

Gasping For Breath **Tuberculosis and Human Rights**

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Menaka Rao (Host): Health rights is not a well explored subject. It was only after the HIV epidemic struck in the late 80s and 90s when patients groups started speaking about human rights in conjunction with health. The HIV movement helped bring patients' rights in the centre of the treatment programme. In case of an age old TB, the idea of patient rights is just about catching up.

Hi, I am Menaka Rao, host of this podcast Gasping for Breath brought to you by Suno India, a podcast platform for issues that matter. In this episode, I interview Allan Maleche, the executive director of Kenya Legal and Ethical Issues Network on HIV and AIDS or KELIN. KELIN was awarded the 2019 Kochon Prize by the Stop TB Partnership and Kochon Foundation during the 50th Union World Conference on Lung Health in Hyderabad, India.

The prize is given to organisations or individuals that make a significant contribution to combating TB. Maleche is a human rights lawyer and has fought cases involving human rights violations of HIV positive people and those suffering from TB.

Allan, could you first talk about the issue of human rights rise in the prevention, treatment and control of infectious diseases such as TB. Please tell me about the health rights violations you fought in Kenya..

Allan: Law and human rights and infectious disease like Tb, I think I'll start from the point where the rights to health is seen as a human right. And for us to define the right to health, we've had a number of legal and policy documents that define what the rights to health is. And leading documents around these include international instruments, that countries have ratified to say that all the citizens should be entitled to the highest attainable standard of health. And this is where we derive the conversation around and why law, human rights and health is important.

And there is a great global interest to try and reduce that burden whether it is HIV, TB, or malaria, depending on the nature of the infectious diseases. And that burden leads to a lot of policymakers, a lot of lawmakers trying to put into place regulations, policies, laws, that would help guide how interventions can get to people.

Now the most important thing around infectious diseases is that people want to know how they spread? How do we stop the spreading? Those who have it, how do we get them to have treatment? And how do we test to get those who have it. And so that's where the law and human rights intersection comes in. Because the moment they want to test someone, the moment they want to collect someone's information, then they are then bordering on the issue of the rights to autonomy. They are bordering on the issue of the rights to privacy. And that's how the

conversation began with HIV to test someone you needed to draw their blood and for that person required to give their consent. And previous history has shown us that there were practices where people are being tested without their consent, and it led to untold consequences to them. And so the intersection of the law has been coming from that perspective.

But a lot for TB it has come in from the perspective of the fact that TB is airborne. And so the likelihood of infecting another person is high. So if someone is infectious the law that knows or wants to know, what is it that can be done to ensure that this does not spread to other people. And so that's where we then have laws that are not specific to TB, but mostly public health Acts that talk about what do you do when a person has an infectious disease.

And this is what led to the case that KELIN dealt with about 10 years ago...regarding three gentlemen who had interrupted their TB treatment. And the public health officer using the strength of the Public Health Act sought to have them arrested, and have them to be confined in prison. So that would not be a risk to the rest of the public. And so that is how we began our engagement on Tb and human rights to basically say- Yes, they may be infectious. But have you proved that to the court? Why are you holding them with other people in prison if you're saying your goal is to protect the public. So you're going control measures are not resonating with what human rights is able to expect. And so that's how the conversation on law, human rights and TB started for us. But generally, the law normally regulates the aspects around how do you test? How do you treat? How do you ensure others are not infected for the case of infectious diseases that are airborne? And then how do you ensure that people are supported in the course of taking their treatment?

Host: TB is an airborne infectious disease. How does one balance the rights- the right to a person's privacy and the right to autonomy with the right of the community not to be infected. What would be the framework to understand that.

Allan: So I think we have had a long debate around where do you balance the rights in situations where one is infectious and could be posing a threat. And I think we have had a number of documents finally developed to try and address these issues. And WHO has developed certain principles along an ethical guidance framework that helps you think through what are the least intrusive measures to have a person confined for the time that they infectious without violating many of these other rights. And so it's not an easy balance, but normally the balance requires that one adopts the least restrictive methods in limiting the person's right? So if you're going to hold them because they have an infectious disease, you need to have created a place where you can hold them- a place that is considered to be humane. But you also have to look at how they are the rights not being violated - their rights to family, their rights to food, their rights to information.

And isolation has been taken as a measure of last resort and not the first measure result. Because in many cases, many Public Health Officers are resorting to it as issue of first resort.

So the balance is very delicate. But the laws and policies recommend that that be the issue of last resort. There could be other preventive measures you could take, like getting the person to wear a mask, having better ventilation in our place, putting the person on treatment early enough so that they can stay being infectious. And then only when when some of these non intrusive methods don't work, that's when the law would then allow for a pass on them to be held in isolation, depending on what's available. And in the case of Kenya, we've actually gone a step further, where we've developed an isolation policy, which then spells around the steps that one must take from a public health perspective before they eventually isolate a person. But that policy has also gone farther ahead to specify what should an isolation room look like and what should need to contain.

Host: For countries that do not have a anti-discrimination law for TB, what kind of legal framework can be used to help TB patients

Allan: So I think the legal frameworks would start off with the Constitution. And South Africa and Kenya give a good example of how the Constitution has been used in situations where we don't have specific TB laws to safeguard the rights of those who are affected by to safeguard the rights of those who are affected by TB. So I think that would be the starting point being the Constitution of our country to see- Does it have provision on the right to health? Does it have provisions on the right to non discrimination? Does it have provision of the right to dignity? And how people are able to rely on those particular provisions of the Constitution? And where is our Health Act again, you try to look at does it have a patient's charter? Does it have rights that spell out for people who access services from hospitals. And how does that work? So a health act and patients' charter again, become important documents. And also, if the country has ratified the international treaties, especially those dealing with economic, social and cultural rights, then that also provides a framework that one will then be able to use, and occasionally can also rely on some of the government policies and regulations, that touch on issues of TB. Whereas also in certain countries like Peru, they may have to be specific laws, where then you can also be able to rely on those particular laws.

Host: To elaborate, Peru adopted one of the most progressive, rights-based legislations on TB which provides rights to access free treatment, to file complaints against discrimination both in public and private sector. More importantly the right to informed consent before a person undergoes treatment.

Allan, I also wanted to ask you about the kind of discrimination women who are suffering from TB face. In India, women are discriminated against and are often thrown out of their marital homes, or left out of inheritance. How do you think we can involve the law in cases like that

Allan: So, I think the stigma that people who have TB face, especially women is enormous. The fact that one, people consider that those who have to be probably have HIV, because of the higher rates of co-infection. The fact that sometimes women would have to get isolated from their families and their children, which makes it extremely difficult for them to be able to provide

for the family, as they do in most cases. And so it becomes extremely difficult for them to be able to live normal lives and sometimes We have seen situations where their spouses have abandoned them because of what they are facing with regards to having TB. I think in terms of seeking legal redress, the law is one option, but we need to try and see how else do we get communities to have more information around TB, around the fact that it's treatable, how do we have more campaigns around dealing with sensitization so that people are less carrying out stigmatising behaviour hard we get such messages to happen for people to understand that TB is a bacterial infection which can be treated and anyone can get it to there is no need to be able to discriminate. So beyond litigation, there's a lot that needs to be done in terms of information giving at health care facilities, in public places in community spaces. That needs to happen so that people have information and people are then able to move from an informed perspective rather than a position of ignorance, which is what has been the case in a number of areas.

Host: We have a law to prevent discrimination against HIV patients. It has a redressal system for those who face discrimination at work, schools, or other public places. Do you think countries need to have a similar law for TB?

Allan: So I think my position is where a country has a good constitution that has the broad human rights covered, you don't need a disease specific law, because then you can rely on the Constitution. Because whether it is right to discrimination, whether it's the right to dignity, whether it's the right to information, whether it's right to housing, then that is specifically covered within the Constitution, and one would be able to rely on this. However, in countries where you do not have progressive constitutions, or in countries where their constitutions do not have an expanded Bill of Rights, then it may make sense to have a disease specific law or have law that spells out what are the rights of those who are accessing treatment or accessing the healthcare system...not just for treatment, but also from the prevention perspective. Now, the danger of having a disease specific law is that you risk getting the good things and sometimes some bad things in the law. You risk having many bad things, and few good things in the law. So it's a very delicate balance to try to go through a legislative process that sees legislators who have diverse interests and trying to be able to reach a particular consensus that leads you to having an extremely progressive law. So for me, my forthright answer is that no, you don't need a specific law, where you have a good constitution, but you do you may need a specific law The Constitution is not strong. And there are many violations that are happening on those who are affected by TB.

I think what drives disease to disease laws depends on the toll of suffering people have faced to see the need of having a specific law. I think that's what drives the conversation to determine whether you need a specific law or not depends on how active people are, how they have been involved in cases affecting them, and they need to have legislation in place. So I think for me, the reason why we have HIV laws is because people have faced untold stigma, and there was a clear consensus on why you need to have a specific law. We need to have a law against this discrimination. Now we've seen a few of the TB cases coming out, but by the time the TB cases are coming out, a number of countries already have progressive constitutions. And a number of

countries already have progressive health Acts. And so it then becomes slightly difficult to advocate for specific TB law in the circumstances. So I would say what drives with our country needs a law not depends largely on how pressing the issue is for them to see. Now we really need a TB law. And I think I mentioned this in our conversation I had with other colleagues at the conference, that people talked about the importance of social protection laws. But I said you can't do a specific social protection law for TB. Because social protection is needed for other diseases. It's needed for the circumstances because there are many poor people. There are many situations and so you can't just say, I'll have a social protection law for TB people only. You then we have to be able to expand it and that is what seems to happen with the case of diseases now. It's not easy to have a disease specific law because they're broader issues you're looking at, and also issues of coinfection that you will not be able to easily address.

Host: I want to ask you about the privacy of patients. In India, doctors and chemists have to compulsorily notify TB patients in a software called Nikshay. The government also gives Rs 500 a month to TB patients in a bank account that is linked to the universal identity card in India called Aadhaar. India does not have a Data protection law yet. What legal issues arise in such situations?

Allan: So I foresee a situation where governments and donors operate more with data to help them plan, to help them (with) costs, to help them know what kind of services they need to deliver to how many people and there are many ways they have learned to collect this data. Especially ways in which that is anonymized and does not lead to people. But of lately has been a push to begin collecting data in a way that it could be linked to a particular individual. We have seen this in Kenya, when a number of donors and the Ministry of Health wanted to collect fingerprints of criminalised populations who are living with HIV. These are drug users, sex workers, men who have sex with men, and that entire community said no. Because they said in the absence of data protection laws, in the absence of ways of safeguarding the. This has been made public to prosecution of agencies will not be willing to engage in such processes. And so that is one way in which I have seen this developed, especially in our in my mind now we have a process that is currently being litigated in court, where the government working with people such as MasterCard, sought to give every Kenyan a unique not every Kenyan, but every person who was in Kenya a Unique Identification Number, which they argued would be useful in providing better services to them, including health care services. Now, Kenya does not have a data protection law. We have our Data Protection Bill, which is currently before the various parliamentary houses. We've already given our input around the weakness of some of that law, particularly the fact that it doesn't give you a proper remedy in case government does breach your rights to privacy, or that your data is sold to third parties without your knowledge. And so among many other things, a number of civil society have least concerns about it. Now, the problem we foresee that many countries in the global south have very few data protection laws, and even where they have the data protection laws, the issue of enforcement and rolling out those particular laws remains a particular problem. So it's not seen as a priority as compared to carrying out police, prosecution or other aspects. So this is something we need to keenly be able to follow and see what could be done in terms of ensuring that this particular data collection

linking to people does not breach people's privacy, because the moment it does, then it exposes people towards ridicule, towards human rights violations. And I would suggest you also look at the Singapore case, which is case is relating to an American who worked for the government of upper hand had access to a database of all people who are living with HIV. And he shared that database publicly after he had fallen out to the institution that he works with. So again, we need to be able to safeguard ourselves from that particular perspective of data protection laws being there in place loose being enforced, and the patient having the right to access their data at any point of time.

Host: Apart from data protection, I am also interested in understanding how we can carrying out projects such as active case finding where health workers go door to door trying to find patients who have TB symptoms. Doctors have to notify patients. Notifying the disease helps understand the burden of the disease. But how do we find more cases of TB without invading the privacy of the people

Allan: I think the measures the measures we need that measures that create a health care system that is sensitive to the needs of the people who are accessing the system. This means I have care system that provides information so that people don't first of all get sick with TB, where the other infectious disease.

I'm trying to say that the health system is not only about collecting data and treating people it's about giving information to people to be able to make a decision. And that's the health care system we should be striving to have, so that people then go there and feel empowered. So that then your problem is not about someone not adhering to the medicine, because the person has been given information and knows why it's important to adhere to that particular medicine. So that's where I come from. In terms of us, looking at how we deliver health services in the context of HIV, and especially in the context of TB, which seems to be more punitive.

Host: During the conference, we saw many protests seeking greater access to drugs and make them affordable. In India, we have a case where an 18-year old girl from Bihar called Shreya Tripathi who suffered from extremely drug resistant TB had to go to a high court to get drugs. What are the larger battles that should be fought for access to drugs?

Allan: So thanks for this question. And I think, yes, there is with there is recourse. And I think and I have demonstrated by a number of good cases that have taken place in India, both for HIV and TB, is to actually challenge the companies that have signed patents that keep the medicine away from those who are poor, and those who are able to afford. So I think that is a critical point that we have to be able to take forward fast if we need to try and change the tide on this particular journey is to ensure one where companies that were registered medicinal patents. We are aware and it is easy to fall into a position we do. So we are policies that affect patents. And we're going to be added with that, again, try to address that. I think the grave patient you talked about eventually did pass away, which is regrettable. But it helps set a precedent around the urgency to be able to take this forward.

Now, we also equally have a similar case in Kenya where the patient passed away because the drug they needed without calling was actually at the stores of the national government. But because he was at the district or county level, the bureaucracy does not allow for the medicine to get to him on time. So again, that those structural issues that one would like to see and one would like to be able to address beyond just going to court around the one access to medicine issue. Then again, walking with community advocates on access to medicine is pretty important so that they can help you know when to engage, and how to pick up on certain issues relating to access to medicine.