



Salamander Trust
The WHAVE Podcast
Episode 6: Transcript
Martha Tholanah
Cervical Cancer

**The WHAVE: Women living with HIV, Advocates, Voices,
Empowered**

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Martha Tholanah is a Zimbabwean feminist openly living with HIV. She works to overcome sexism and make women living with HIV, young women and LBT women more visible in a male-dominated political and social landscape. She is passionate about women's rights; access to HIV related treatment, disability rights, and functional health systems. A trained family therapy counsellor, qualified in medical rehabilitation, Martha established and headed both the health program at Gays and Lesbians of Zimbabwe (GALZ) and the Network of Zimbabwean Positive Women (NZPW+).

In this episode focusing on cervical cancer, Martha highlights that cervical screening is free in Zimbabwe for women living with HIV, but any follow-up treatment needed after screening must be paid for. This is something women often can not afford. Martha also talks about the lack of funding for peer support, and the related issue of burn-out affecting activists who support others.

Martha Tholanah
Zimbabwe
March 2019

Introduced by Angelina Namiba



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The WHAVE

My name is Martha Tholanah, I live in Zimbabwe, I'm a woman living with HIV and I'm speaking to the WHAVE podcast.

There's been a lot of education around cervical cancer in Zimbabwe. There's a lot more awareness.

We actually know that people living with HIV, women, are the ones getting cervical cancer, dying from cervical cancer, and mainly it's because they can't afford the treatment.

People have been getting screened. The screening had been free for women living with HIV but then at some point people began to get worried when some fellow women that had been screened were found with cancerous cells and were referred for further treatment, when we go further if you are found with anything, women can not afford the treatment, it just means, yeah, you are on your own, if you are not employed, if you do not have medical insurance, then it means that they had to pay. In a way as people reported back to their colleagues around how they experienced the further referral and management people started to ask, why am I even being screened if I have no recourse if I need further treatment? Because it may take me maybe over a year or more before I can find the money. So the issue is finances, the issue is also the transport infrastructure where we don't have a proper public transport system. If you don't have money for transport, you can't go. If you have money for transport you might reach the health facility, they ask you to pay and you don't have the money to pay for the service, you go back home without getting the treatment.

Even for me, I'm in an urban area, and for a lot of other women living in urban areas it's not much to get on a local bus to get to the health facility but sometimes you don't even have it. And for women in a rural area who has to travel a longer distance and pay more than we do, and their options for earning money in the area where they stay are very slim if at all they exist.

I think there is a lot of unfairness. I'm just very angry with what I see and the devastating effects of how a programme not dealing with citizens needs actually drives people to desperation. I think what I find in health facilities that is unfair is when women are told that they presented late. Because a lot of women when they present with cancer they are told they presented late. But is it of their own making that that they presented late, or is it that they presented, they were screened, they were referred for further management, the further management point said they had to pay, and they didn't have any means of payment. Which is a tragedy, it is very unfair, because I think the country needs to put resources in terms of making sure that when someone gets screened, no woman is turned away because they can't afford the treatment. Most facilities are demanding payment up front. When relatives see you are really sick, they might sell their property to make sure you get treatment, and I find that they are spending much



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more than what could have been spent if they had got the early treatment of the precancerous lesions.

Then also, when I say screening is free, it's free for women who are HIV positive, and only if they actually present medical records. That is in public facilities. So for women who are not HIV positive, who are HIV negative, they have to pay. Last time I checked at the bigger hospital here, they were saying women have to pay \$25 for the screening. I had also gone for my screening that day, and I was thinking OK, so for women who are negative are they assuming that all those who are negative actually have the means to pay? You know with high unemployment, we know a lot of women do not have that kind of money.

Once that happens that you can't afford the treatment, people suffer quite a lot, and they end up dying even in pain. Because I can assure you that the palliative care it's just in a simple, if it's my sister, I try to look after my sister, without any professional guidance, without anything, just doing the best I can because it's my sister.

What I do applaud the National AIDS Council for, they actually started looking at non-communicable diseases, NCDs, and we know the biggest NCD is cervical cancer, which is something we have been saying – we need to be involved as women living with HIV. When they have their stakeholder meetings, we need to be included.

Unfortunately there are divergent voices. Someone released a letter that said demands from people living with HIV, which said NAC must stop dealing with NCDs. And to me and other women, it came as a complete surprise. So for that I think it's because we no longer have a robust treatment literacy programme like we had before the advent of ARVs. Some people yes, they have the passion to be advocating for the rights of people living with HIV, for the access for services, but I think without looking at the evidence which is being produced – and I think a lot of the evidence around cervical cancer has been generated within Zimbabwe itself. Annually in Zimbabwe, 3186 new cases are diagnosed every year. These are estimates for 2018 so they are very recent. Cervical cancer is the leading cause of female cancer in Zimbabwe. And also, in terms of common cancers in women, it's the top one in women aged 15-44 years, so a whole generation of young women is being affected by this.

As women, we need answers, and we need solutions. This is why we say let's sit together at the table, let's discuss and hear us, and stop calling our issues as anecdotes. But also what needs to change is among communities, people like me and fellow advocates and activists to keep ourselves informed. I compare with the time before ARVs in Zim, and when people got sick we had this system of supporting each other particularly with information, and information is the power that made a lot of us live.

As supports, networks of PLHIV, ASOs, there was funding to support that community work, but now it's non-existent. At the moment, one has to try as



much as possible to be connected to the community, to continue giving that support, while taking also, if you can, another job, where you earn some money so you can feed yourself. It leads to serious burnout because both are full time – you are doing two full time jobs, that’s what it’s like, except one you are not getting paid, and the other maybe you get paid but for one to survive. But then it means how much can you put into that unpaid work in terms of keeping up with information, with the new evidence that is being generated, the new trends, the new guidelines, new information, new good practice that are coming up from others, how much can you keep up, and I’m just finding that for a lot of us in Zim, we have the passion but without the financial and material support, and we no longer have that system where we give each other as activists sessions and make sure we are updating each other, informing each other about new trends.

I see people get frustrated because if I don’t have the updated information, if I’m doubting, I say I can’t answer now but I’ll find out for you. And because you have a whole list of things that you need to do for your paid work it may take some time and I think it’s frustrating for someone who is desperate and really wants this information. In a way I think we are not doing ourselves, or our fellow advocates or fellow citizens any favours by rushing into just giving information even though it might be outdated. Because sometimes you think I haven’t used this information for a long time, I need to check if it’s still relevant. But how many people are able to do that, because also the other thing is that a lot of things we have to check on internet and internet data is very expensive as well.

Peer support, treatment literacy and advocacy is still highly highly relevant although it seems the focus has shifted from that and it doesn’t seem that anyone wants to support that and also when activists get burnout what happens – there’s no... people say oh just look after yourself, but how do you look after yourself when you are now known as an advocate and an activist, it’s like you are on call 24 hours a day. I know people deal with burnout differently, but getting together with others, debriefing, doing something together so you reenergise and get back into the system to provide that advocacy and activism work.

It’s worrying because it seems we are forgetting to look after ourselves, we are more concerned about and we are pushed to look after others and we don’t look after ourselves. You can’t continue to look after others if we don’t look after ourselves.

Especially dealing with these cervical cancers it also drains you as the person who is trying to give support. You know you can’t give the money for them to get the treatment, you can’t give the money for their pain relief, but just being there, and watching that person in pain, I empathise a lot when I see people with cancer, particularly women with cervical cancer when you think this could have been stopped in its tracks when they presented for screening. I think it’s a skewed system altogether, when we talk about women being important and being valued, but I think the biggest demonstration of how women are valued is how we take care of their health, especially within the public health system.

