WEEK 2 MEDICINE & THE ARTS – CHILDREN'S VOICES AND HEALING
ME AND TB: CHILDREN'S ACCOUNTS OF TUBERCULOSIS AND THE CLINIC

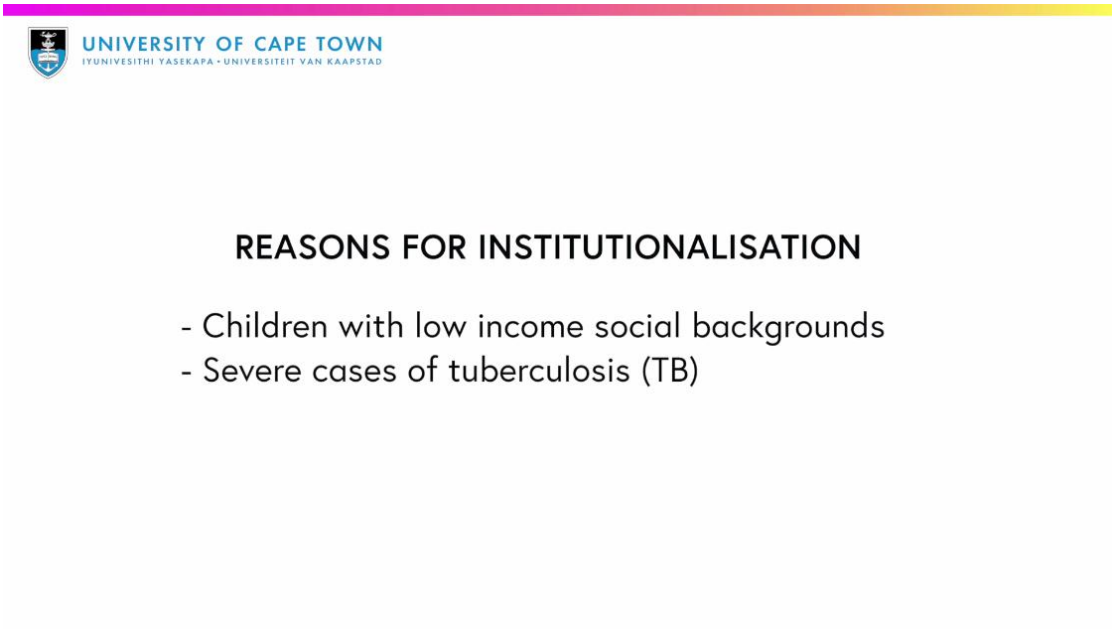
00:00:00

My name is Dr Kate Abney, and as a medical anthropologist, I'm concerned with the challenges that people take up when they're arguably at their most vulnerable-- when they're ill, when they're sick, when their body has a certain type or has been diagnosed with a disease. Being a medical anthropologist doesn't mean I'm a medical doctor.

I'm lucky enough to be in a situation where my discipline is rooted in humanities, but I have incredible access to medicine, medical practitioners, medical spaces. And the research that I'm presenting with you today was based on my PhD, where I worked for a year with paediatric TB patients.

Now, children are unique for a variety of reasons. But in this situation, we have children who have been institutionalised because they are from lower income social backgrounds, as well as very severe cases of TB. Now, this could be standard pulmonary tuberculosis, or it could be a drug resistant strain.

REASONS FOR INSTITUTIONALISATION



Here in South Africa, we have a burgeoning TB epidemic, and that is attenuated by MDRTB, multiple drug resistant TB, as well as XDR, or extensively drug resistant TB. These strains of TB take longer to treat, and they are much more costlier to treat. So institutionalisation at a TB care facility like the one that I worked in is often deemed necessary.

And within South Africa, and especially the Western Cape, given our TB epidemic, there has been a very politicised rights discourse in the media as well as within the Department of Health. And this is very much along the lines of individual rights versus collective rights.

What do you do with an individual who is infectious? They may be undiagnosed. They may be diagnosed and not taking their medication. What you do with an individual who really needs lifesaving treatment, but who also may potentially be infecting their community in which they live? You see, it's not as simple as it may look.

So TB facilities exist for inpatients to live there, for children to go to school there. They eat, they sleep, they drink, and they take a lot of pills there in order to get better. So my research really presents a child's eye view within a clinical space. How do children think about institutionalisation, pharmaceuticals, the drugs that they take, and their illness experience, or as Arthur Kleinman calls it, their illness narrative?

Now, in terms of paediatric TB in the Western Cape, we have a very severe situation on our hands because children under 15 years of age make up between 15% to 20% of the overall TB burden, and this is a really significant number. Children present us with a bit of an anomaly because whereas they are vulnerable or susceptible to TB infection, they cannot transmit the disease. There's also no gold standard for TB diagnosis, so this means many of the child patients that I worked with were subjected to a number of diagnostic tests, which were not only invasive, but in some situations, extremely painful.

So one of the patients I'll introduce you to now is named Scott. He's 10 years old, and he made this rendering of the inside of what his ward, ward three looked like. And he said, we look like pilchards in a tin.

PILCHARDS IN A TIN PHOTOGRAH

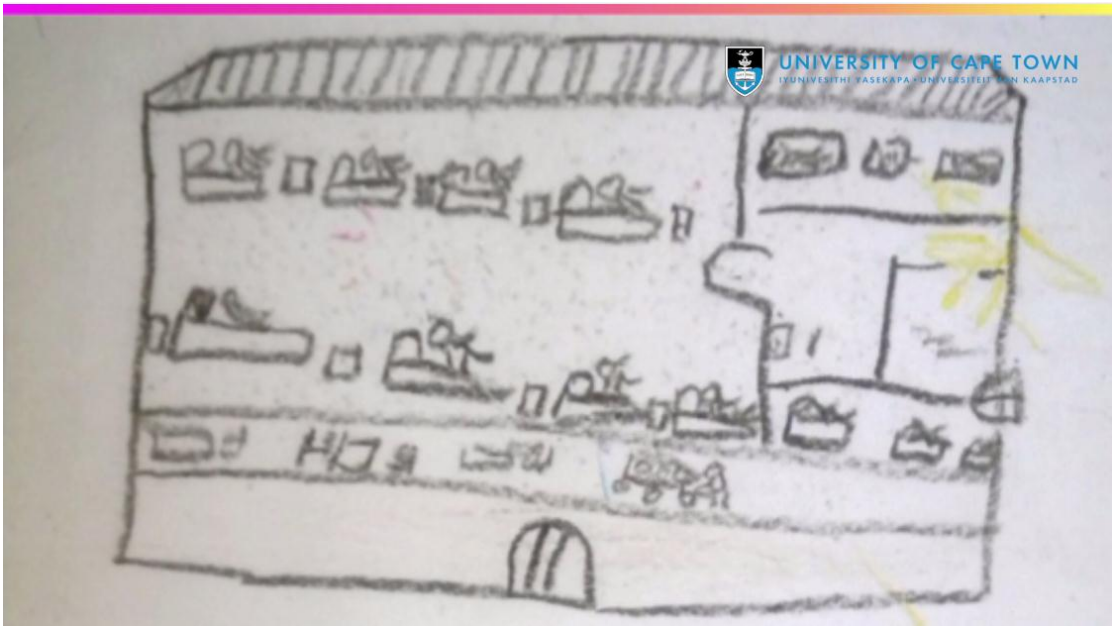
Now, if you're familiar with South African vernacular, pilchards are tin fish. And it's commonplace in many kitchens across South Africa.

The top image shows us inside sleeping.

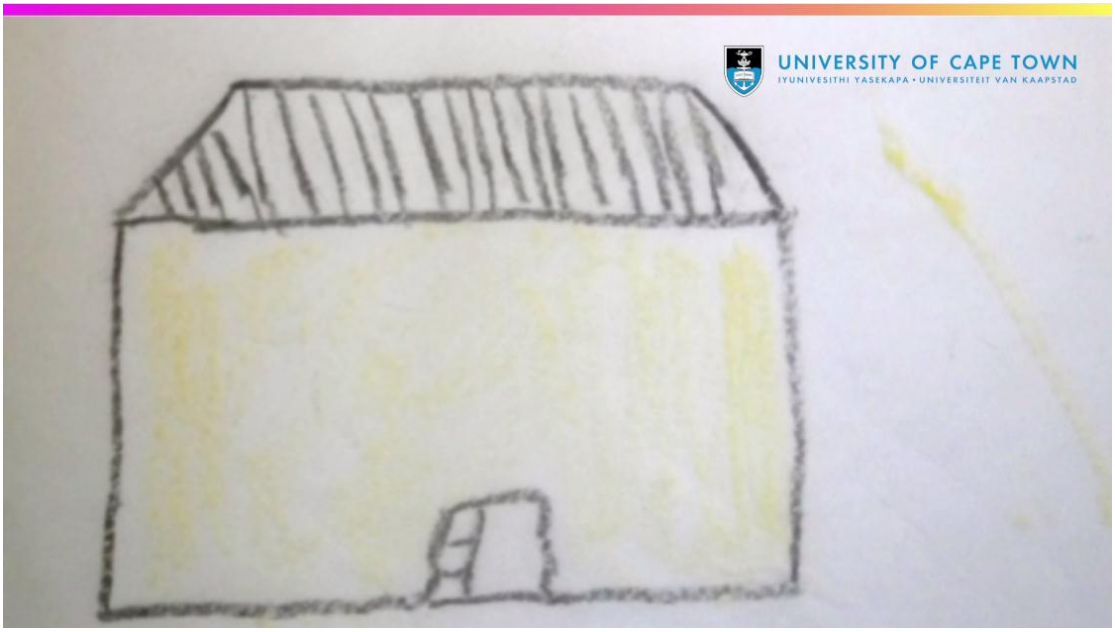
We look like pilchards in a tin.

DRAWING OF THE WARD

TOP DRAWING ZOOMED IN



BOTTOM PICTURE ZOOMED



But all the other buildings are different. On the outside, they're the same. They have yellow walls, they had red roof tiles. But inside, they're different.

Now, this is when he makes a distinction between the severity of the TB, the type of TB patient, as well as the facility that those patients live within. So he said, for the MDRs, that's the big bad TB. But then he also says that for the XDRs, the hospital is a prison because XDR TB usually will take years to treat.

In the next picture, we see a photograph from a little girl named Gabby. Gabby was eight years old and this was her third time with tuberculosis. This time around, however, she had MDR, or multiple drug resistant TB.

PHOTOGRAPH OF BEDS AND OPEN WINDOW

She took this picture, and she said, I sleep on the bed over there. The windows are open to let the TB out, but it gets cold sometimes. Now this is a direct statement about what she observes, the clinical strategies to ventilate the space and to aerolise TB particles.

In another exercise that I employed with the children I worked with, I would sit with the children and we would talk about drug side effects, and we would talk about the different types of drugs. TB drugs are extremely toxic. They're extremely powerful. They're very potent.

And again, Gabby-- she loved photographs-- took a picture of the big, white ones. And she says, I took a picture of these big white ones.

WHITE BIG TABLETS

They make me want to vomit, and when I do vomit, it all comes out.

So clearly, Gabby didn't really like her TB medication very much. But the drug she was speaking to is called PZA, or pyrazinamide, and it's a mainline TB drug. And it has a variety of side effects including dizziness, including nausea, and then also some that are more severe. So children were very aware of the side effects of their drugs.

This is an instance where as much as I tried to not be a hindrance to children's pill taking, nurses were not exactly thrilled with me being present for pill taking. And after about my first month of research, they asked me to no longer attend, because I was a distraction. Again, children have to fit into biomedical routine, very regimented daily habits that are enforced by clinicians, by health care workers in order to cure them of their TB.

Gabby took another picture.

BIG YELLOW TABLET

She said, I took a picture of these big yellow ones. They stick to my tongue if I don't drink them with water, and sometimes they're too hard for me to swallow. The nurse says to just take them all in one go like the other patients do. I can't do that. I take them two by two and slowly. That's my way.

Here's evidence of a little girl who's taking an extremely toxic drug. It's called terizidone. It is an MDR drug specifically for MDR patients, and she is actively employing her own pill taking strategy that is not complicit with the strategies that nurses are asking children to adhere to. So again, children have voices. They have a certain sense of agentive action that they can employ within a clinical space, and it's quite important that we're cognizant of these processes. They're very sophisticated.

One day, we happened to be playing with clay, and a little girl named Shelley, nine years old, decided to create a little figurine. And she said, this is where my TB is. It hurts me when I breathe. Well, Shelley had pulmonary TB, so it would have been painful for her to breathe at a certain stage.

She had a very distinct understanding of where her TB was residing within her body.

YELLOW SCULPTURE

In another exercise, a little girl named Rue, who was five years old, created a small figurine. And she said, TB is a little man who's eating my stomach and my lungs. She had gastrointestinal tuberculosis and pulmonary tuberculosis.

RED CLAY SCULPTURE

So again, there is a very, very articulate and accurate understanding of what TB means to these children.

And in this last image that I'm going to show you, it is a figurine produced by a boy named Gladwin, who's 13 years old. And he said, to me, TB is a little man with a knife. He's eating away at my brain. He said this because he had TB meningitis, which is a TB infection within the meninges of the brain.

BLUE CLAY STRUCTURE

As a medical anthropologist who gets to work with children who are living in arguably a very unique circumstance of being treated for TB, I would like to think that the work is challenging. It's fun. It's also extremely exhausting. But I'd like to think that this work can translate into better policy as well, the far reaching implications being that we can improve the conditions with which children undergo treatment under as well as hopefully their long term health. Thank you very much.