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Interview

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Interviewer:

DHRUBO JYOTI

Email: dhrubo127@gmail.com
Writer and Journalist,
New Delhi

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MEDICINE, SOCIAL WORK, AND VULNERABILITY DURING COVID

A CONVERSATION WITH DR. AQSA SHAIKH*

DHRUBO JYOTI†

Introduction:

Dr. Aqsa Shaikh, MBBS, MD (Community Medicine), is an Associate Professor at the Department of Community Medicine, Hamdard Institute of Medical Sciences & Research (HIMSR). She was appointed as the Nodal Officer for a Covid Vaccination Centre, the only transgender person to be in that position. She initiated a Citizen's Collective called Helping Hands through which some 7000 families have been helped in Delhi with food during the Covid 19 lockdown. Dr. Shaikh is an author of several medical books, and blogs with the Times of India, Women's Web, and Youth ki Awaaz along with other publications. She received the Youth ki Awaaz Award for the best article on Mental Health. She is also a recipient of the Himalayan Green Awards for her services in Health Education.

Dhrubo Jyoti is a journalist and writer based in New Delhi. They work with the Hindustan Times, India's second-largest English daily publication, and write on national affairs at the intersection of caste and sexuality. As one of a handful of Dalit professionals in South-Asian journalism, they cover national and regional elections and focus on India's 300 million people from the lowest castes. They are one part of the Queering Dalit Collective, and are closely linked to the movement around caste and sexuality in South Asia that aims to de-center upper-caste voices from the centre of LGBTQIA+ movements. They write narrative nonfiction centred on casted experiences of love and desire in South Asia. They hold a master's degree in Astrophysics and a diploma in Journalism, and are interested in exploring the links between caste and desire, especially queerness through the works of BR Ambedkar.

* This interview took place on 19 November 2022. This interview was transcribed with the assistance of Ms. Zubaida Ifshan, a student of the Department of B.A. Programme, Jesus and Mary College

† Writer and journalist based in New Delhi. Email: dhrubo127@gmail.com

Dhrubo Jyoti (DJ): **You were telling me about when you yourself got Covid and you were at the other side, you saw the various kinds of issues that people were facing. If you could elaborate from there?**

Dr Aqsa Shaikh (AS): So,when the vaccination started on the 16th of Jan 2020, we started it with a lot of enthusiasm, with a lot of optimism and hope, that finally we have a substantial tool to fight against this pandemic. Speaking of my experiences as a trans person who was heading a vaccination centre, in the first couple of months, I was never seen as someone who is different, and I was just seen as any other medical officer irrespective of my gender.

It was only in March when I tweeted about it and asked if I am the only trans nodal officer of the Covid vaccination Centre in the entire country, that's when you know we restarted the discussion on this topic, as to why other trans people are not able to reach this stage. Meanwhile as part of our research team which works on trans-care related projects, we also looked at how the trans and queer folx face structural barriers and access to health care, especially which is aggravated during pandemic times and specifically speaking about vaccination, as to how it is not inclusive for trans folx.

So there was also a shift of conversation to this important aspect of inclusion of trans people in research and service deliveries of public health systems, like these. So the experience was overwhelming and I remember some of the people who had come to a vaccination centre *only* because they had heard about me as a trans nodal officer and they wanted to see and find out how a trans medical doctor looks like! Because all my life their imaginations and observations of a trans person is that of a historical community who comes during the birth of a child or during weddings, and at signals, and it was beyond their imagination that trans people can be doctors and not just doctors but also heading a vaccination centre. So, this was a very good opportunity to change the narrative about trans people, and the perception that people have about trans people that they are uneducated and into acts which according to the society are immoral. So that was a good opportunity and I could take forward the conversation on this very important topic.

DB: I wanted to ask you about the differences and discrimination in access to vaccines and health care as you may have seen in 2021, especially for trans and queer people?

AS: So when we speak about stigma and discrimination, it may be in a very active form, as generally the perception is that trans people are not allowed into health care facilities, or they are not being vaccinated and so on, but I think we need to take the conversation to the *structural discriminations* which happens against the marginalised communities. So as I spoke about the safety and efficacy of the vaccines, and one of the concerns that we trans and queer folx had is that *we* have not been included in the research conducted around this vaccine and this is being used on us – we are different than cis gender people because some of us are on hormone replacement therapy (HRT) and some of us are on other treatments.

DJ: As I was mentioning, the readers of the journal wanted to learn a little bit more about the pandemic response. As a medical doctor you were not only at the forefront of dealing with it, but also as somebody working with all the community members and you had a first hand account of *all* sides of the problem. So I wanted to start off by asking you a little bit about when the pandemic struck, what was the kind of response as a doctor that you found?

AS: Right, so if we speak of this pandemic which is now the third year, when initially the first few cases started to happen we came to know about a few medical students in China who were diagnosed in Kerala, and then we had someone coming from foreign travel from Italy getting diagnosed. So we all thought that it's going to be a few scattered cases here and there, because for centuries we had seen nothing like this. So, no one at that point of time had predicted or thought about how big this problem would get. and later when the nationwide lockdown was announced, we had only a few cases and that seems like a decision which was taken out of proportion and very suddenly without preparation and enough warning to people. So in these first few days, which was in March and April, the problem was not due to the disease, but the problem was due to the lockdown which was announced, and how that affected the livelihood of the migrant workers. And we had the scenes where the migrant workers were walking on the highway in bare feet with all their luggage and everything, because the means of transport were cut off, and that was a very scary memory of the first wave of the pandemic. But not many people at that time were having Covid or reporting Covid, and we didn't have much mortality in the first wave, so it was the response which was more fatal than the problem to which this response was directed at.

DJ: Dr. Aqsa, I wanted to ask you that in March-April 2020 when the country is just learning about this new disease and many people did not have a sense of what it was, if you could just tell us a little bit about how you were seeing the ordinary people but especially members of the LGBTQ+ community just coming to terms with this kind of new thing that was coming up?

AS: If we look at the pandemic, and the three waves that have happened, and each of them was characteristically different, and the situations were different. If I were to specifically speak about the first wave – you know the first couple of months were just to understand what's happening – to understand that there is a lockdown and curfew in place, and at that point of time we were more involved in providing ration and food than providing medical treatment. We were more concerned about, for example, the dialysis patients who were not able to go to the dialysis centres, pregnant women who on their delivery dates were not able to go to the labour rooms, and people who needed their usual medication who could not get that.

Also this was the time when the vulnerable groups, like people who stay single or who used to stay in paying guest facilities, especially people from the queer communities, they were suddenly removed from their houses, and also some of them went back to their natal families because

universities were shut down. That led to a big surge in mental health outbreaks in marginalised groups and migrant populations. So, in the first half of the first wave, that is say from March to May, we were more attuned towards responding to the crisis of the lockdown, to loss of employment to loss of safe spaces and regular health care access, rather than in fighting Covid, and also there was a lot of misinformation, which only aggravated in the second wave. So yeah while we were fighting the pandemic, we were fighting more of these things than the disease per se.

DJ: And if you could tell me a little bit more about that, in the first wave a nationwide lockdown had been imposed and at a very abrupt notice and over the next few months, how did you see the community members, what are the kind of issues that you witnessed, and what kind of challenges were seen?

AS: Speaking about the first wave, and especially when we speak about the queer community, the challenges were that they had to vacate their safe spaces and go back to their natal families, they were forced back into the violence, or there was extreme dysphoria because they could not do the gender expression as they would have in safe spaces like their rented apartments or pg's in metropolitan cities, and we were flooded with the calls of mental health crisis.

We could see that a lot of the community members were pitching in for providing queer support and mental health support and we had a lot of calls related to violence of all forms that started coming in. And we also saw especially when it comes to trans groups like hijra, kinnar community that their usual traditional professions like badhai or sex work were disrupted, and at that time no one was looking at them, thinking that they might need some kind of support. A lot of trans folks who were on ART or TB treatment, suddenly could not access these treatments after a period of a month of stock of medicines which they usually have. The community was facing a crisis on multiple fronts right from livelihood and essential medicines to mental health care support.

DJ : Dr. Aqsa, could I ask you to elaborate a little more on the mental health aspect?

AS: We need to understand that there are communities, groups and individuals who are more vulnerable to mental stressors and subsequent illnesses, because of their risk profiles, and one of those groups is of course the trans and queer folx communities. And we know that these communities even in the non-pandemic times, do not have access to queer affirmative mental health care services, and this only got aggravated during the pandemic times. Everyone was facing uncertainties with reference to education, jobs, what will happen to their near and dear ones, and in general the pandemic and what will happen in terms of their own health and their loved one's health, and all this led to the eruption of a crisis which was already there in conception. When it came to the response of the government to this, it was completely absent, the focus was more on isolation and quarantine facilities, taking care of passengers at airports

and other stuff and no one was thinking about the mental health crisis and especially about the vulnerable groups.

So it was only the community members and some of the NGOs, (most of NGO's offices were also shut), and it was a difficult time for the people to switch to online mode, because it was a completely new way of working. But still we could see that a lot of community members came forward and provided peer support, and it was in all forms of support financial, medical support, mental health support which was provided. So yes, there was a huge role of the community in helping its members tide over this situation.

DJ: I wanted to ask a little bit about how the insidious and damaging effect of stigma and misinformation that had on the community was in some ways just as damaging as the virus and the disease, so if you could tell us a little bit more about it.

AS: So you know when we are in a crisis – the underprivileged, the marginalised and the stigmatised sections of the society do face more stigmatisation and marginalisation, and we felt especially for the Muslim community for instance with the Tablighi Jamaat which was initially blamed for spreading the disease across India. We also saw some instances in Hyderabad where people had put a poster saying that the trans folks are spreading this virus, we also saw something similar during the monkey pox outbreak that had happened where gay men were implicated for spreading the disease. So, whenever an infectious disease comes up, then you know the stigmatised groups get further stigmatised. I remember during that crisis when in the first few phases of Covid, people would not roll down their windows to give money to the trans people who were asking for money at the traffic signals for example, they would not roll down the window because their was this fear that these are the people who will spread the disease to the passenger in the car but no one thought the other way round, that the passenger in the car could actually be spreading the disease to the vulnerable trans person on the other side of the window pane.

So there was a lot of stigmas attached and also when trans people spoke about their vulnerability, then there was this further questioning of why is the trans community still into acts which society considers immoral like begging and sex work, why are they not getting an education, why are they not getting employment, and you know there was a shifting of the blame back on to the community.

DJ: Dr Aqsa , I remember you became the first person to head a nodal vaccination centre and I wanted to ask you about your experience, not just in dealing with people who were coming, but also in managing this humongous exercise.

AS: So you know in 2020 for around 8 to 9 months before the vaccine was launched, we were fighting this battle against the disease very one-sidedly [sic] in the sense that we did not have treatment and we did not have any form of protective measure. And when the vaccine came and

it was the fastest developed vaccine in human history, there were a lot of suspicions, there was a lot of mistrust, especially with reference to how these vaccines have been developed, whether they are safe, whether they are effective, whether they will be available to people or not. And on the other hand there was also hope that finally we have something by which we will be finally able to control this pandemic. I remember in September 2020, which was only 6 months post-pandemic, I myself got Covid the first time. I was admitted to the hospital for 10 days. During those 10 days I interacted with a lot of Covid patients who were admitted in the hospital. I was on the other side now, and had an insider's kind of perception about how the pandemic affected healthcare workers. So because of these experiences which I had, you know made me take up this responsibility of becoming the first trans nodal officer in a Covid vaccination centre and that showed in the kind of passion that me and my team had when we launched the vaccination on 16 January 2020, because we came in with a lot of optimism and hope that maybe we have a solution to the suffering that the pandemic had unleashed.

DJ: If I could just ask you about when you were talking about how we have to go towards the most structural issues?

AS: So if we were to look at the structural barriers and exclusion faced by the transgender people this time, I think an example of that is the trans people were not included in the clinical trials of the vaccines that were conducted, and a common concern that a lot of trans folx had was you know, that we are different from cisgender people, we use hormones, we use treatment against TB, HIV and so on. So how safe is this vaccine for us and we did not have answers, because none of these vaccines was tested on trans folx because they are a protected group that has not been included in the trials. Another example of systemic exclusion or you know not having enough understanding, is during registering for the vaccination you had to use the Covid website or the app, and these apps use the other gender and were a lot of furore around it that you know you have male gender, you have female gender but there is no transgender, in spite of the NALSA judgements having come in 2014 and where people were saying that in 2020 you are still othering the trans community members, so there was that concern which was there.

And these vaccination drives, for example you know were conducted in places which did not have facilities for the trans folx like for example had no separate queues, and no separate washrooms, and they were often misgendered because their documents would give a certain name and gender marking whereas their self-identification was something else. So, there were a lot of issues that the trans community faced, there was no communication campaign, for example, to address their concerns or to specially include them in the vaccination drive. So while on the surface it may seem that there was no *active* discrimination, all these structural discrimination and factors led to poorer access to vaccines by the trans folx, especially in the first phase of the vaccination.

DJ: I wanted to ask you Dr. Aqsa, that India has largely seen three waves of the pandemic come and go. Was the experience different, and how different were they in subsequent waves? If you could tell us a little bit more about that.

AS: So in the first wave as I mentioned earlier, the cases were less but we suddenly had a nation-wide lockdown and the problem was more due to the lockdowns than due to the disease. We did not have much idea about what disease is, what is the fatality rate, what is the treatment, we did not have a vaccine available against it, these were the issues.

When we came to the second wave, that was the worst. And this was where we had a severe oxygen crisis in many places in the country, especially in Delhi. And suddenly in one month the cases peaked, and we did not have enough oxygen supplies for the people, and we lost a lot of lives also during that phase. So that was a very very difficult time, and that was when vaccines were already been launched so, this was three months after the launch of vaccination, and people were doubting the efficacy of the vaccine (who had taken only 1 dose by that time), so there was also a lot of *vaccine mistrust* or lack of vaccine confidence which had stared show by then.

This was also with time when a lot of research on repurposed drugs had come, so there was a huge problem of you know, which drugs work and which do not work. There was random use of drugs – we also saw a lot of homoeopathic and ayurvedic medicines being pushed like Coronil, if you remember at that time and then the fungal infection of Mucormycosis came in, and people were losing their vision because of it so, that was a very devastating phase. Things got better before they got worse again and the third wave hit us. Though it was the most infectious strain of the virus, it was the milder version of the virus. Most of the people by now were only getting home isolation [sic], they were not getting admitted to the hospital, and there were no oxygen crises. Also there was this question about herd immunity, and how many vaccine doses to take, children were getting affected a lot in this phase and there was a question about childhood vaccination. So yes, you know through these three phases we have seen different issues and crises of the pandemic.

DJ: And was the experience of trans queer folk any different when it came from wave to wave, especially in the kind of hurdles they faced in accessing health care?

AS: So if we look at the first phase, as I mentioned this was completely disruptive – whether you look at the trans community which is part of groups or whether you look at individuals from trans community, they were suddenly uprooted from their safe spaces from their professions, and there was this huge crisis about how to survive.

When the second phase arrived you know everyone was getting affected, irrespective of whatever [social spaces they belong to]. There was just a huge oxygen crisis, and you know a lot of trans people were facing difficulty in getting admission to a hospital, and getting access to oxygen therapy. And you know what happens in the emergency room is that the subconscious

biases, prejudices, and discrimination that the health care providers have, they came to fore. So, there were instances of how the triage was done, and regarding who should be given priority in treatment and admission to the ICU and so on, you know people who are more vulnerable got left out, and that also included visibly trans folx.

In the third wave, by that time the vaccination was quite old. By then we had one year of vaccination, and more of the questions were around the vaccination whether it is safe for queer and trans folx, should they take 2 doses and how to take them, there were issues more around that. Fortunately not much of a health crisis per se, but you know by this time the social isolation, the domestic violence had aggravated that, and it had come out in full force and they were the issues that the community was facing.

DJ: I know that I have taken quite a bit of your time so I will ask just a couple of more questions, one is as somebody who was both at the forefront of this fight, but also given your long medical background, what do you think are the lessons from the pandemic that can be learnt for more inclusive and better trans health care?

AS: See you know we saw that the pandemic had disrupted even the nations, you know which had good medical infrastructure, like some of the European countries etc. We could also see how in countries where the public health system was strong, like for example in Vietnam. they could manage the crisis well. So there was a lot of discourse around increasing the budgeting for the health care services, we saw how in the rural areas people were dying of Covid, their bodies were disposed of but, you know no one really knew that they had Covid because there were no testing facilities or enough awareness. So, one important lesson that can be learnt was to focus on basics, because it is not the first pandemic and it's not going to be the last, and if you have a strong basic infrastructure to provide services, then you are better prepared to fight a pandemic, and that was one important lesson.

The second important lesson was, you know apart from improving the budget, is the training of the manpower or the human resource, and what we realised is that a lot of resources are used for administrative work, and their talent could have been better used. This also includes the front-line workers like Asha's and ANM's, they had no clue about public health, about pandemic preparation, and they were suddenly thrown into this battle unprepared. So another important question, especially for the front-line workers was how pandemic preparedness could be included in their training.

The third important thing was public health surveillance, in the sense that this was the time when we finally started to invest in laboratories and the virology labs, and in places which could isolate streams. We finally started investing in the vaccine manufacturing capacities and could therefore meet our domestic demand and also to some extent the international market. So, this raised the questions of what are the priorities, where is the budget going, are we giving enough to

research, to public health surveillance, and that was one very important reminder or lesson from the pandemic.

Lastly I would say that there was a lot of focus on digitalisation during the pandemic response, whether it is the Arogya Setu app, or whether it's the Cowin app. We saw a lot about how India has the capacity to quickly develop digital solutions but lags in putting in place efficient safeguards which lag in scaling up. There are still a lot of places in India which do not have adequate electrical supply or internet facilities or digital literacy, and that could lead to the exclusion of vulnerable sections of the society was another lesson that digital health is a good add-on, but in a country like India that should be done with a lot of accountability, and also taking in consideration the situation on the ground.

DB: Lastly, and this is a two part question, one is that we saw in the course of the last two years that many trans and queer community groups had to actively step in to fill the gaps in health care, in accessing benefits, in accessing vaccination and they had to do a bunch of things, you yourself were involved in many of those efforts, so one if you could tell us a little bit more about the efforts that the community groups, and two, moving forward what is your vision for more inclusive and better health care systems for the community members?

AS: So speaking about the crisis that the pandemic had thrown at us, I think a lot of marginalised and vulnerable communities took up this crisis as an opportunity to fortify their response. I think when it even comes to the trans and queer community this is what happened, a lot of trans and queer folx who were not you know able to use a Zoom call previously were able to do that now. You could see a lot of research with the trans and queer folx that could now be conducted digitally or online. We saw how people from different parts of the country, who would have otherwise not had an opportunity to interact with each other, could now do so over a Zoom call.

So I think that the community responded very beautifully to the crisis by building bridges between the various sections of the communities across India, and not only in India but across the world. And we could see a lot of community organisations that came forward and a lot of legal intervention happening in terms of PIL's since this was also the time of the pandemic when the Trans Act and the Trans Rules came in India. So I think that the community responded very well, and I hope this solidarity will continue in the future.

Second is, in terms of the vision for an inclusive healthcare system, I think we need to understand that right now though we may be speaking about one or two marginalized groups that is trans or queer folx, we need to understand that there is marginalization at multiple levels. We saw very strong wave of examples of Islamophobia during the pandemic times, we saw very strong exclusion of persons with disability and when I say persons with disability, generally it comes to mind that I am only talking about people with physical disabilities but let's also think about people who are deaf, people from the blind community, people with intellectual disabilities, children with autism and so on, and how they were excluded from the health care

system. Women unfortunately continue to remain a vulnerable group, and there are multiple layers of marginalisation from caste, tribes, geography, and so on.

And therefore if we want a health care system which is inclusive, then that's not possible unless we include these communities in the designing and redesigning of these health care systems. It is not possible unless we have *community participation* in the true sense. And as I always mention that nothing moves without money in the world, and therefore it needs increased investment. To make a hospital is expensive, but then to make an *inclusive* hospital is even more expensive, they have to put in ramps, you have to make sure they are accessible to wheelchair users, that there are toilets for trans folk, and that the institution invests in training for sensitisation of its workforce.

So ultimately there has to be accountability and there have to be budgetary provisions for making these systems work. And for that I think there has to be a nation-wide discourse on putting health into the priority list. As you know when it comes to the priorities that the nation and the people have, health comes somewhere in the lower rung of the top ten priorities. So I think the pandemic should have jolted us and should have helped us put health in one of the top priorities that any nation should have, and that should therefore have translated to increase budgetary provisions especially in the primary health care. I hope the people who are planning and who are envisioning this for the country will take this into account.

DJ: Thank you so much Dr. Aqsa, for sparing the time and talking to us, and giving me the time. It's been a great pleasure talking to you and learning so much about all this.

AS: Pleasure.