Rethinking disability: the social model of disability and chronic disease

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Abstract Disability is commonly viewed as a problem that exists in a person's body and requires medical treatment. The social model of disability, by contrast, distinguishes between impairment and disability, identifying the latter as a disadvantage that stems from a lack of fit between a body and its social environment. This paper describes the social model of disability and then considers how it might deal with chronic disease or impairment and why medical professionals should learn about disability perspectives to improve their practice.

Keywords Disability · Impairment · Chronic disease · Social model

Introduction

A standard medical approach, indeed a common lay-person's approach, to thinking about disability involves viewing it as a problem that exists in a person's body. As a consequence, that individual is thought to require treatment or care to fix the disability, to approximate normal functioning, or perhaps as a last measure, to help the individual adapt and learn to function despite the disability [1]. So construed, disability is primarily an individual's medical problem in need of treatment. As disability scholar Liz Crow notes, this medical model of disability holds that "a person's functional limitations (impairments) are the root *cause* of any disadvantages

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experienced and these disadvantages can therefore only be rectified by treatment or cure" [2]. No doubt, many individuals with musculoskeletal disorders present themselves in the clinic as people looking for a cure, a treatment, or help dealing with their condition. But, as with many chronic conditions, many of them will not find a cure nor will they find complete relief for the symptoms they experience. Recognizing how their lives may be disabled—and what can be done about that—involves taking a closer look at what we mean by disability and its attendant disadvantages.

Effects of the medical model of disability

One result of the common medical understanding of disability is that people with disabilities often report feeling excluded, undervalued, pressured to fit a questionable norm, and/or treated as if they were globally incapacitated. People with disabilities often express frustration when they are met with pitying attitudes or incredulity if they speak about anything positive related to living with their conditions. Many memoirs and books now attest to this common experience (e.g., *Encounters with Strangers* [3], *Waist-High in the World* [4], *Moving Violations* [5], *The Rejected Body* [6]). For many people with disabilities, the *main* disadvantage they experience does not stem directly from their bodies, but rather from their unwelcome reception in the world, in terms of how physical structures, institutional norms, and social attitudes exclude and/or denigrate them. As Lois Keith remarks, "Doing disability all day long can be an exhausting process. I don't mean having an impairment, in my own case not being able to walk. Like most disabled people I can deal with this. I mean having to spend a significant part of each day dealing with a physical world which is historically designed to exclude me and, even

more tiring, dealing with other people's preconceptions and misconceptions about me." [7]

The social model of disability

In response to the traditional medical model of disability, disability activists and scholars have offered a social model of disability [8], which relies on a relatively sharp distinction between impairment and disability. Within the social model, impairment is understood as a state of the body that is non-standard, defined as "lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body" ([8], p. 22). As such, impairment may or may not be met with a negative evaluation by its possessor [9]. People who are blind from birth, for instance, often understand their blindness as a neutral way of being, rather than as a deficit or a problem. Consider Deborah Kent, who reports that "…from my point of view, I wasn't *like* a normal child – I *was* normal. From the beginning I learned to deal with the world as a blind person. I didn't long for sight any more than I yearned for a pair of wings…I premised my life on the conviction that blindness was a neutral characteristic" ([10], p. 57–58). Similarly, and even in regard to acquired impairment, Oliver notes that "impairment is, in fact, nothing less than a description of the physical body." ([8], p. 35) Disability, by contrast, is the "disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities" ([8], p. 22). The point of making and emphasizing this distinction is to show how much and sometimes all of what is disabling for individuals who have impaired bodies has to do with physical and/or social arrangements and institutional norms that are themselves alterable (e.g., stairs vs. ramps; presentation of data using only auditory means vs. universal design for communication, restrictive definitions of job requirements vs. expansive accommodations for different modes of performing work, etc.). People with impairments of a particular kind may be in a minority [11], but they are typically not thereby rendered incapable of work and social relationships. They need a more inclusive framework in which to participate.

In addition to pointing to the tangible environmental and structural changes that could be made to be more inclusive for people of differing body types, the social model of disability focuses attention on the attitudinal obstacles faced by people with non-standard bodies. Other people's expectations about quality of life, ability to work, etc. for a person with a disability not only affect the ways in which physical structures and institutional norms are made and sustained (based on presumptions about inability to perform), but also can *create* additional disability by making it harder for such individuals to feel good about themselves. For instance, Jenny Morris raises concerns about how "all the undermining messages, which we receive every day of our lives from the non-disabled world which surrounds us, become part of our way of thinking about ourselves" [quoted in 7, p. 22].

The impairment/disability distinction is powerful in lending support to people with disabilities who face unjust treatment and the tendency to medicalize their problems. In the words of one disability activist, it tells us that "ableism needs the cure, not our bodies." [quoted in 12, p. 18]. Indeed, as Crow acknowledges, the social model has done wonders for the disability rights movement. "It has enabled a vision of ourselves free from the constraints of disability (oppression) and provided a direction for our commitment to social change. It has played a central role in promoting disabled people's individual self-worth, collective identity, and political organization. I don't think it is an exaggeration to say that the social model has saved lives" ([2], p. 207).

We should not, however, lose sight of the fact that people living with impairments can experience negative effects tied more directly to their bodily conditions. People with impairments that involve, for example, fatigue, pain, depression, or chronic illness may want both to overcome social barriers and discrimination that oppress all people with disabilities, *and* to voice their desire to remove or address the troubling accompaniments of their impairments, through medical or other means. They may want attention to what have been called "impairment effects" [13]. No doubt, many medical professionals who might be sympathetic to the disability rights movement in general also see the downside of impairment effects and aim to address them with their medical expertise.

The social model of disability in medical practice

So how might a medical professional appropriately integrate the social model of disability into practice, particularly in relation to disorders that are often chronic in nature? Several scholars have articulated important aspects of this integration [e.g., 14, 15]. Two additional points are worth exploring here. First, we must ensure that medical professionals talk candidly about negative impairment effects while maintaining full respect for individuals with disabilities and fighting for disability justice, for full inclusion of people with disabilities in society. Second, perhaps, we should think more openly about how we understand the place of chronic illness in the disability/impairment distinction.

Recognizing impairment effects without sanctioning disabling practices

Discussion of the negative effects of impairment was, for a long time, excluded from disability rights writing, in large part because of the worry that acknowledging such realities would

undermine the important work of addressing disability oppression and discrimination. The gains made by the disability rights movement are still fragile and partial [16]. Given the pervasiveness and depth of belief in the medical model, people with disabilities may hesitate to acknowledge publicly any difficulties they experience. Jenny Morris expresses the worry this way: "For many this feels a very dangerous thing to say, in that we feel it makes us vulnerable to non-disabled people turning round and saying – 'there you are then, we always knew that your lives were awful because of illness or incapacity, we always knew what a tragedy it is'." ([3], p. 13). As a consequence, concerns about the negative side of impairment are sometimes discussed among people with disabilities privately, but rarely voiced in the public realm.

Reassurance and demonstrated practice that disabled people can talk about negative impacts of impairment in the clinic as well as in public, without fear of being treated as inferior, is central to treating people with disabilities justly. This may require education regarding disability rights and disability pride. Physician Kristin Kirschner, for instance, sees disability studies as a way to help enact a more biopsychosocial model of medicine and to address the troubling legacy of medicine and bioethics in respect to disability: "ignorance, lack of attention to and training about disability, top-down goal setting and decision making, resource and power inequities, and so on" ([17], p. 60). Calls for cultural competency in medicine might expand to consider disability competency as well [18].

The social model reminds us to be careful about what we presume to be irremediable through social change and to question the ways in which we currently understand disability. Challenging standard definitions of disability and impairment will require listening carefully to the experiences of people living with those impairments and thinking creatively about possibilities for inclusion, accommodation, and accessibility.

Rethinking chronic illness

How much could social change—even radical social change—actually impact the disadvantages of living with a condition like chronic pain? Can the social model of disability really handle chronic illness? Susan Wendell, a philosopher who lives with myalgic encephalomyelitis (ME), challenges readers to think carefully about their intuitions. On the one hand, Wendell argues in favor of ending ableism and working to address the oppression and discrimination experienced by people with all kinds of disabilities. On the other hand, she *also* would welcome a cure for her condition. Her position, set forth originally in her book *The Rejected Body*:

"I want to have more energy and less pain, and to have a more predictable body; about that there is no ambivalence….Yet I cannot wish that I had never contracted ME, because it has made me a different person, a person that I am glad to be, would not want to have missed being, and could

not imagine relinquishing, even if I were 'cured.' … I would joyfully accept a cure, but I do not need one." ([6], p. 83–84)

In a subsequent paper, Wendell reports that her readers have expressed surprise at this statement [12]. If she would welcome a cure, then how can she believe that contracting ME is something worth experiencing? Is she just trying to make herself feel better, given the lack of available cure? Isn't the impairment itself really her problem rather than societal attitudes or barriers?

To help explain her somewhat complicated position, Wendell considers a new distinction: healthy vs. unhealthy disabled. The healthy disabled are those who have bodily conditions that are "stable and predictable for the foreseeable future," who consider themselves healthy, and whose *medical* needs are typical for a person of their age. Someone who is deaf, paraplegic, or living with down syndrome may readily fit this description. Of course, one who is healthy disabled need not remain in that category continuously, but Wendell suggests that the broad distinction may nonetheless be useful. The unhealthy disabled, by contrast, have conditions that require medical treatment, that if untreated or untreatable cause individuals to feel ill and unable to take advantage of otherwise available opportunities, and that may fluctuate rapidly.

Having made the distinction, we might be tempted to think of the healthy disabled as clearly falling within the bounds of the social model, but perhaps not the unhealthy disabled. Wendell cautions against this move. She wants us to think broadly about the experience of all kinds of impairment, with careful attention to its diverse forms, meanings, and effects. She advocates acknowledgement not only of what is valuable about impairment (e.g., advances in understanding the structure and contentious nature of what is "normal" and what can be done to accommodate difference, rethinking of self-identity and social values, experience of and appreciation for alternative modes of functioning, etc.) but also what can be troubling about it (pain, fatigue, insecurity of health, etc.).

Part of this project requires rethinking the nature of illness itself. Why should we be willing to acknowledge that living without a limb is an acceptable form of human diversity [19], while living with an illness is not? Wendell asks, for instance, "Is illness *by definition* an evil, or have we made less progress in recognizing chronic illnesses as potentially valuable differences than we have in relation to other disabilities?" ([12], p. 30) If we see deafness and paraplegia as different but not necessarily lesser ways of being in the world (if we can celebrate them as distinctive ways of being that may even sanction a certain kind of cultural pride), then why not do the same for chronic illness or "unhealthy" disabilities? They too promote different ways of understanding and appreciating the world, of conceiving the self, of questioning the foundations of "normal." For most people, the difference has to do with suffering, physiological or mental suffering that cannot be remedied by social change. But Wendell carefully parses the significance of

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suffering, noting that "although most of us want to avoid suffering if possible, suffering is part of some valuable ways of being." ([12], p. 31). Some conditions of the body may be inseparable from physiological suffering (e.g., living with chronic pain or nausea), but the ways of life that people form within them may be quite valuable, and the suffering they experience may play some significant constituent role in what brings the value. Perhaps, not all who live with such conditions long to be rid of them given the chance; others would welcome the opportunity to eliminate the suffering, but might still value the perspective they have gained through it. As Wendell notes, "there are, I think, many versions of disability pride." ([12], p. 31).

Conclusion

The social model of disability points to several ethical considerations for health care professionals. First, many impairments and their effects that are presumed by the non-disabled to be quite negative may not be experienced as such by people with disabilities, or at least not in the ways the non-disabled presume. Listening to and engaging openly with the testimony of people with impairments is important. Non-disabled frames of reference have their own epistemic limitations. Consider the words of Harriet McBryde Johnson, a lawyer, sometime politician, and disability rights activist who employed a personal care attendant for much of her life. In her collection of essays, *Too Late to Die Young*, she remarked on how the kind of daily personal care for the body she relied upon is not undignified, but in many respects a deep form of comfort and connection that makes her wonder about the oddity and loneliness of a supposedly fully independent life. She says "I sometimes think how strange it would be to do these morning things in solitude as non-disabled people do, and to regard, as many of them do, a life like mine as a dreadful and unnatural thing. To me it is so natural to feel the touch of the washcloth-covered hands on flesh that is glad to be flesh, to rejoice that other hands are here" ([20], p. 251).

Second, even when the experience of impairment is negative, the *reasons* for the negative experience are often quite different from what the non-disabled presume. Again, many autobiographical accounts of living with impairments and fighting the disadvantages of disability explicitly point out that the *main* and sometimes the *only* disadvantage of the impairment is not physiological, but social; the ugly and unwelcoming attitudes of others, the strict insistence on the standard modes and levels of functioning, and the physical impediments to access all make people suffer. In this respect, the social model is very powerful at pointing to the ways that social norms can be disabling.

Third, even when the experience of impairment is negative and for reasons closely tied to the impairment itself (and not due strictly to social barriers), it still may not be *overwhelmingly* negative. As Wendell points out so well, suffering is something we generally seek to avoid if possible, but suffering is also an inevitable accompaniment of some quite valuable ways of being [see also, 21]. Attending more carefully to the negative aspects of some impairments that seemingly cannot be accommodated or remedied may spur greater research, not just for ways to "cure" but also for social and technological ways to facilitate inclusion.

Finally, given that impairment is often not what it is presumed to be, we should be wary of our tendency to *fear* it as mightily as we often do. Presuming that we live long enough, we will all, eventually, be impaired in one way or another, if we are not already. Learning to accept this fact will not only perhaps help to eliminate the us/them divide that continues to segregate many people with disabilities in social life but could be used to diminish the desperation with which many people seek the elusive state of perfect health. Reducing our fear doesn't mean that we cannot take measures to prevent impairment, only that we recognize how we can learn to live with them when they inevitably come, and how making social accommodations now will be beneficial to all of us in the long term.

Crow remarks that disability pride comes "not from 'being disabled' or 'having an impairment' but out of our response to that. We are proud of the way we have developed an understanding of the oppression we experience, of our work against discrimination and prejudice, of the way we live with our impairments." ([2], p. 223). This kind of pride surely does not require ignoring the negative side of some impairments, just as it need not involve "supercrip" stories of overcoming personal tragedy. It comes from the hard work of making the world a better and more just place for everyone, no matter what their bodily conditions may be. The social model of disability deserves more uptake within medicine.

Compliance with Ethics Guidelines

Conflict of Interest Sara Goering declares that she has no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.nt>

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