Literary and Cultural Disability Studies: An Exploration
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Lecture – 40
Medical Education and Disability

Dr. Hemachandran Karah: Hello and welcome all. Today is going to be a most exciting session because we have been talking in this course about medical model, medical humanities, Hippocratic oath, clinical aspects of disability, schizophrenia quite a lot of things. But we never had an opportunity to explore medicine from its core for that reason we have here Dr. Satyendra. Dr. Satyendra is a real doctor he is a medic and an academic too but more importantly he identifies himself as a disabled he is a wheelchair user. There may be good many doctors who have disabilities but they do not necessarily identify and want to reform medicine from inside. So, we have such a person welcome Dr. Satyendra on board

Dr. Satyendra Singh: thank you so much, Dr. Karah

Dr. Hemachandran Karah: It will be great if you can introduce yourself and then we can go on from there.

Dr. Satyendra Singh: Hello everyone and I am Doctor Satyendra Singh I am associate professor of physiology at University College of Medical Sciences which is the constituent Medical College of University of Delhi. I am also founder of medical humanities group at my medical institution and I am also a person with locomotive disability

Dr. Hemachandran Karah: What do people mean by medical education, we know it's teaching and learning about medicine. But what is it that fascinates discussion about it everywhere.

Dr. Satyendra Singh: Well, in India we have the maximum number of medical schools in the country there is around in fact in the globe we have around 512 medical colleges in the country and this is a very huge number. So, medical education is the training part where we teach undergraduate medical students and the post graduate medical students into health care. And considering the geographical status of India, we already have a

very skewed doctor and patient ratio. So, this is the whole aspect of the health care and when we talk specifically about medical education. It is the training of the undergraduate or the postgraduate students towards becoming a complete human doctor. So, it entails both MBBS as the entry level and then MD, MS at the second level and the third level is the super specialization.

Dr. Hemachandran Karah: And what are the components of normal medical training.

Dr. Satyendra Singh: Yes so, the normal medical training is around four and a half years of medical education which we call as undergraduate medical education or MBBS in India bachelor of medicine and bachelor of science. So, it is four and a half years and then it is followed by a mandatory one-year internship after that the candidate becomes a certified medical doctor or medical graduate. He can have his own practice or if he wants to further a career in other specialty then he can go for post graduations. So, for an Indian medical graduate or we can say an MBBS doctor the typical period is five and a half years.

Dr. Hemachandran Karah: So, basically one studies intensely and learns how to do surgical procedures and learns about various aspects of medicine and then one has a year to have a hands-on experience with hospital life patients and so on. So, is this what it means?

Dr. Satyendra Singh: Yes actually, if I give you more details about this whole five and a half year MBBS curriculum. It is structured into three professional years the first professional is about pre-clinical subjects which includes anatomy physiology and biochemistry it consists of two semesters. And after that we have para clinical subjects in which we have pathology microbiology community medicine and pharmacology and forensic medicine. And finally, we have clinical subjects in which we have the traditional clinical subjects like surgery, medicine, gyanian-ops, pediatrics ENT Ophth and these specialties. And from second year onwards students they try to go to the clinics. So, they have the patient interaction from the second year onwards however now medical council of India restructured the whole curriculum. So, after a very long day of 22 years from this year onwards from August 2019 there will be a new competency based medical education curriculum which focuses on early clinical exposure. So, those students who want to become doctor they do not have to wait for one long year to interact with the patient.

Dr. Hemachandran Karah: So, there is something called competency now in place and what does that mean?

Dr. Satyendra Singh: The competency basically means what are the abilities and attributes which are expected of a doctor. So, these are the various traits the minimum traits which are expected of an Indian medical graduate or an MBBS doctor. So, now there is a shift in the teaching style in the medical curriculum and it is now outcome based. So, we are now looking at what are the minimum competencies or what are the minimum attributes which an MBBS doctor must have. So, they will be evaluated on those competencies those are outcomes. So, this is the new curriculum which we are talking about.

Dr. Hemachandran Karah: Well, in some sense before this hospitalization I mean corporatization and most importance given to hospital ways of doing things. People always learnt medicine through some kind of apprenticeship meaning hands-on approach to healing treatment and so on. Is this going back to the original ways of doing it or is it any different.

Dr. Satyendra Singh: In some ways, it will be similar to what you mentioned which is shadowing a physician. If you look at the entry level of a student into MBBS in India at the age of 17 to 19 they apply for medicine. So, in India what is happening is that a student is getting into MBBS without having experience without having exploring the other streams. On the contrary, if you compare it with the US or UK there after 12th class, they undergo graduations. So, they have a grounding in various subjects be it medicine be it arts or humanities or social sciences or engineering and then they decide if they still want to pursue a career in healthcare or medicine.

So, here in contrast in India the students are entering into a medical field at a very young age of 19 years but they have not even explored the whole world. So, there is a basic difference between the U.S and the Indian system of entry of a student into medical profession. Secondly again at the entry level in the NEET examinations which gives entry to the candidates into the medical field, it is entirely an MCQ based entrance examination. It only tests your cognitive abilities it does not test your analytical skills or abilities whether you are cut for this field which is very highly competitive and whether or not you have those analytical abilities or not. So, we are not checking any behavioral aspect into this one I think which is a big policy lacuna in our system. We are only testing people on the basis of their cognitive levels. But when they enter into a course

which is four and a half years of MBBS followed by internship and if you add to that three years of post graduation and two years of super specialization it is a very very long course. We are not even touching that aspect of whether they are up for it as per their mental abilities are concerned or not.

Dr. Hemachandran Karah: And also, I think this has to do with our larger environment I mean none of us are asked or made to think or allowed to think.

Dr. Satyendra Singh: yes, that is one thing. And the second is I think the patriarchal attitude in India, I mean children are treated like children even when they are 19 plus even the teachers call them bachas and children; they do not consider them as adults. And then at this year they do not have any choice if your parent has your hospital and it is inadvertently thought that you will become a doctor and take care of the hospital. Even, if you have an aptitude for say music or say for other things people never ask you. So, I think this is a typical mindset the patriarchal attitude which is there in our society.

Dr. Hemachandran Karah: Well, hundred years ago Mr. Flexner submitted a report in America saying that medical schools have very low output in terms of quality and they are just producing students who just know something about anatomy about biochemistry and surgery but they are not producing fuller doctors. Hundred years later the Flexner report was in 2010 I think it was revisited to take stock of medical school curriculum medical school engagement with human conditions which involve ethics and much more. Where are we how much have we traveled from there in general and India in particular?

Dr. Satyendra Singh: Well, there was a landmark report Alexander Flexner when he gave that landmark report the Flexner report it brings out a lot of reform in the curricular structure in U.S and Canada medical schools. For the very first time, they questioned the status quo over there and that brings a series of reforms in their curriculum. And that is the reason if you compare that with Indian medical schools for example even after 100 years of Flexner report in UK still they questioned even Flexner 100 years ago. He said that the medical school should not be only place for the riches and they should also open doors for those who are poor or those who are from the marginalized communities.

So, they talked exceptionally about the social responsibility or the social accountability of the medical institutions. So, based on that, the schools in U.S were reformed they changed their structure. Initially it was a typical compartmentalized medical education. For example, for two years we talked about the subjects like anatomy biochemistry and physiology. But we did not cover the clinical aspects it was more of a theoretical stuff when we are talking about medicine, we need to talk about clinical medicine right from the day one. So, those things happen after flexible reforms in U.S.

In UK also now they are talking about diversity and inclusion how they can open doors for those people who are from the marginalized background or racial politics people from the minority background.

In India we are still not up to that particular level with the advent of this new competency-based education curriculum still there are a few changes which are there and probably we hope that now the time has come in India at least that we will be teaching our students about a complete holistical approach. And how to deal a person and treat a person as a person and not as Michael Foucault calls as a typical case or an OBD number or a patient number this and that.

Dr. Hemachandran Karah: So, that makes us move to the idea that patient care should be at the heart of medicine medical training and not machines deeper understanding of the body and so on and clinical examples. Patient care should be prioritized rather than otherwise is that right Satyen?

Dr. Satyendra Singh: Yes, definitely because initially the focus was even in India and many parts of the country, we still feel that doctor is a god which is not so, we are just human beings which are doing our duty. But still the cultural context is such that we are treated like superhumans or gods and patients more or less I mean they are considered as someone who has no autonomy, they cannot take their own decisions. And in many parts of the country, it is very common that the decision of the women patients are taken by either their husband or someone who is in the family a male usually takes a decision. So, we do not give that autonomy or that respect to the patient who is there.

It is very surprising because medical schools or hospitals are the places where patients come and our existence as a medical doctor or a health care professional is only because patients come to our doors. We are what we are only because of patients that is why there is now these shifts towards patient-centered medical education. Patients should be

at the heart of all decisions whatever decisions we are taking we need to take into consideration the choices of the patients, the wishes of the patients and what does he want. We do not want to impose our thoughts on the patient.

Dr. Hemachandran Karah: What does that practically mean Satyen in terms of training a young person to become a doctor in terms of practice and in terms of curricular reform.
I am asking three different things maybe you can address one by one. So, that will be very useful for the listeners here.

Dr. Satyendra Singh: The first thing I talk about is the curricular reforms. So, if we typically see the structure in the medical schools or medical colleges in the country or elsewhere also in the typical schools or colleges in India. The typical culture is that the teachers are considered as experts. So, there is this model which we call as sage on the stage and teacher thinks that he knows everything about the subject and the audience are students they have no choice they have no wisdom and they have no opinion. A teacher comes in the class and gives a lecture and goes away. So, he treats the audience just like empty closed minds. He comes with an information there is an information overload which is transmitted to the closed brains and that is the end of it. On the contrary now there is a shift now this was initially criticized by an educationist Paulo Freire who gave the theory of oppressed he wrote the book Pedagogy of the oppressed. So, he talked about this banking model of education which is the same one that we think that there is a there is an operation. Because we think that we are the experts and the people who are there they are not experts this is again a violation of the adult learning principles. The audience who are there, they are no more children to whom you can dictate now they are adult people they know about what their goals are what they want to do. And we need to involve them in these teaching learning methodologies.

So, now there is a shift that from siege to sage on stage we are moving towards guide on side. Nowadays we do not talk about teachers we usually say that there are facilitators. We now give the students who are there in the audience we consider them as an equal partner in this learning and both of us learn in this exchange both the teacher and the students.
So, we are basically facilitators we nowadays the culture is that we are using problem-based questions in our curriculum specifically because we are dealing with the patients

who can have lots of signs and symptoms. So, we need to arrive at the correct diagnosis. So, in this scenario we do not want an MCQ approach because that is not suitable in this what we need is that the doctor needs to know have a critical analytical attitude. So, that he can arrive at the diagnosis considering the signs and symptoms which will vary from place to place there are different terminologies in different states. There is very common lingo used in Hindi languages which patients often use when they are saying that they are having this particular illness and you will not find those terminologies in the medical curriculum. They will define the character of their pain as different ways that we are feeling *harart* we are feeling *uchati* and things like that which are part of the normal lingo which is not there in English or it is not there in the curriculum. So, that way we need to understand that and we need to know that. So, that is why the role which is very important as far as training a medical student is concerned is that we need to understand about the experiencing learning ways. And that is why I think there is a greater role of medical humanities currently the problem with the medical education is that it is heavily based on now we move on to this disability studies it is heavily based on the medical model of disability. That is the flip side of medicine and it actually changed my mindset also.

As I shared with you that I am a person with locomotive disability. So, till I complete my 12th I was totally ignorant not exactly ignorant I think I would say that I never embraced disability as part of my life or part of my existence. And when I entered into the medical college at Government Medical College, Kanpur. In the five and a half years of the curriculum when I read about medicine, they re-established or reinstituted this notion that I am the problem. So, this is what the medical model of disability says that you have a problem let us fix it. When I went to my medical school again, I realized that when I was in clinic and I have to come back to the 12-1 lecture my hospital was on the other side of the road my medical college was on the other side of the road. So, it needs to take some time. So, I was the one usually and apart from me there was one of my colleagues and she was having Duchenne muscular dystrophy. So, the two of us we were people who used to enter the classroom 30 minutes after the classes started and that time, we cursed ourselves that our disability is our problem and because nowhere in the curriculum we were never told about the social model of disability. So, this was in a way a sort of what you call as internalized stigma or internalized discrimination. This thought process was deeply ingrained into my psyche that I am the part of the problem.

The things only changed when I came to Delhi and I finished my MD and joined here as a faculty in university college of medical sciences. And when I faced discrimination for the first time that was the time when I read the older PWD ACT of 1995. I read about the United Nations convention on the rights of people with disabilities and then I came to know that people only have impairments for example I am having a physical impairment. Those who are blind they are having visual impairments those who are deaf they are having hearing impairments. It is the society which makes us disabled by their barriers and what are these barriers. These barriers are if there is no ramp, I having an impairment of polio I will become a disabled. If there are no Braille formats or no web accessibility a blind person will become disabled. If there are no sign language interpreters a hearing aid will become disabled correct. So, that was an eureka's moment for me an eye opener for me and then I realized that what are we doing we are teaching the future doctors that you are the part of the problem that disability is a problem.

And that is why it was very strange for me that it only took a world report the world health organization's 2011 world report on disability which very clearly in black and white stated that physicians globally they lack on how to deal with patients with disabilities. They are never not taught about that and the reason why they are not taught about disability is that the syllabus or the curriculum of MBBS is very huge and vast, yes there are so, many diseases and what we are producing is our global doctors. We are teaching you into medicine you can come remain in India you can go to US you can go to UK anywhere. You might find TB tuberculosis highly prevalent in India, leprosy very common in India. But when you go to U.S cystic fibrosis would be very common. You cannot say there is no excuse that you do not know about these conditions. So, there is a problem that the course is so, vast and still we are teaching the vast course we are teaching all these disabilities as per the medical model of disability. So, I think the time has now come where we need to include disability studies into the medical curriculum.

I gave you my personal example that I completed my MBBS I did my MD until then despite being a person with a disability despite having lived experience of disability I never thought that I only have an impairment and the barriers exist in the environment or in the atmosphere. So, imagine what about those people who are non-disabled. How they will learn from these things that you know we need to view disability as a human rights model and not as a medical model of disability.

Dr. Hemachandran Karah: Well, very nice thank you Satyen. The thing is now you are talking about disability at the same time you are also talking about the challenges in bringing a comprehensive curriculum which include labels, clinical jargons, issue's themes connected to several human conditions. Maybe, a mid path could be to teach the budding doctors about the art of listening. Maybe because the art of listening entails not only to listen to what patients say but also listen between the lines about what they say. This kind of approach may enable doctors to see the points that you are raising about the difference between impairment and disability, disability aware medical training and so on. Do you agree with me Satyen?

Dr. Satyendra Singh: So, I completely agree with you but the problem is that in India, the problem is that the students join MBBS at a very young age. So, they are still exploring. the life now and what happens is that when they are in eleven to twelve, they are looking for competitive examinations, how to clear MBBS entrance examinations. So, their focus is typically on the MCQ examinations. And they join the MBBS then again, their focus is, you know how to pass examinations or think about the post credit examinations. What is happening in this phase, is that because I interact with the students when they come into the medical college on the very first day when you listen to them, they have very high hopes. They want to serve the society. They have very noble intentions. We want to change things. We want to help the media and the poor. We want to do specialization. We want to bridge the gap between the health care and the lack of doctors and things like that but unfortunately, after sometimes after one or two years when they pass out, we have done this longitudinal study on the empathy decline in the medical students. We have used the empathy questionnaire on them, and we have found that there is an empathy decline in the medical students of the same batch I found from first clinical year first MBBS year to the final year.

Dr. Hemachandran Karah: Why, why does that happen?

Dr. Satyendra Singh: So, why it happened, this is the reason why, because there this cynicism comes and there is this empathy decline comes they are very empathetic in the first year and then they suddenly become robotic when they are doing their internship. The amount of patient overload which they normally see in the internship and the

number of patients which come to the OPD outpatient departments in the government hospitals they we have very long queues. And in everyday and OPD, we see around one hundred patients. We hope that, there is a scope for the art of listening, but if you look at the logistics usually a doctor is hardly getting two to three minutes to see a patient and what is happening in the tertiary care hospitals because my hospital is a tertiary care hospital, in my OPD, there is a doctor with their physician is also seeing the cases of people who are having sneezing or cuff, mild cold, and he is also seeing a patient who is having a renal failure. Now the problem is, look at this, a disparity that people who can be treated at the primary health care center. They are also coming to the tertiary care hospital. So, where is the time for doctors to understand this art of listening. Moreover, there is a very important point, listening also comes from the verbal and non-verbal behavior.

A very important part of communication skills is the non-verbal. When you are sitting in in your OPDs and how you are interacting with the patient can you gauge from the way he is entering into your clinic about can you diagnose his gate or how he is feeling about that? These are very important things, and these only come when you train your doctors in these things. Because if I give you an example, there was a patient who went to the Gyno-OPD, she was pregnant that she had gone there for Antenatal checkup. she was accompanied by her brother-in-law she was a blind lady and the gynecologist; you know she did the examinations. After general examination, rather than saying those findings to the blind lady, she told these findings to the brother-in-law, and that time the lady shouted at the doctor, I am blind but I am not deaf, I can listen.

Dr. Hemachandran Karah: I can relate to this episode as yet another blind person. The doctors talk to the person who comes with me.

Dr. Satyendra Singh: The reason is many times the doctors want to help the patients but the problem is that even in their five years of MBBS they have never ever interacted with a deaf person and they do not even know that a deaf person who comes to see you can actually lipread and the doctors are not aware of that. Many times, there is a laptop between a doctor and a patient which impedes this communication because they are not aware that even deaf people can lipread. So, these are very small, small things which should be the part of the curriculum that is why I am saying that, these are very important things, which needs to be there. And how do we expect a doctor to understand

these things, they are not themselves today a disabled person. How can they understand these things? The one other thing is that, they do not have time because the curriculum is huge. So, I think the opportunity lies in narrative medicine. If they are reading the narratives of doctors as patients, doctors become patients, there are so many narratives that can help them become hugely empathetic. Rita Charon has pioneered the field of narrative medicines. Then there are patient narratives of people with disabilities when they write about their lived experiences. For example, in a health care or when there are cancer survivors there is a recent novel ‘when breath becomes air’; a doctor wrote this novel and shared his experiences. So, these are the things because the problem is that in India, when children join MBBS and he in his life has never read about literature. What is the role of literature in shaping health care they cannot even think that you know arts has a big role in medical education. I told you about you know, mentioned about communication skills. Now one of the very important things of your verbal and non-verbal communication is that you hone your observation skills if you know how to interpret a painting. So, art is a medium which can hone your observation skills and a doctor needs to have a very high observation skill.

And moreover, you know, now recently, the world health organizations, they have declared a burnout as an official medical disorder. And very often we find that you know, medical doctors after a certain period of time, they face this, burnout situation. And one of the possible ways out is medical humanities when there is a joy for learning, when they discovered this joy in writing and reflectively sharing their experiences of their good patient or their worst patient or the challenges in healthcare. So, I think our future doctors need to know about these things that there are avenues from the social sciences, which plays a very important role in improving the patient provider relationships

Dr. Hemachandran Karah: Certainly, rewinding a little bit before getting into the idea of disabilities competence that you are working on. Can you say a bit more about well they do not get training in literature, medicine, arts, human experiences communication that is understood. I get that point, but what is the nature of training, I mean, they should be given simulation exercises about what is a typical patient behave like, a patient of a particular problem, say gynecology or brain disease they should have models to think about and work on as a student, what does it involve?

Dr. Satyendra Singh: Now, I completely agree with you, and in fact, many of the medical college in India in isolation, they are utilizing these simulations as innovation. In our medical school, also in fact one of the thesis topics which I gave to my postgraduate student, that was because I told you that in India right now, we have a traditional curriculum, where in the first two semesters or in the first year of preclinical, we do not have any interaction with the patient. So, I gave her the thesis topic of early clinical exposure. How you can bring an early clinical exposure by using virtual patients. So, we created two virtual patients. which were online virtual patients. So, you can log on to the system, and you will find that there is a three-dimensional patient you know, standing in front of you and then you appropriate few questions. You can ask various questions you can take the history alright, and the patient will answer and this will give you some idea on the basis of that, you can create your provisional diagnosis you can ask for lab investigations, and you can propose management.

The funny thing is that the virtual patient is very smart, So, if that virtual patient is, for example, it is a male patient and if the student becomes over smart and he asks about menstrual cycle. So, the virtual patient immediately says, can't you see that I am a male? So, in India, the problem is that there is a huge load of patients, and the strength of medical student is increasing. Initially in our colleagues, there were a hundred children, now it has become 150. Now it is going to become 200. So, each to give the experience of simulation to all 200 candidates is very difficult. So, I think there is a role of these virtual patients because we created these virtual patients. So, you can use them on your laptop, you can use them on your mobile. You can use it from the confines of your home and this will give you an idea. You can take their history, and you can ask wrong questions also. So, but definitely you will go in the wrong direction but at the end of that, you compare your result with the ideal result, and you will know where you are at fault. So, this is the art of clinical reasoning where the student learns by committing mistakes.

On the contrary in real life on real patients, you cannot commit mistakes. So, there is a huge role of a simulation in medical education. For example, we are also teaching our students delivering cardiac resuscitation CPR. How to give those techniques because we have those artificial bodies where they can do those CPR techniques and they can learn on their own but these are costly. But not all medical colleges have been afforded that

but it needs to be there because until unless there is real experience, it is futile to teach them, you know, theoretically.

Dr. Hemachandran Karah: So, what you are saying is this simulation exercises are good but they should not replace a real clinical patient experience or experience with patients and listening to them.

Dr. Satyendra Singh: Yes, because I will give you another example from the disability field because I have seen many people, they are using blindfold exercises.

Dr. Hemachandran Karah: That is another simulation.

Dr. Satyendra Singh: Yes, to give non-disabled people an experience of the problem; they ask non-disabled to sit in the wheelchair and navigate. They blindfold you, and will ask you go and have a cup of tea. So, that is one idea to tell them that what are the problems of people who are disabled. Point taken. But there is a flip side to it. There is another school of thought who says that this is a very negative approach. There is a recent paper on that and they have found that this is a negative approach because the nondisabled person when he sits in the wheelchair or when he is blindfolded, he perceives the negative experiences and then he thinks, oh, my god, I am so, lucky that I do not have these disabilities.

So, there is another school of thought because you are giving them that experiences which are hindering for them. So, this is another thing because I have over the period of time learned this phenomenon that I am disabled. and I am proud. I take pride in my disability, the reason being because this disability has given me the power of resilience and perseverance, which I could not have got otherwise, had I been a non-disabled.

So, definitely you can tell them about the barriers. You can tell them that if there are no ramps, then you will be in a problem when you are on a wheelchair, but when you are giving that experience that you are so lucky that you are having legs or you are having eyes. I think that is a very poor way to teach simulation to these people. I do not subscribe to that school of thought.

Dr. Hemachandran Karah: That is true and also for example, living with blindness and being blind is not living in darkness. It is the idea of not missing light exactly in some way or connecting to light culturally in many significant ways, both but both are possible.

Dr. Satyendra Singh: In Mumbai, there is this guy called Bhowmick. So, he you know, train blind people in clicking photographs. So, he has this organization blind with camera, and he has given this quote that diminished sense does not mean diminished life

Dr. Hemachandran Karah: correct very beautifully said. So that takes us to your original contribution here in our context, disability competence in medical education. What is it, Satyan? What are the competencies or expectation of competences, this competence will add to it.

Dr. Satyendra Singh: Yes, so, now we have this new curriculum, and this new curriculum is usually in sync with the global practices which are out there. The competency framework is not new it is there in US, it is there in Canada, it is there in UK also and now in India. So, broadly, we the medical council of India have framed five roles of an Indian medical graduate which means that what are the minimum which is expected from an MBBS doctor in India.

So, within those 5 domains, the first domain is that an Indian medical graduate should be a clinician. So, that means that he should have an adequate knowledge of patient medical knowledge and patient care. Yes, the second thing is, he should be a communicator. So, which covers both verbal and nonverbal skills. The third is that he should be a professional which takes into consideration the role of ethics, the professional behaviour and the next is that he should be a lifelong learner which is a very important skill for a medical doctor. Because science is changing enormously every time we are seeing in newspapers that we have evidence based medicine that this drug does not work, we have a new thing. So, a doctor has to constantly engage and he should know what are the skills by which he can become a lifelong learner and the third is interprofessional education, he should also know that when he is working as a doctor. He is working a team. So, he is actually a leader of the team but he should know how to communicate with the nursing professional. How to communicate with the physical therapist, how to communicate with the patient who comes in the emergency, and there is a huge crowd

outside. So, these are the real-life skills which are never taught but these are very important in managing the situation, diffusing the emergency. So, they should also know that they have a role as a leader also, and because now technology is replacing these things. We are talking about team-based skills. So, these are the five broad roles of Indian medical graduate. So, under these five roles, we have defined disability competencies.

So, how we have defined those disability competencies? The one thing was that I consider myself as an expert. Yes, and write down the competency this is the end of it, yeah that is not a democratic way, because these are my personal biases. I am a person with locomotive disability. I do not have any lived experience of someone who is blind or deaf. So, it is unethical on my part to be their voice without asking them. So, the approach which we used was that we research literature, and we find that many of the papers which are there in the disability competencies are either expert commentaries or they have interacted with the medical teachers or medical educators. So, there was a there was a general flaw in this approach because they never took into consideration the real stakeholder. The voice of the disabled. So, what we did was that we identified three broad shareholders. The first one was disability rights activists. So, we had focus group discussions with disabled rights activists.

So, that the; second one was doctors with disabilities, yes, we are talking about disability. We are talking about health care professionals. But where are the voices of doctors with disability. Now, I am very happy that gradually now even the Madras high court recently has given a judgment where for the first time they have mentioned doctors with disabilities. Similarly, I was in the committee which framed the rules for the rights of personal disability rules in Delhi in that there is again mention of the word doctors with disabilities. So, we had FGDs with the doctors with disabilities.

The third group was the medical educators. What do they think are the competencies, which should be there in the curriculum. So, based on these FGDs, we interviewed them, recorded their experiences, and then we came out with 57 competencies which were quite large, and then we shared them with the disability list serves, which are there on various groups. We asked for their feedback because those afterwards were done in Delhi it was not pan India consultation. So, we also got feedback from the other disability groups from pan India. Based on that, we modified our competencies reduced them to 27. So, now we have these 27 competencies, which we think that any health care professional be it a doctor be it, you know, a nursing professional be it a physiotherapist,

or be it somebody else alike professional. They need to know when we are talking about disability

Dr. Hemachandran Karah: I see and you said you counted 27. Can you walk us through some of them?

Dr. Satyendra Singh: Yes, we have a defined them and I told you there are five roles. For example, the first role is as a clinician. So, during our focus group discussion, this issue came out that you know what is the definition of disability we want our medical students to know? Then again, there is a huge controversy on this. We do not want to use the definition, which was there in the Rights of Persons with Disabilities Act or which is there in the Americans with Disabilities Act of course it is different. We used a human rights approach. We used the UNCRPD as the benchmark because there was one stakeholder in our focus group interview, and he said that he is having celiac disease. Now gluten intolerance or celiac disease is not a recognized disability in India. Similarly, my senior grab is, but these are recognized disabilities in U.S. So we do not want our medical student or future doctor to get confused between these things. So, we said that even the UNCRPD, they have shied away from defining disability they mentioned it as an evolving concept.

So, we have used that particular concept to talk about disability that you do not have to learn the definition and as per the RPD act or as part of the ADE but you know what is the sense in UNCR, the first thing. The second competence is that an Indian medical graduate in India disabilities certification is a huge thing. All the entitlements are linked to the civil certification. So, in that we have said that, an Indian medical graduate must know how to certify a disciplined person based on functional competence. Now what is the meaning of this functional competence, I will give you a real-life example recently, there was a candidate Dr. Mahmoud Salam, who has done his M.B.B.S from Jaipur. So, he become certified doctor he came to Delhi. He did his residency in RML hospital and then he applied for post graduation and he was rejected for post-graduation The reason given was that his disability was 80% yes, and how was that calculated. Now he is a person with locomotor disability. He uses crutches the certification was that they asked him to keep his clutches on one side and try to walk it is same as asking a wheelchair user to leave your wheelchair and show how to walk. In that way his percentage will be 90%, and that is how he got 90% percentages and MCI a has a bar on 80%. So, our logic was that and future doctor must not know about exact percentage, but you should know

what is a functional competence. When you are defining a disability certification with the help of assistive devices, whether he can carry on day-to-day activities or not and when you challenge this in the high court. Now, MCI later on amended this particular clause and this is the same thing, which is there in our competencies.

Then third thing is that we have also stressed in the communication part of competencies that a doctor must know about the nonverbal communication as well as the things which are expected in the specific culture. We see specific culture, we are giving respect to, you know, the deaf culture. So, we should know that they have a different culture, and we should acknowledge their deaf culture also. So, similarly, other people also from the disability sector, we need to know what are the right terminologies for example, autistic people prefer the word autistic blind people they are not averse to the word blind. So, rather people should know that there is a difference between person with the disability, the fancy term and disabled person. What Michael Oliver talks about in the social model of disability and how to criticize. So, these are the things which we want our students, they must know, and they must gather this information through tools which are granted in medical humanities through the lived experiences through narrative medicine, through arts and through the history of medicine.

Dr. Hemachandran Karah: Wow, that is an impressive list, actually, that means somewhere we are talking about close interchange dialogue between clinicalism that is a deeper clinical understanding of the body and mind. And politics and culture connected with the disability. So, in some sense an awareness of both together is what is called disability competence.

Dr. Satyendra Singh: Yeah, absolutely, because this is my personal experience that you know I was a very strong proponent of nothing about us without us. Before I was involved in this project. I was involved in this project there was an eye opener for me. Because what I learned was that during our focus group discussions that the people who were disabled rights activists, they are talking about all the rights of the disabled people. On the contrary the group, which were doctors with disabilities they were not even aware of their rights, though they were people with disabilities, they were having lived experiences but shockingly, because they were trained in the medical model of disability. None of these were aware of their rights. So, that time I revisited my thinking. I reflected

on my understanding you know what, the idea nothing about us without us is very good as an advocacy tool. But in policy making, I mean, imagine a situation where there is a disabled person who has absolutely zero knowledge of the rights it will create havoc. So, you have to need a balance between these things, and that was a huge takeaway for me from this project.

Dr. Hemachandran Karah: Now, where do we go from here so, now that we have conversation in a deeper way about disability in medicine where do we go from here?

Dr. Satyendra Singh: Yeah, this is a very good question because you are asking me, and I am answering you but we are talking to people who are already converted. And specifically, people who are joining this call because they have an interest in disabled studies, but what we want is to change the attitude and behaviour of the society, and it is very difficult to change because it takes years. So, that is our larger goal how to change the attitude and behaviour of those people who are not interested in disability for that if I give you the example of medical education. Now, fortunately we have this new curriculum. So, there is an opportunity now because there is a scope of elective in this. Moreover, I personally believe that this disability is not something which should be taught as an elective mode. It should be in the longitudinal part of the curriculum from day one to the final year. So, for that the new curriculum is there. So, my second thing is that I am finding what are the ways in; various years in which we can introduce these things as part of the ethics training module so I will be doing that exercise after this time, I will be identifying the gap areas where we can use these things. And I will be preparing a module specifically for medical students. So, and then we will send it to the medical council of India, how to use that. They have already sent our competences to the medical council of India but the second part is that these are just a piece of paper or competencies. We need to prepare the teaching learning methodologies to attain these competencies. We cannot give a lecture on these things, people need to visit those places they need to interact with these people because now we have 21 disabilities, they need to go to the NGOs also to these communities also they need to hear their experiences also. So, we will define those teaching learning methodologies. What is the best part, how we can best use disability studies in medical education curriculum.

Dr. Hemachandran Karah: And also, in tandem with medical humanities right. Because disability studies can and can most definitely instilled disability competence in medical education and an awareness of human diversity. But medical humanities can do some more because it can for example, you were talking about narrative medicine. So, it can get in such skills into medical education and training, is that right?

Dr. Satyendra Singh: I think, yes, definitely, because that is what I am looking forward because as I told you, we have a medical humanities crew. So, the teaching learning methodologies, which we shall be using for these will involve literature, history of medicine there is very interesting Augusto Boal's Theatre of the Oppressed, which we use very often narrative medicine, the role of poetry and these things. So, that this becomes a wholesome, interesting course because people who are not interested into literature they might have been interested into poetry. We need to take into consideration the people's choices. So, that is why we will use the tools from the medical humanities for this particular course.

Dr. Hemachandran Karah: Wonderful, Satyen, I think we had a very fruitful and also a comprehensive discussion on medical education in reference to disability and much more. Thank you, Satyen.

Dr. Satyendra Singh: Thank you so much it was a pleasure