Literary and Cultural Disability Studies: An Exploration
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Lecture – 42
Medical Humanities and Disability

Dr. Hemachandran Karah: Hello. Welcome all of you again, this time the title is medical humanities and disability. Well, you may be wondering we are doing a course on disability studies and why medical humanities. So far, you may have observed there is some tension between the medical model and social model and I have indicated many times that both the models are required. But we need to have a critical understanding of practices of medicine and even health. For that reason, there is a robust field as old as disability studies and I guess it has very close linkage with disability because disability is a very important human condition. So, understanding medical humanities with some attention to disability therefore is very helpful. Well, there are controversies about the name itself medical humanities because some say it is a very restricted term focusing on just medicine and doctors. Some say health humanities will be a much larger and comprehensive term. We have here Dr. Shuba Ranganathan from IIT Hyderabad, who understands both medical, humanities medical anthropology as much as disability studies. it is quite a privilege to have her here on skype. So, let us start straight away Shubha can you tell us about yourself and then we will go on from there I mean your work in medical humanities and so on.

Dr. Shubha Ranganathan: Hi Hemachandran, nice to be here again. Thank you very much first of all for inviting me to join in this conversation about two fields which I am just beginning to learn about actually. So, Hemachandran has been quite generous in his introduction to me but I am just dipping my feet in the waters of both disability studies and medical humanities. But I do think that medical humanities both as an approach as well as a discipline does offer quite a lot of promise for looking at questions of pain, suffering, illness, disability through a more holistic and interdisciplinary perspective. So, my own background my training has been in psychology and I have been working on health and mental health. But I have also been working on health and mental health from a more anthropological perspective. So, medical anthropology would be the closest field that sort of describes the kind of work I do. So, I do think it is really important to have

more of interdisciplinary work. Nowadays so, bringing together you know psychology, literature, anthropology, sociology, cultural studies all of these in looking at questions of health and illness. So, and given that disability studies is also framed by the social model of disability which you know looks at not just a biomedical approach it is very important to have these conversations.

Dr. Hemachandran Karah: Great Shuba. So, let us begin with the term medical humanities what does it comprise Shuba, what are its broader persuasions and how does it inform many things like illness, patient's experience doctor-patient relationships and much more how does it inform?

Dr. Shubha Ranganathan: Yes. So, I mean the origins of medical humanities actually does sort of historically go back to the field of the practice of medicine. Not just the disciplinary field or the knowledge base of medicine but more of the practice of medicine with the recognition that medical education needs to include topics which are not directly from biomedicine but which are related to engaging with patients for instance topics on communication, topics on representation of illness or representation of the body in art in literature in sculpture. So, medical humanities as a broad term I think it encompasses various disciplines as I said and it is really a way of understanding what it means to be human, what it means to deal with questions of illness or healing or suffering. So, in that sense much of the medical humanities courses typically have their origins in medical schools. And their aim is to inculcate a sense of the social science in the practice of medicine. So, to train their doctors in how do you engage with people who have different belief systems regarding the body or regarding pain or suffering. As well as how do you understand the different kinds of social contexts in which you know you are practicing. So, it was more of I would say with the intention of in a way humanizing the practice of medicine but American humanities since then has moved beyond that has been beyond the medical school as well has been beyond medical curriculum and medical education, yeah. But I would still say that largely many medical humanities courses and programs are sort of related to medical schools.

Dr. Hemachandran Karah: That seems more or less obvious because in the first place as you rightly said it was meant to humanize medicine. Because in the latter half of the 20th century onwards, I think arrival of huge technology industry like MRI and ever-

increasing influence of pharmacology and pharmaceutical industries medicine has become more of a corporate enterprise and doctors increasingly are trained to focus on just pathology of the body and not the experience of illness. So, there in some sense dehumanizes the entire enterprise even astute students get dissuaded from listening to patients when they become doctors. So, in a sense I think as you say medical humanities in some sense bridges the gap between medicine as a science and as an art may be an art that deals with human experience. So, this is being the origin medical humanities has both the side. On in itself, it can function as an independent field where people like you and me and I mean we can for example dig into a literary archive in Indian scenario and come with its own interpretations of illness, care giving, health, suffering and so on. Or one can design curricula in such a way, it helps medical training or medical education where professionalizing care giving and treating becomes fully holistic so to speak. So, well going from there Shuba, how does it actually work in the medical field. Let us talk about for example dehumanizing. So, how does it humanize things I mean we understand that reading literature and the novel we become sensitive but one can just read them and just forget you know what I mean and how does it even help a doctor?

Dr. Shubha Ranganathan: Well, I mean at a very basic or obvious level I would say understanding the diversity of human experience across the globe. So, there is no one way of being ill or being well. There is no one way of defining even what is illness and what is health. So, I think even the recognition of that heterogeneity and that diversity is something which would be important. So, for instance when do people go to a doctor or go to a clinic for reporting a symptom? When you are looking at health seeking behaviours looking at people accessing health services people who are engaged in health seeking behaviour if they see themselves as having a problem or they label something as a problem and potentially and illness but again how in some contexts people might not even see. For instance, let us take something like pain which is such a in quake kind of experience, it is very vague very difficult to define very subjective and it is the one you know physical symptom or physical category really which can only be identified there is no known diagnostic test for it can only be identified by report of patients. In some contexts, people might see pain as a normal part of everyday living and some context people would not report it. So, for instance I have a student who was working on pain and she is working on pain and she went to a government doctor in a government hospital recently. And she described the project to him and he said you will not find

those kinds of patients here people do not come here for chronic pain. They just take whatever over-the-counter medication they can get their hands on and they sort of get on with their lives I mean they do not necessarily label a problem as chronic pain or even see that as something to get help for. But you change the class you move to you know an in one upper class spectrum or a middle-class spectrum. You move to a middle class or you know upper class you move to a different social demographic and you see a lot of pain clinics and pain centers and Ayurvedic treatments for pain and all kinds of service providers. So, I think medical humanities at a very practical level is about you know giving the knowledge to doctors. And a lot of this knowledge comes from medical anthropology about the diversity of human experience and then I would say another very practical kind of application is about communication.

Dr. Hemachandran Karah: Can you explain more?

Dr. Shubha Ranganathan: For example, communicating pain is it a tingling pain or a stabbing pain or a deep pain. You know, there are lots of 100 varieties of pain.

Dr. Shubha Ranganathan: Yes, not only in terms of the kind of words which are used but even for instance in terms of how much to talk. So, like in the Indian context you know the field of medicine is also very hierarchical. So, it is very clear that the status of a doctor is different from a status of a patient. It is very clear who directs the conversation it is very clear that patients respond, patients answer. They do not direct the conversation they do not steer the conversation in specific ways and if patients are not asked the question, they may not report. Or if patients think that they are expected to say yes that is what good patient behaviour is. So, I think even understanding the psyche of the specific patient who that one is working with and then learning to communicate.

Dr. Hemachandran Karah: So, in some sense first, medical humanities can aid cultural competence and also empathy and bringing empathy and communication role together in medicine training. For its own sake how does it work, Shuba, generating knowledge. For example, your student went to government hospital but what if your student digs up folk narratives and come up with explanations on illness and grandma's medicine and so on. What does it do to medical humanities?

Dr. Shubha Ranganathan: It changes the idea of what is medicine and it changes the idea of what is healing and that healing is not necessarily the bio medicine dominated kind of feeling which we understand. Healing is not just the sort of the absence of cure I mean this was one of the papers I have written. Yeah. So, I mean I brought it up because even the notion of cure is something which has usually been defined from a very biomedical frame, right. But feeling healing may not necessarily overlap with cure I mean it may extend it may be beyond that. So, I think in terms of spurn. So, there are contexts in which patients do not just want to get treated they want to feel wholesome. So, that and then you have wellness movement which is really about propagating that right not about being well not just about being well and not being safe but about having a full and complete sort of life about being better than well. And then there are some contexts when for patients it is not just about whether they get well or not but about the process and the path to feeling they do not want that path to be an unpleasant or a painful or a troublesome one. Process of treatment and healing to be something which involves them or where they understand what is going on. I mean it can go the other way as well, they meet some patients who do not want to know anything about their disease and they just want to get rid of it. To impart the idea to doctors that there is not necessarily one perfect way of doing things as a doctor I think that is something which is really important that there is no black and white.

Dr. Hemachandran Karah: Most definitely because existential questions do not have yes and no answer, they cannot fit into objective type answers nor they can be narrated in five minutes of patient doctor interview. It looms large and imparting that knowledge to both the patients and doctors and the health system at large is important task that we all have for now. And hence the relevance of medical humanities as a field, I guess. But bringing this disability component how does it work Shuba? Because see on the one hand, we have feminist scholars usually talking about care giving in the private sphere. There are those who talk about access to health as human rights. For people with and without disability; there are others who get into phenomenology of illness and disabilities and together. Also, like Carol Thomas who talk about impairment effects I mean she said in the social model do not delete the challenges the impairment poses because it is real it is very very real. So now where do we fit this whole different kind of labels. We will talk about labels then real situations like you did mention about pain you

did mention about suffering. I would add illness and disability then how where will it go? how does it go?

Dr. Shubha Ranganathan: So, when it comes to disability, I think the social sciences their contribution to disability studies is also very central. Recognizing that what is really needed in the understanding of issues of disability is a social science perspective. And I mean here so, in the social sciences you know there is a material discursive perspective which is really about arguing that there is a material context social phenomenon at the same time there is also a discursive context. So, taking a very extreme radical constructivist position that all kinds of appearances or all the categories are socially constructed sometimes can be equally damaging even while be enabling because it may not necessarily you know recognize a very real material context in which people are living. So, you think of caste being one very good example for that. So, I mean it is all very well to sort of argue from a radical constructivist or you know argue that caste and poverty are all at the level of discourse at the level of language and you know there are constructions of the mind but that does not recognize the very real conditions of living that people are housed in. So, the material discursive perspective in the social sciences bridges both and something like that is important even in fields like disability studies or for instance in fields which I work in mental health as well where you have a similar sort of situation of some extreme position that there is absolutely no such category as mental illness and or the idea that mental illness is a myth or it is just a construction or is just a means of social control. And while there is an element of truth to it. I would say to over generalize it would be to sort of negate or deny the kind of suffering that people go through. And ultimately, I think so, from disability studies the learning for me especially for the area of psychosocial disabilities that mental health has taken is to recognize the voice of the person and how people choose to identify themselves. So, one person might choose to identify themselves as a disabled, someone might not choose to use that label one person may choose to identify or to oneself as having an impairment. So in a very medical sense. But for me I think what is important is to sort of allow a plurality of different options or different approaches.

Dr. Hemachandran Karah: Great. So, doctors now let me talk about doctor's dilemma now. See on the one hand, doctors know a lot about human body and they have a box of labels maybe a big box of labels connected to the bodily functions and non-functions.

And on top of that, they have a commitment for their professionalism maybe do no harm something like Hippocratic oath. So, I am here to treat my patient and the person who is sitting in front of me is my patient. So, I myself have experienced this once I enter the doctor knows that I am visually impaired and if I go with eye pain then instead of focusing on the pain the focus for next half an hour will be about focus on curing my blindness. And even if I insist no it cannot be, doctors somehow because of the commitment for their work and a commitment for curing his or her sympathetic attention, real genuine attention will be about curing. So, given this but a person who is hardened in disability rights would see that as a I would call it even insult but somebody who is as much committed who can understand doctor's predicament may be more understanding. So, I am just giving a real-life conversation in a doctor's consulting room.

Dr. Shubha Ranganathan: Absolutely, I mean how doctors choose to define the problem may not necessarily be in sync with how patients choose to define the problem. I mean in the field of mental health; this happens all the time when let us say if a person who is diagnosed with schizophrenia complains of some kind of physical pain or physical symptoms. A psychiatrist might be very quick to assume that this pain is also somehow psychogenic in origin or you know the label of schizophrenia or mental illness sort of over defines the patient for them just as you know in your case. The level of disability over defines your identity. So, I think even learning to listen there doctor patient communication is not just about doctors talking and thinking but about really learning to listen. I think that is a very important feature.

Dr. Hemachandran Karah: It seems like a very difficult task; I mean in some sense we expect from doctors which is not actually practiced by other professionals. So, I do not find in my own profession teachers not necessarily teach from a student's point of view. There are aggressive PhD supervisors and just who talk about rules and not the person. How are we going to? Really this seems more like an ideal rather than a doable situation, is that a fair description Shuba?

Dr. Shubha Ranganathan: Are we placing too much of a burden on doctors?

Dr. Hemachandran Karah: Yes, I mean maybe I said that.

Dr. Shubha Ranganathan: Yes, I mean that is how I read it at least. No, I do not think so and I do agree with you that this is some empathy you know the qualities that we are talking about but piece of listening empathy you know qualities of care right I mean these are required in a variety of other service professions also. And increasingly you know the best I would say the best service professionals are those who are able to imbibe those qualities. So, I do not think it is an unfair burden on doctors. I mean, the response would be as to why should doctors be exempt from that. I think it is also about medicine in at least as practice the traditional way has very set ideas about what is a success and what is failure. Successes and what are the failures of medicine. So, someone refusing treatment for a condition that they could possibly cure you know be seen as a case of failure for a doctor. I mean, if the person chooses to do it for whatever reason either religious cultural beliefs or practical reasons whatever it might be seen as a case of failure in medicine even when you know as social scientists we know that treatment and cure is not the only or even perhaps the most important thing. So, it is really about bringing the shift changing shifting the language from cure to care by recognizing that care itself cannot be defined in a singular way

Dr. Hemachandran Karah: Great. The humanities, medical humanities are in that context care context talking about something like narrative medicine, what is that Shubha?

Dr. Shubha Ranganathan: What is narrative medicine? So, I mean the narrative perspective is all about the power of language and stories it is about how we understand our lives as storied constructions. So, we live out stories in our lives which means that you know there are characters there is a plot there is some idea of what kind of ending. It might be there, there is a sense of action and movement stories are about happening things happening to people. So, these are just descriptions they are not like factual descriptions of what is true but it is about someone having tuberculosis and how it affected his or her life and what they did and what happened to them. So, stories are really about that. And yeah, I think in medicine it is even more important. You know, we talk about illness narratives, correct that especially when people are affected by some serious kind of disturbance or disruption in their normal life story and there is a tendency to then ask the question why me? And there is a tendency to weave a story around that which is your illness narrative.

Dr. Hemachandran Karah: I could recall this nice autobiography Dr. Paul Kalanithi's 'When breath becomes air' he was diagnosed with stage four cancer and he was a leading neurosurgeon and he had only a year to live and that triggered him to write that remarkable self-reflective I mean he wrote to live. He wrote so, that he can discover his meanings in the final stage of his life. I mean existential drive to write that is what prompted him to write such a very nice autobiography. So, what you said now about narrative medicine we are storied reality and we are all made up of feelings and these feelings cannot be just generated or captured by statistical analysis or blood chemistry blood report we tell ourselves and caregivers tell us something and you or you only need to visit a patient who has recovered and just still listen to him or her. And that immediate caregivers how they recall the battles lost and won, you know it is all about their spirit of resilience and much more. Well, Shuba that makes me slowly move to your work in medical humanities. I would say it is a very fine work of cultural psychiatry. Well, I am defining it that way I am sure you define it much more in a nuanced way.

Because 10 minutes ago, you said mental illness for example cannot be defined just by a label because it is also an experience. It is also a spiritual it also connects with one's spiritual universe, one's well-being, one's past one's future one only has to listen to Reshma Valliapan's interview a couple of weeks ago in our course. The way she defined her condition schizophrenia, it is not there in any book of that is defines schizophrenia. You know, for her it is all about her commitment to multiple urges sensations voices and commitments that come from inside; that kind of definition I never that kind of definition I never heard anywhere.

Dr. Shubha Ranganathan: Yes, because it is a first-person narrative. But in the field of mental illness, the expert perspective has a certain definition about what is Schizophrenia but of course the experts are not schizophrenic. And it is only until now, we are now with the survivor movement and you know people like Reshma arguing that we are also experts by experience you know given that the doctors the psychiatrists the clinical psychologists they do not know what it feels like to see visions or to hear voices or to have compulsive urges for instance. But people who experience a condition do know, I mean they know some of it. And that kind of knowledge is equally valid if not more it is equally important if not moving that is what the experts by experience perspective really argues. So, do we need a user survival movement in the field of

medicine broadly in India? I think so. you know I think for too long, patients are not seen as consumers. They are not seen as people who were using and accessing a service and I think they are seen as recipients. In a sense, not necessarily as having rights but getting benefits seen as recipients who are getting benefits either from the state or from the system even if it is private practice right, there is no concept of patients' rights. I mean, it is almost you are made to feel as if you are obliged with the medical system for getting the services you require. Even if you are in private practice and you are willing to pay and all of that you still have to wait in a waiting room for a long time you are still told what you need to be doing or how you should keep doing it. I do not think you are taken on board. Your perspective is not taken on board.

Dr. Hemachandran Karah: Well, tell us about your work with on field Shuba. Mahanbao Sect and you have written good many amount of articles on field work. You went to those temple lived there participant observation and yeah maybe you can begin there, maybe I can chip in whenever I need some clarification.

Dr. Shubha Ranganathan: So, my work began with an interest in looking at extreme states and I was looking at women's experiences of trance and possession in healing temples and healing shrines. So, I was looking at women who went to different kinds of healing sites because they had some kind of difficulty which they attributed to a case of possession and black magic. And for a case of being possessed by ghosts being a victim of black magic and they went to temples or sites which are seen as having a power to heal these kinds of cases. And part of the healing process in the temple also involves going into a trance. I have done field work to try and understand the narratives around possession around illness around healing context. And I think it has very important implications for even telling us as to when do people label a problem as a problem? So, how do people define what is illness and what do people look for when they look for healing. So, what I found is that for many of the women it is also about accessing a space which is very accepting which gives them a kind of freedom and a space which they otherwise cannot necessarily access in their everyday lives which breaks them from the mundane and the monotonous routine of their everyday responsibilities. And gives them a space to just be and it also builds a community network of fellow sufferers so to speak in ways which otherwise are not necessarily directly accessible to people. So,

pilgrimages I mean staying in healing shines they offer a range of opportunities for women in certain contexts who sort of broaden their experience.

Dr. Hemachandran Karah: I get this point about them getting into possession and they seek temple rituals. You, Sudhir Kakar and many have detailed documentation about such states of mind and spiritual experience. But modern medicine would dismiss it this in one statement as or one word as superstition. Nonscientific bit or even rationalist our own humanities people many may also see it as a source of exploitation of poor people. So, how do you deal with such contradictions when working on such things for yourself as an academic and working from the field of medical humanities. So, was that a clear question Shuba?

Dr. Shubha Ranganathan: Yes, I understand the question. I think that kind of dismissal of these kinds of local healing practices as a superstition or as unscientific or irrational comes from the notion that there is one way to do science. And there is one kind of science which is or should be universal but when you come from the perspective of medical anthropology. It starts from the presumption that there is not necessarily one way to be human or to experience humanity. Then you do not categorize behaviours or practices as either rational or irrational or as either scientific or superstitious. But you look at them as practices and you look at them as beliefs. And so, in my own work whenever you know this question did come up and I had to address it even at a personal level the only way I found to do that was to understand that this is asking the question of you know whether people are really possessed or not? Whether people are being in a real trance or in a fake trance? You know whether it is a case of faking or it is a genuine case? Asking the question of which one is it that is not the right question.

From the vantage point or from the perspective of the individual, how they define their reality. So, when you recognize that there are multiple realities and if you live in a universe there are ghosts there gin there are people who use black magic there are things like that if that is something which is conceivable in your universe. It is very possible for you know to define yourself as possessed and to go into a trance whereas if you live you live in a like you know in a disenchanted

Dr. Hemachandran Karah: Like seeing body as just a machine made up of parts

Dr. Shubha Ranganathan: Yeah, I mean it is like the place of religion, right

Dr. Hemachandran Karah: No, I am talking about disenchanted world or outlook

Dr. Shubha Ranganathan: Yes, see the same kind of difficulties and the same kind of issues which came up with the enlightenment. You know, religion suddenly had a very different kind of status from its previous dominance. So, if you live in that kind of rational disenchanted universe then you are not going to go into a trance. You are going to see things as very unreal and that is your reality and I am appreciative of that reality as well. I do not necessarily like to even use terms like spiritual or spiritual healing or you know because it almost seems to sort of glorify a certain kind of reality. So, rather than thinking of spiritual experience as something which is necessarily or a higher level of playing for their non-spiritual experience. I mean I am not necessarily sure that you know that is also true. Because the reason I say this is because now in the field of health itself you know you have this additional dimension of spirituality and with that the WHO definition of health. It is not just physical or mental but also spiritual health which I think may again not necessarily hold true for everyone right. So, I think my own work sort of pushed me to be very deeply appreciative of the different kinds of realities that people are inhabiting and the problem often is that when there is crosstalk between doctors and patients or between survivors and service providers. So, that is I think where medical humanities can come in.

Dr. Hemachandran: So, I mean introducing medicine and health services to context of healing experiences of healing I mean differential experiences of healing and formative concerning care giving and care receiving all that will certainly make medicine wholesome. It seems that is the goal of medical humanities and that is where disability studies can scholarship can also benefit and offer. Because disability studies certainly see disability is more than a broken body and broken mind. So, similarly this wholesomeness can add but you had a very important dimension. While working on many healing traditions, you do not necessarily privilege one over the other. You merely aim for democratizing and validating many kinds of human experiences and that can feed into health services including doctor training. Can we put it that way Shuba?

Dr. Shubha Ranganathan: Yes, I think that's a very good way of putting it.

Dr. Hemachandran Karah: You know what we are just nearing one hour there, Karthik really alerted me, very nice talking to you Shuba. Hope listeners will really like it, thank you so, much for coming on Skype.

Dr. Shubha Ranganathan: Thank you Hemachandran it is a pleasure.