of consideration given to personal experiences of disability within the context of medical practice. Deborah Marks, for instance, addresses that the subjective experience of

patients with a disability facing diagnosis or treatment is often unconsidered (46). Therefore, for medical and nursing education the value of the personal experience of disability as an embodied experience would not only enable looking at the phenomenon of disability from another perspective but will expand the approach of clinical medicine to become more inclusive.

In what way then, does the outline of approaches and conceptions of disability in this study expand the comprehension of disability within the practice of medicine and nursing? One of the aims of this paper was to challenge and broaden the traditional framework of understanding disability in medical and nursing education. This extends beyond the individualistic view of disability and turns towards a more multifaceted definition of disability based on a bio-psycho-social model, emphasizing the holistic and personalistic approach towards the person with a disability and related care (47,48). Such an approach, in other words, aims to expand the nursing and medical profession curricula by moving towards a more integrative approach which will recognize disability not only as a concept, medical or social condition but also as a human experience. As the science of nursing and medical education is in constant development, it is essential to engage in collaborative efforts with other disciplines that address this subject matter, such as Disability studies, or Special Education, adopt a comprehensive and interdisciplinary approach to disability, and assess an individual's disability experience holistically. The initial step of a holistic approach in such a perspective suggests that an individual with a disability is regarded in their total personhood, and disability is viewed as a complex human condition that necessitates a multidimensional approach. This means that an individual with a disability is not simply a biological entity; rather, complete personhood encompasses psychological, social, spiritual, and metaphysical aspects. Additionally, each experience of disability is unique, and shaped by specific circumstances, socio-cultural context, and history. While

physical impairment is a crucial aspect of the disability experience, it is essential to consider other factors and aspects of functioning as well as specific life circumstances and experiences. Such suggestions correspond to the recent discussions about disability in medicine and nursing which were processed in 2016 at *Michigan State University Centre for Ethics and Humanities in the Life Sciences* which underscored the necessity for a paradigm shift in how healthcare professionals conceptualize and engage with disability (49). The traditional medical model, also in such a context, is being increasingly challenged by perspectives that recognize disability as a form of diversity. The subjective experience of patients with disability brings not merely a new understanding of the world of disability, but opens up a possibility for new insights about the experience of disability. In such a perspective, *cognosco ergo sum* replaces a strict sense of *cogito*, which opens up a possibility for a dialogue between medical staff and a person with a disability, or her/his family as a proxy.

In addition, medical professionals, particularly those in nursing, can facilitate a more comprehensive understanding of disability and access to disabled patients by eliminating the barriers and biases associated with disability in a broader socio-cultural perception. This should not be interpreted as a means of rectifying or preventing the shortcomings of individuals with disabilities. Instead, it entails addressing the obstacles and biases within the medical or nursing practice itself, through self-critical epistemological communication about the concept of disability and expected direct interaction with people with disability.

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Competing interests

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