

Chapter 2

The Models Approach in Disability Scholarship: An Assessment of Its Failings

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Abstract The present chapter contends that the models approach to studying disability, when used in India, has little descriptive or explanatory ability and has become a way of evaluating research studies and judging them. While critiques of medical models approaches to framing disability have facilitated aspirations and demands of disability rights movements the world over, its present use in the Indian academic context requires critical examination. What is known as a medical model framing of disability cannot as conveniently describe or explain disability in the Indian context for multiple reasons. One, the social role of biomedicine in India is a complex one because of the prevalence of different kinds of treatment traditions that are accessed variously and whose conceptualization of treatment, object of treatment and corporeality are different in different ways from those of biomedicine. Additionally, the models approach intrinsically affirms a progressive historiography; the progression is from a moral or religious model to a medical model and then to a social-contextual model. Such a historiography is inadequate while tracing the genealogy of disabling conditions such as leprosy in the Indian context.

Keywords Models approach • Medical model • Social model • Alternative medical traditions • Leprosy history

2.1 Introduction

Disability studies conferences and seminars in India usually bring together a set group of scholars who are fairly well acquainted with the major debates of disability studies (DS), which is dominated by Western scholarship. But every event also

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brings newer researchers working on disability to the fore and face to face with the more established scholars. Often, such exchanges turn into tense encounters where an “established” scholar, in the discussion that follows the presentation of the “new” scholar, characterizes the latter’s work as bearing strong resemblances to the “medical model”. This subjection to a trial where judgement is made on the “new” scholar influences the participation of the person in future disability studies conferences and scholarship. The “medical model crime”, if one may use that term, refers to research pertaining to rehabilitation of a certain category of disability or the use of terminology that draws heavily upon the biomedical framing of a disability, or even focuses on the individuality of the disabled person and not on the social environment. The “crime” may be that the findings presented belong to the perspective of a rehabilitation or educational professional, one that does not adequately or fairly represent the “voice/s” or perspective/s of the disabled informants. Such kind of moral labelling forecloses the examination of the data presented or an analysis of why or how it might be “medical”. Such research may in fact contain important disclosures about the culturally¹ specific context that we belong to and research in. The present chapter critiques the “models” approach to studying disability, that is the use of the “medical model”, the “moral or religious model” and the “social model”, which has become a way of evaluating research studies. This chapter may also be seen as a status report on the way the models approach has been adopted in research on disability related to India. It discusses the practice of using the “medical model” and “social model” to judge and evaluate a piece of research which occludes the use of these categories as heuristic tools. In order to use these categories as heuristic tools, scholarly research would also have to test the efficacy of the categories themselves while employing them to describe or explain their research data; if not, these categories stand out as Holy Grails that limit critical advances in disability studies. This chapter investigates the role played by the models approach in research related to disability in and outside of the Indian context. In order to do so, the chapter examines recent scholarship that draws on field studies and research in social medicine and medical anthropology that attempts to historicize disability. A second intent of this chapter is to present a close reading of critiques of the models approach that have received lesser recognition in disability studies scholarship as the more prominent research, and scholarship has wholeheartedly embraced the models approach. Such a reading becomes essential for researchers and scholars so that they may engage with the models approach more critically while not denying that its adoption has facilitated a necessary corrective to the erstwhile one-sided conceptualizing of disability as a medical phenomenon and experience.

¹The term culture, for the purposes of this chapter, may be understood as “configuration of learning” and as a way of going about the world.

2.2 Elaborating the “Models” Approach

What is the “medical model”? And what does charging a type of research as being medical model entail? Medicalization of disability has been identified as presenting a restrictive understanding of disability. All practices that address disability as disease or as deficit conditions that can be cured or fixed in some way are considered to medicalize disability. This charge of medicalization in theoretical terms is called “the medical model” within disability studies which is primarily driven by the disability rights movements in the UK, and the corrective is supplied in the “social model” framework. Variations of the models approach include the “strong social model” that emerged in Marxist-style disability studies discipline in the UK in the 1970s as well as critiques of the “individual model” or the “deficit model” that were widely used in the American context a little later. These theories of medicalization and efforts to practice the social model as a corrective have served several purposes over the decades:

- (a) To enable disability as a category of politics—disability rights movements in different parts of the world have embraced the social model of disability as an attempt to demedicalize and depathologize disability and thereby enter the identity politics paradigm. The medical model has played an important role in putting disability on the social movement map. Tom Shakespeare refers to this as a “political strategy” in the UK context. In the American situation, critiques of medical or individual approach—that resulted in various systems of dependence such as institutionalization—were used to enable the “independent living movement”.
- (b) To change law and policy from an orientation that focused on addressing only the individual with disability to a focus that would address the structural factors such as physical and social barriers and restrictions. The UNCRPD is a good instance of such an initiative. The Americans with Disabilities Act (1990) in the USA and the Disability Discrimination Act in the UK (1995) are both legislations that are based on social models approaches. They refrain from defining disability on the basis of biomedical characteristics (which address only the individual) and turn the onus on treatment of disabled people as well as physical and social barriers that hinder independent living. These laws emphasize the improvement of social factors that enable a better quality of life for disabled people alongside rehabilitation measures that focus on correcting the impairment in the disabled person. Similar features are the mainstay of the UNCRPD which is to guide future disability laws the world over. The Rights of Persons with Disabilities Bill that is still being debated in India, a bill that seeks to be in compliance with the UNCRPD, upon being passed, will replace the fairly medically oriented existing disability law in India, the Persons with Disabilities Act 1995.
- (c) The models approach has played an important role in furthering the rights-based approach and enabling disabled people as participants in decision-making related to education, employment, law and policy related to

access to public spaces over the last few decades in India. As a result of this, disability has emerged both as a sociopolitical and as an identity category within disability rights articulations. Participation of disabled people in all forms of public life has become a reality in many parts of the world over the last three decades. The rights-based approach has been able to effectively check the advance of different eugenic practices, bring about the termination of dehumanizing practices of psychiatric institutions and introduce the practice of ethical medical procedures.

- (d) The models approach has facilitated the emergence of disability as a non-negative category or as one that does not predominantly indicate a “state of injury”. Disability as a category of diversity is being forwarded by several disability activist groups in the West in imitation of the civil rights movement in the USA. This argument has also been used by identity movements by other minority and marginalized groups such as the LGBT and Dalit (socially and economically marginalized) communities. This emergence of disability minority identity has aimed to move beyond the rights-based framework to one that demands a sociocultural identity, i.e. a move towards an identity politics framework, a good example of which is the deaf community’s assertion of deafness as a linguistic minority.

While the models approach has facilitated a strong social movement framework in policy making and governance, how can we appraise its role within academic research? Tom Shakespeare, an important voice in the disability movement in the UK as well as disability studies scholarship makes an important assessment of the models approach. Shakespeare argues that one of the problems with the social models approach in disability studies over the decades is that it has been posited as “unchanging”, as if its fundamental ideas are “correct and indispensable” (Shakespeare 2014, p. 20). The British social model, he says, is probably “one of the only areas in academia that still proudly maintains allegiance to Marxist orthodoxy” (2014, p. 20) that it persists as an outdated ideology-based academic framework. Shakespeare’s primary move is to pronounce that the distinction between impairment and disability, as forwarded by the models approach scholars, is an artificial one. He argues that the distinction between “biological/individual impairment and social/structural disability is conceptually and empirically very difficult to sustain” (2014, p. 21–22). Social circumstances and biology are inextricably twined in cases where the impairment is caused by social conditions. He cites cases of impairments generated by poverty and malnutrition and in situations where pain-alleviating treatment may not be available easily because of controls placed on distribution of drugs or poor income. In the latter case, the social restriction combines with the impairment in such a way that we cannot argue that the mere lifting of the social restriction would reduce the effect of the impairment, because the social restriction is brought into play by the very existence of the impairment. Further, Shakespeare argues that impairments are socially constituted as well and not only biologically. In the case of mild intellectual disability, the level of IQ that determines the having or not of impairment is determined socially. He explains that “dyslexia may not become

a problem until society demands literacy of its citizens” (2014, p. 23). He elaborates on social expectations that cause or exacerbate impairments and therefore impact the psycho-emotional well-being of a person with a physical impairment such as a spinal cord injury or a person diagnosed with a degenerative disease like multiple sclerosis. In such situations, removing the physical barrier or an economic barrier may not facilitate well-being because of emotionally distressing factors such as negative reactions from family members or colleagues at work or even the hyper-visibility of media representations of multiple sclerosis. Shakespeare cites this situation as one where we may not be able to distinguish between the impact caused by disablement and the impact caused by impairment.

A more recent critique of the models approach comes from Aimi Hamraie. She criticizes disability studies (hereafter, DS) scholarship for not adequately theorizing the “models framework” (Hamraie 2015, p. 110) as an “epistemic apparatus that the field of DS constructs” (2015) which enables the field to make truth claims about histories and epistemologies of disability. She argues, adopting insights from Foucault’s method of archaeology, that DS scholarship does not go beyond articulating situated knowledge. Hamraie, then, is interested in placing “the models framework within broader conversations in the history and philosophy of science in order to foreground the constructed, contested and contingent nature of systems of knowledge about disability” (2015, p. 111). The “models framework”, according to her, is not critical or self-conscious of its adoption of the progressive historicizing of disability which it assumes to be true, i.e. the progression from a moral model to a medical model and then on to a social model. The assumption that this progression is true limits DS scholarship from investigating messy contexts that show evidence of a mixing of moral and medical factors. The framework also tends to mischaracterize non-biomedical medical technologies as belonging to a premedical moral realm. She proposes the method of historical epistemology to be incorporated within DS research so that this field of inquiry may also reveal “the material effects of knowledge upon bodies, techniques and systems and analyse the systems of formation of knowledge (savoir) that make bodies intelligible” (2015, p. 115).

Both Shakespeare and Hamraie’s analyses have important implications for the present chapter as well as for the changes it seeks in contemporary disability research in India. They demonstrate the limits of the models approach within the Anglo-American Western context but do not grasp the complexity of cultural situatedness of the models approach and the problems that arise when we try to study disability in contexts that are as distinct as the Indian one. While Shakespeare’s critique casts the non-West as socio-economically different, Hamraie dismisses the cultural approach to studying disability as just another social-contextual approach that is invested in the ideology of situated knowledge. There appears to be an assumption that culturally different contexts can be described and known in terms of concepts that are native to Western epistemology. For instance, the use of the term “global South” is adopted and it succeeds in marking out the regions labelled thus in terms of socio-economic difference or in terms of religion and sociocultural practices. The category “global South” however misses the point that culturally different contexts may be so because their ways of knowing about and going about the world

are peculiarly constituted. We may be researching a context that may not be at all intelligible through concepts such as “moral”, “medical” and “social” and may therefore require us to develop a set of methodological and theoretical tools that will reveal what those concepts are. A culturally contextual way of theorizing would have to consider not just culturally situated knowledge but how that knowledge is conceptually and methodologically different. The scholarship reviewed here offers insights into these conceptual and methodological differences that disability scholarship pertaining to the Indian context would have to take cognizance of.

If we are to take the Indian context as culturally different in its engagement with concepts affiliated to the disability cluster—impairment, illness, medical diagnosis, family, development of institutions, social practices, notions of the individual, plural treatment practices—then it becomes relevant to critically investigate the relations between cultural context and disability theory carefully. In due course, precaution will be taken not to settle for categories of cultural difference that have been posited by the West with which to study India, in other words Orientalist categories. Harish Naraindas warns against the tendency to succumb to viewing and studying India as exclusively “religious” when compared to other cultural contexts (2001). Another instance is the use of karma, supposedly a category of fatalism that is peculiar to India, as an explanatory frame with which to comprehend all notions of and attitudes towards disabled people. The chapter will conclude with a reflection on issues pertaining to theorizing disability in the Indian context and what this review of the models approach can bring to such a theorizing.

2.3 Formulating a Cultural Critique of the Models Approach

Medical model research is classified as such by virtue of certain determining factors: one, the dependence of the research on biomedical categories that are treated as fixed and treatable; two, that the affected person exists (within the realm of the research study) as an individual entity whose voice is undervalued and to whom the treatment is administered after verifying that he or she requires a certain procedure established through objective methods of enquiry. Three, that there is a notion of “deficit” or “tragedy” associated with the individual affected which presents disability as a burden, flaw or negative aspect of the individual’s personality. Given that these are the criteria for determining aspects and phenomena in the research field as medical model, what are some of the concerns they raise when collecting disability-related data?

Insights from disability-related fieldwork: Sociological and anthropological ethnographic fieldwork undertaken by disability researchers has revealed that it is not easy to identify and classify phenomena as being part of a medical model; it is not a useful way of classifying responses. Respondents do not use biomedical categories to identify themselves as disabled (Staples, 2012; Mehrotra, 2013). James

Staples's ethnographic research in Hyderabad is about "how and when notions of 'disability' were invoked" (Staples 2012, p. 558) and why they were being invoked. His interest was in finding how disability is constituted discursively and in everyday practices. Significantly, his essay, "Culture and Carelessness: Constituting Disability in South India", begins with an affirmation that the official discourse of disability in his field area is definitively set within the medical framework, be it the government's categorizing of disability or NGO approaches to addressing disabled people's needs. He observed the ways in which disability is invoked rhetorically in the context he studies to identify the distinctions between the official discourse and people's use of the concept. Like Shakespeare, he finds categories of impairment and disability limiting, as there is a far more complex interaction between notions of the individual that are grounded in moral practices of individual selves and families. While interviewing medical practitioners and rehabilitation experts, he finds that they are quick to morally judge their patients who come to them for disability-related treatment by calling them "careless". They attribute "carelessness" as the cause of disability and the "carelessness", usually a euphemism for actions resulting from being poorly educated or being poorly informed, ranges from the patients' faith in non-medical cures such as visiting shamans or offering sacrifices at places of worship, to their inability to care for the disabled family members by accessing timely health care. Social structural factors such as poverty, unemployment or the hardships experienced because of poor lifestyle of migrant labourers were hardly ever identified as causing disability, factors that were highlighted by the social model. These medical practitioners who were themselves not in favour of the patients espousing religious remedies for their disabling conditions did not hesitate to assume a god-like position in dismissing patients' lifestyles as being immoral.

In his informal conversations with lay people in Hyderabad in southern India, such as auto-rickshaw drivers, street vendors, shopkeepers, students and other people he may have met in waiting rooms of clinics, Staples finds that the rhetoric is not very different from that of the medical practitioners. They identified poverty, inability to take care of oneself, improper sexual relations, not accessing reproductive health care and as individual failings of the disabled person or as failings of the disabled person's family. What is important to note here is that social structural problems are identified as personal failings of disabled individuals. These responses then trouble standard DS notions of "medical", "moral" and "social". The medical model, which is also known as the individual model, is almost absent in these exchanges where it seems to be an individual's moral responsibility to ensure a proper upholding of social structures.

Further, Staples finds that his respondents' "stated views about disability were frequently strongly at odds with their relationships with actual disabled people" (2012, p. 566). In their personal interactions with disabled people, the sense of personal responsibility attached to people not accessing timely health care vanished and was replaced by an attribution of their disability to fate, god's will or not having the resources to access timely medical care. Staples also adds that attribution to fatalism was rhetorical in nature and respondents seemed somehow aware of using fatalism rhetorically to respond to certain questions. Staples qualifies the fatalism as

a rhetoric because of his awareness of the types of treatment that the affected person had sought out in the hope of a cure before deploying such fatalism. He also finds that the fatalism serves as a rhetoric that is part of being in a disability context, rather than being indicative of what the person really thought of their condition, or of someone they knew or lived with. The significant finding here is that causes of disability in disabled people known to the respondents were differently attributed when compared to causes attributed to “disabled people” as a more general and abstract, third-person category. It would be inappropriate to categorize these responses that invoke fatalism routinely as being purely of a “moral” variety.

Fieldwork conducted by Veena Das and Renu Addlakha in Delhi also has significant implications for an assessment of the models approach. Das and Addlakha (2001) find that notions of personhood are located not at the individual level but at the intersections of the family and the state. They adopt the method of listening in on rumour, gossip and other talk around the family of the disabled individual instead of a method of collecting data drawn from interviews where the word disability is enunciated explicitly. They find using the names of disabilities or impairment limiting in trying to understand the social relations of women with facial disfigurement and those diagnosed with psychiatric illnesses. They study the daily practice of kinship and domesticity within the familial context in relation to disability and impairment. With regard to one of their case studies, they find that the parents of a woman with facial disfigurement, in their attempt to give her as “normal” a life as possible, forgo kinship relations and social interactions with their extended friends and family (Das and Addlakha, 2001). In relation to this particular study of a woman with a facial disfigurement, in a post-Partition Punjabi family, the authors find that within that specific context, there appears to be the presence of “connected body-selves” (Das and Addlakha 2001, p. 520) and no evidence of the individual as we standardly know it, as a constituent of the “medical model”.

In Staples’s work as well, we find that there is a dependence on talk about disabling conditions by the affected individual and people around them (2012). Neither of these studies focuses on how well-versed affected individuals, their families and health practitioners are in the medical definitions and rhetoric of their conditions, and so they do not lend themselves to conclusions about the ineptitude of people when it comes to being informed about medical notions. These studies point to the uselessness of categories used within official discourses to relate to the way that affected individuals and their families know themselves. Both these studies destabilise the significance attributed to disabled people’s agency by indicating that this agency is not located at the individual level but at the level of social interaction. While a key method of the models approach is to give primacy to the ‘voice of the disabled person’, these studies emphasise that acts of speech are to be acknowledged and comprehended in the context of and alongside social interaction. The constitution of disability is found at the interstices of interacting voices of disabled

persons, their family, their kin² and people around them. Based on the observations of their respondents' actions, these researchers have shown that the social responses to disabled people may only be recorded through observation of their actions and not through a record of their opinions, which may be formulated in a particular manner to be in sync with popular discourses.

Historical research and the medical model: Attempts to study the history of disability in the Indian context show that categorizing something within a medical model occludes rather than explicates an occurrence or a phenomenon. Leprosy serves as an illustration. A disabling disease with a long history of moral stigma attached to it, the only way leprosy could be made more socially acceptable was through a process of medicalizing by emphasizing its disease status. The case of leprosy is an important one as it demonstrates a more complex relationship between disability and the medical realm than what is understood as the medical model. It would be necessary to examine briefly the sequence of events and ideas that led to the moment when the medicalization of leprosy or its establishment as bacterial infection lent it a more tolerated social identity.

Buckingham's (2002) study of leprosy in colonial south India, particularly the Madras Presidency, shows that the earliest responses to leprosy in India, prior to missionary involvement, were governmental and medical in the early 1800s. Her study of responses to leprosy in the colonial Indian context complicates the DS models approach of a historical progression from a more moral framework to medical framework in knowing and treating disabling conditions. Her work focuses on the extensive research that was undertaken by authorities in the colonies when they encountered leprosy. This research, in the first half of the nineteenth century, arrived at findings that were similar to those of experts researching leprosy in Europe. Buckingham also documents that medical systems indigenous to the Madras context such as Siddha and the more pan-Indian Ayurveda had identified and distinguished between as many as 18 types of leprosy of varying kinds and degrees.

Leprosy discourses in India took a more moral turn later, in the mid to late nineteenth century, and became contextualized in a religious realm, most likely because of the West's experience of leprosy as a strongly moralized condition at an earlier period. When the missionaries took over leprosy governance in India, it became increasingly a matter of the "moral model". The leper's body was an important site where the contest between religions was dramatically played out. Christian missions that settled in India brought with them a story of leprosy that was plotted within a narrative that typified the leper as the innocent sinner, a reprobate

²Shakespeare's critique of the distinction between disability and impairment cited earlier in this chapter assumes that the voices of people around the disabled person, in the multiple sclerosis instance that he describes, may be negative, thus adding to the emotional aspect of the impairment of the disabled individual. This kind of an assessment of the voices of people surrounding the disabled person is difficult to make in the contexts studied by Staples (2012) as well as Das and Addlakha (2001). For one, the reactions of the people surrounding these individuals lead them to take actions of different kinds in Das and Addlakha's study. Two, what these "voices" say has to be understood in context and weighed as being rhetorical or not, as Staples's study demonstrates.

who had no role in being cast as such. It was projected that Christianity would save the leper through a programme of salvation that would ultimately become an important tool for conversion of natives into the new religion. What is significant about this emplotment, something that is often forgotten, is that leprosy was presented as a “problem” that needed solving, an idea that may or may not have been present prior to missionary intervention. Another significant aspect of the plot was the casting of other religions and their customs as being villainous to those affected by leprosy. A third feature of the leprosy story is that leprosy served as the stage on which the presentation of Christianity as a reformed and continually reforming religion could be performed. Medieval/early Christian characterization of leprosy as an evil condition and the leper as one who was despised and ostracized was shunned in the later Christian rendition that was prevalent in colonial India. The link between the missionary approach to the disease and the (then) new public health discourse was strong. Hospitals and asylums run by the Mission to Lepers received funding from the British government in India, thus supporting wholeheartedly the missionary initiatives. Significant actors of the BELRA (British Empire Leprosy Relief Association), such as Rev. R.G. Cochrane, were invested in Biblical notions of leprosy and applauded the transition the religion had made from severe Old Testament beliefs to the New Testament practices of bringing salvation to the leper:

It has happened that God in His mercy has overruled the mediaeval misunderstanding regarding leprosy and used it for His glory. Through it He has wrought a marvellous work, leading His Church into fresh avenues of service among people who, the world over, were utterly despised and rejected. ... God reveals to men from time to time human injustices which must be put right, and through His servants He issues the challenge that these things must not be (Cochrane, 1961, p. 22).

The public health view of leprosy, in its attempt to provide a rational aetiology of the disease, presented an orientalized picture of leprosy that succeeded in further moralizing the emergence and existence of the disease in India:

Leprosy may be regarded as a malady of uncivilized or partially civilized races, and its chief predisposing causes comprise personal uncleanness, overcrowded and dirty dwellings, combined with a dietary that is deficient in quality or insufficient in quantity.... The eradication of the native filthy habits and customs which predispose to, and assist in spreading, leprosy is recognised to be a matter attended with many difficulties; it would therefore seem that the hope for the future must lie in the education of the rising generation in the elements of personal and domestic hygiene. (The Lancet, 1913, p. 1557)

It is not hard to detect the moral tone that guards this seemingly scientific “public health” discourse in the report above. Evidently, the medical and moral had become so deeply intertwined that the more scientific of interventions had to be ushered in by those actors who were in fact working as social reformers and political activists. It was Gandhi and others who intervened around the 1940s, armed with up-to-date scientific knowledge about the disease so that measures such as sterilization of leprosy-affected persons and segregation based on sex would not be adopted. Gandhi was convinced that the procedures adopted to stall the spread of leprosy

were under-researched. He demanded that efforts be concentrated on the medical aspects of leprosy so that information emerging from that field could be disseminated to all parts of India. When people came to him with questions about leprosy prevention and treatment of persons with leprosy in colonies and villages, he directed them to Dr. Ernest Muir's work on the diagnosis, prevention and treatment of leprosy. Interestingly, Muir's work on leprosy, in general, differed from previous as well as contemporary medical scholarship, in that it rigorously attended to scientific medical efforts at addressing the disease. It was during Muir's tenure with the BELRA that leprosy-related projects in the British colonies became invested in medical research that would thwart the disease's march. Muir's term in India also saw an increase in the use of *chaulmoogra* oil in treating leprosy.³ The history of leprosy in India serves to show that the framing of disability historicizing that is inherent to the DS models approach cannot adequately describe histories of disabling conditions in the Indian context. Another challenge leprosy history throws up is that different forms of treatment persisted through the centuries whose epistemology varied drastically from the biomedical knowledge system. Can those modes of treatment be assigned the category of the "medical model"?⁴ Or is the notion of the "medical model" inherently related to biomedical forms of treatment?

A plural medical context: A third area of research that enables a critical examination of what the medical model means in context would be the prevalence of multiple treatment conceptualizations which challenge the very criteria that constitute the "medical" as per the models approach. Unlike American or European contexts where the turn to alternative systems of medicine is more recent, India has a long history of plural medical practices. Thus, it becomes important for us to examine the links between certain underlying conceptual and epistemic frames of these practices, be it text-based ones like Ayurveda, Unani and Siddha or others like bone-setting and indigenous birthing practices. These practices are not only systems of knowledge or methods of medical practices that are different from biomedicine but also systems that are grounded in epistemological bases that vary from that of biomedicine in the Anglo-European American West.

Ayurveda and Siddha conceptualize the human body as "a system of relationships defining functions which manifest themselves through the structures" (Jayasundar, 2012, p. 42). In Ayurveda, a function is constituted by collective effort of various factors, including structures (as in biomedicine), biochemistry, electric and magnetic activities and the mental and emotional status of a person. For instance, these systems do not assume the duality of mind and body or conceive of the body in terms of separate systems such as the skeletal system, the endocrine

³*Chaulmoogra* oil was used in Ayurvedic treatment of skin diseases for a long time prior to its emergence as an ointment expressly used for the treatment of leprosy. Its use in China and Burma at the same time is also variously recorded.

⁴The question this chapter raises is at a tangent from Hamraie's (2015) research question that points to the problems of designating only biomedical forms of treatment as "medical" and not other forms of medicine that were based in humoral systems.

system and so on. A function, in Ayurvedic terms, reflects the whole system of a human being where a variety of components work together to constitute it (Jayasundar, 2012). Siddha practice does not regard disease in terms of organs affected, so the concept of organ is not a useful entity within the Siddha tradition. In Siddha, different substrata of the body are composed by substances that nourish them, be they items such as food and water that nurture the earthly or gross parts of the body as well as subtle substances like *prana* (the concept of air circulating through hollow channels of the body) and thoughts and intellect (Sujatha, 2012).

Ayurveda uses the concepts of *vata*, *pitta* and *kapha*,⁵ the *tridoshas* (three elements), that refer to “a set of parameters which include functions like movement, transformation and support and growth, respectively, and other physico-chemical and physiological parameters contributing to these functions” (2012, p. 43). The *doshas*, however, literally mean “that which can become impaired and also [have] the potential to impair other tissues” (2012, p. 43). These *doshas* include physiological as well as psychological functions. The concept of health within this system of medicine is not linear (as in biomedicine) and refers to a homeostatis or fine balance among the *doshas*.⁶ Thus, “disease”⁷ as well is a result of imbalance in the *doshas*.

“Diagnosis” in Ayurveda consists of an assessment of any deviation from the state of equilibrium of *doshas*; the impaired *dosha* has to be identified. “Diagnosis” here includes the evaluation of the inherent mental and physical constitution of the patient, age, occupation, the season in which the “disease” has manifested itself, the immediate living environment of the patient including the weather, the food habits of the patient and so on. Ayurvedic “diagnosis” is aimed at knowing the root cause of the disease condition. As the method of treatment is tailor-made for a specific patient, it is important to know all these factors; sensitivity to context is of prime importance (Jayasundar, 2012). Ayurvedic diagnosis also pays keen attention to cause of the “disease”, why something is happening to the patient, rather than merely knowing the symptoms or what is happening to the patient. These treatment traditions provide personalized treatment to each patient, thus not repeating the same method of treatment even for two people who may have the same symptoms and, in the DS framework, the same impairment. Given this, it would be impossible to have a common diagnostic category and thus follow an objective system of naming and labelling diseases. Contemporary DS, framed within the models approach, discredits attention paid to the individual in biomedical treatment procedures because this attention locates the “problem” within the person of the

⁵*Vata* refers to air, *pitta* refers to fire or heat, and *kapha* refers to characteristics of fluid or fluidity such as unctuousness, coldness, heaviness, sluggishness and so on.

⁶For instance, if there is a variation in one of the *doshas*, the components of the other two *doshas* are automatically affected. If the dryness of *vata* increases, there is a decrease in the oiliness of *pitta* and *kapha*.

⁷The quotation marks around a word/concept in this discussion indicate that the concept is not native to the system of medicine being discussed and is a placeholder term that refers to a somewhat similar notion.

individual affected. But it is important to consider that the critique here is of the objective nature of biomedical knowledge that decontextualizes the person by treating him or her as representative of an infected body. The other systems being surveyed here depend on subjective experiences and the narratives of those experiences as *sui generis*.

Siddha tradition believes that the only source of knowledge for treating the living human being is the living human being; “one can never study the flow of *prana* in a body that is devoid of *prana*” (Sujatha 2012, p. 86). Siddha practitioners believe that cognition is something that everyone is capable of because they include perception and inference (2012). So also, as in Ayurveda, knowledge of the “disease” is based on how the patient experiences their ailment (Bode, 2012). The context is important to “diagnose” the disease as well as the information given by the patient; both contribute to this process of diagnosing in ways that are different from the biomedical system. These systems then deploy narratives of the patients to develop the treatment. In a volume titled *Multiple Voices and Stories: Narratives of Health and Illness* (Mishra and Chatterjee, 2013), the editors discuss the significance of narratives in non-biomedical treatment practices. The volume of essays draws on studies of narratives of practitioners of different medical and treatment systems as well as the patients. Though the introduction to the book acknowledges its debt to the emergence of illness narratives within biomedical practices as a guiding framework (Mishra and Chatterjee, 2013), it becomes clear as one reads through the essays how and why narratives are intrinsically part of these treatment traditions.

Ayurveda and Siddha systems, as also bone-setting traditions, depend heavily on the knowledge that a person has of themselves and their bodily functions; therefore, the narratives of patients play an important role in developing the treatment. Treatment in Ayurveda is denoted as *chikitsa*, which includes procedures “aimed at removal of disease-causing factors” (Jayasundar 2012, p. 51) as well as repair of imbalances (2012). The root causes and not surface-level symptoms are the focus of treatment—another reason that the narratives of patients form the corpus of knowledge which also forms part of the treatment. Siddha and Ayurvedic practices address the patient in context. In order to know the context of the patient, these systems need the active participation of the patient to inform them of their contexts in terms of environmental factors, daily activities and bodily functions. This gives the practitioners a sense of minute changes in the routines of the person, including why they may have done something differently on a particular day. Details like this invariably involve a narrative that describes the social context of the person being treated. Treatment in turn is developed to address the specificities of the individual’s condition in context, thereby giving us a different theory of individuality, one where the treatment is individuated, not the person. What this demonstrates is that the context and the individual are contiguous; the separation between the two does not exist in the conceptualization of “patient”, “disease” and “treatment”. In disability terms, this translates to knowing the individual lesion or condition as well as the social context of that condition. The “social” then is not separate from the “medical”; it is intrinsic to it.

With regard to these complementary and alternative medical practices, it is important to engage with the charge that is often levelled against practices such as bone-setting and the *dai* (midwife) tradition, not so much Ayurveda, Siddha and Unani, that they belong to unscientific or premedical and therefore irrational practice systems. Within the DS framework, these practices may also be characterized as evidence of the “moral model” or the “religious model”.⁸ In her study of bone doctors in Rajasthan in 2009–2010, Helen Lambert finds that the practitioners describe their work in terms of “moral” practices (2013). On observing the narratives she compiles, it is clear that her use of the word “moral” indicates “ethics” and is therefore descriptive, to convey the sense of appropriate action, and not be confused with the evaluative use of the word “moral” in the “moral model” of the DS framework. These bone doctors commenting on the ethics of their practice claim that they provide “decent, affordable” (Lambert 2013, p. 35) treatment to their clients and do not make a profit by exploiting them. Lambert records that on occasion these practitioners provided free treatment as well to clients who could visibly not afford the fees. A few respondents also characterized their work as a form of “public service”. This kind of discourse of providing affordable treatment and service could easily be typecast as belonging to the “moral” or “charity model” in the DS framework. However, it is significant to note that the bone doctors’ narratives of themselves match the narratives of their clients who state that they prefer them to government hospitals that charge exorbitant amounts as fees, for medicines and tests as well as for the plastering procedure. The characterization of their work as public service is a reaction to the doubts expressed about the rationality or viability of their profession by biomedical practitioners. The rhetoric of charity, then, appears to be a way of establishing themselves as ethical practitioners in the face of threats from biomedical institutions that are supposedly manifesting unethical practices.

In case of the “bone doctors”, they are also *pahalwans*, or wrestlers, who belong to a community in which the tradition of *pahalwani* and bone setting is passed on from generation to generation (Lambert, 2013). This was also true of Siddha *vaidyas* (medics) and Ayurvedic practitioners before the government’s support of these traditional medical systems, through AYUSH, gave a fillip to more widespread teaching and imparting of these systems. Their knowledge of the “art” is not textually acquired but gained through a lived practice of an “ethics of the self”, to use a Foucauldian formulation. In a sense, it is through knowledge and practices related to one’s own corporeality that they have the expertise to treat others who approach them to treat joint dislocation or broken joints. If one were to cast this information in terms of the DS models approach, these systems run the risk of being identified as belonging to the “moral model”, which is many times a euphemism for methods and practices that are pre-Enlightenment.

⁸Hamraie (2015) also makes this point in her chapter with regard to the West that humoral medical practices have been relegated to the moral model because of the progressivist framing of DS, which necessitates that the medical, in the sense of the biomedical, be regarded as an improvement on the “moral” (implying humoral) practices.

These systems are also community based, meaning that one has to be born into a certain community or caste group to be able to continue a certain practice. This is also true of Ayurveda and the *dai* tradition of midwifery. Chawla's (2013) research group in the Jharkhand area examines the epistemic aspects of the *dai* tradition and argues that it is one instance of subjugated knowledge or subaltern knowledge that is suppressed by the development discourse which gives primacy to propositional forms of knowledge and not practical forms of knowledge. While this line of argumentation belongs to a larger set of discourses on subalternity and development, this chapter is concerned with how the disregard of certain kinds of knowledge that are intrinsic to a specific cultural context demonstrates a kind of cognitive enslavement (Dhareshwar, 1998) to not just Western epistemic frames, but also to the indifference that Western epistemic frames bear towards non-theoretical forms of knowledge.

2.4 Conclusion

If studies of disability are undertaken to reveal insights about this phenomenon that we call disability, then we would have to retool our theoretical and methodological toolboxes so that they serve our purposes appropriately if not adequately. It is time to recognize the limitations of the DS models approach and develop theoretical and methodological tools that are context-sensitive. Insights from existing research, reviewed in this chapter, strongly suggest that the very notion of the individual as distinct from the "social" that is intrinsic to the critique of the medical model is conceptually unavailable in certain contexts. Second, the progressivist routine that DS scholarship is imbued with runs the risk of turning disability research in all contexts into a primarily moral discourse that is more invested in fulfilling its reformist function than developing a knowledge base. In wanting to adhere to the agenda of a "transformative scholarship" that "serves a remedial function", researchers should not forget that it is "necessary to correct omissions, inaccuracies and faulty logic" (Linton 1998, p. 531), even if it means that these "inaccuracies and faulty logic" (1998) are created by what may be considered the founding ideas of DS scholarship. A theoretical retooling would enable research that is not restricted by temporally and culturally specific conceptual frames such as 'moral', 'medical' and 'social'. Methodologically, disability research would require that we not assume that "voices" of disabled people are available to us just because we are able to conduct interviews with them. Conversely, speaking to persons related to or known to the disabled person, about them, or a health practitioner who treats them does not mean that the concerned research study would fail to reveal significant insights about the conceptualization of disability. This chapter does not propose that another more appropriate set of models replace the existing models framework or that a new model that is more sensitive to diverse cultural contexts be formulated; rather, it has tried to critique the use of models as limiting and looks forward to a scholarly practice that is more critical of the theoretical and methodological tools it adopts.

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