

TALKING BACK



**REMEMBERING THE
LOST DECADE**

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Date of interview: **November 2012**

LEBONE MALELE (LM): Telling me stories and what's the important stories that you'd like future generations to remember you know of. We'll start off with the beginning a story has got a beginning so what would you say is the beginning of HIV?

CATHERINE SOZI (CS): With HIV! I think I first, I know I came across HIV first when I was at medical school. I did my training at St. Mary's Hospital in London and in the late 80's I think it was around 85/86 when I, when the first HIV patients were being treated in London and interestingly enough they came from East Africa, from Uganda and I remember the first patient I saw was a gentleman who was being ventilated in then, in fact we weren't even calling it HIV then we were calling it HTLV3 and because there was so little information around then it was just known as an infectious disease and this gentleman was on a ventilator in intensive care unit. Everybody had to do barrier nursing, gloves you know the whole, whole sort of mask and he came in with fever, shortness of breath not being able to breathe properly, ventilated and you know eventually passed away after about a week and I can remember even then, I hadn't even graduated as a medical student then and I remember sort of the rounds being done you know because we were, I was doing my clinical medicine at that time and you know it's really quite vivid sort of standing out this glass booth looking across, this African man being ventilated and everybody saying 'you know this contagious disease, we don't know what it is, it's something to do with this virus that is spread' you know and now you know increasingly we saw more Africans coming in and that was my very first contact. After that, that was my first contact with then what became this HIV, after that then being when I graduated in '87 and did my clinical in '88 my first attachments were in Eastern part of London, East London and there large communities of Ugandans and Kenyans and that kind of thing were living and then when I began to interact in out-patients in some of the hospitals there like New & General Hospital even the Royal London Hospital which is in White Chapel I began to see more and more Ugandans with HIV and then began to sort of also get stories from home about people who were sort of had chronic diarrhea you know then it got a label at home was known as slim disease and that's when my first contact with the virus came and I think it's at that point I decided 'you know what this is what I'm going to be working with' you know because it just, see because even though I'd done my training in London, my whole pathway was to say that 'I'm only here for training I'm going home anyway after this and if this is what going to be I'm going to be faced with then that's what



I'm going to be dealing with'. So ja so that's where it all started and I remember that when I then after I had done all my postgraduate training in '93 I left London and instead of going straight to Uganda I saw an advert in the British Medical Journal which said 'we're looking for doctors to work in rural mission hospitals in South Africa' no less so I came to and spent; in '93 I came to and worked in Jane Furse Mission Hospital which was then in the homeland which is now in obviously in Limpopo Province and when I was there for about one and a half years there was HIV and at that stage actually I remember AZT even being on the shelves in the hospital. We had huge numbers of people with on TB, TB and Leprosy was a big component and TB particularly so I remember sort of running these clinics with you know we TB patients, big wards of people there for months and people coming in for treatment those defaulters and who's not on keeping treatment and then going to outreach clinics and you know following up in the communities and all the rest of it and I remember even at that stage doing the Elisa test you know for, yes and I remember the AZT drugs in a blue, like this blue packet and I remember having a meeting with our you know all the other doctors around how we use it, how it works and looking at the guidelines and yea so that's that far back when I remember my first contact. So when I'd finished at Jane Furse I then returned home to Uganda and by that stage I had a lot of friends a lot of members of my family who were obviously had HIV and were actually having AIDS related illnesses then so I remember the, you know the Cryptococcus the diarrhea that came at that stage you know. I remember one particular cousin of mine who had Cryptococcal Meningitis and I remember the headaches she used to have and the pain she, and whatever pain killers we tried and at that stage we Fluconazole could treat the headaches but it was so expensive and I remember poor girl she had a three year old daughter and she'd just sit in the room you know closing all the curtains and you know my dad and I would be shipping in the Fluconazole tablets for her to take and the Analgesics, the pain killers for the headaches were just not working and eventually she passed away. But I remember those days without antiretrovirals you know those days when it was really the runny diarrhea, the watery diarrhea that just made people waste away. The coughs that just kept going and people didn't know whether it was Pneumocystis or TB and I remember the skin infections. In fact I remember the Herpes Zoster you know people present with real pain and burning and you know one side of the face with blisters or the chest and at that stage the opportunistic infections were just running rife and you know the symptoms were just so difficult to manage. I remember you know the pins and needles that people would have in the soles



of their feet and somebody telling you that you know had trouble, 'I can't even put my feet on the ground because it feels like hot, hot coals' yea so those days and all that was really before the era of ARV's. I remember that in the then it was the early 90's that antiretroviral's had started being talked about but it was so far you know the dialog was in the US and I remember you know at that stage I'd been working in private practice, I'd done some private practice work. I had some patients who could afford to be on the antiretroviral's and you know you were talking about \$10,000 a year you know and at that stage we were doing dual therapy actually, two drugs even before the discussion on three drugs and trying to sort of really manage people on that and really the symptom control then was the emphasis. I remember being in dialogs with, with sort of colleagues working with WHO and UNAIDS I hadn't joined the UN at that stage where you know they were talking about drug access and the conversation of you know 'oh no Africa's will never be able to afford antiretroviral's and even if they do you know these drugs are toxic and they need to be taken at a certain time'. I remember that dialog around 'oh no but they won't' you know 'they won't, they don't even have watches, they won't even be able to tell when it's 6 'O clock to take the drugs' and thinking that guys no this, that cannot be. So when I joined, I eventually joined a centre called the Mildmay International Centre and this was a group of English ladies who were setting up what they called a model that was being replicated, that was being done in London around managing HIV as a chronic illness and one where the focus was on managing the symptoms making them you know manageable, making sure that people lived with dignity, were symptom free particularly pain free and so the Government of Uganda together with funding from DIFID and the World Bank set up this basically they called it a palliative rehabilitation centre and focus was on rehabilitation and on symptom control and I was the first Clinical Director there that was in one998 and we had when I was there even though the focus was on Cryptococcal we then access to antiretrovirals and we partnered with some Pharmaceutical companies to provide us with medication at very low cost so that patients who were, who had AIDS basically could start on triple therapy at that stage but triple therapy also meant that you needed to manage their opportunistic infections and their symptoms particularly around pain and we also started looking after children, children who were identified in the community as having the virus and also then started working with adolescence, survivors basically of long, yea so exactly of PMTCT programme and dealing with sort of the adolescent issues that come through not only



having HIV but going through adolescence and onwards and that was 1998 to 2000. It seems like a long time ago.

LM: About 12 years.

CS: It's 12 years and some of the issues are still the same you know some of the issues haven't changed very much which is a bit disappointing but it's been a long journey I think. Now of course you know then it was sort of ARV's being managed sort of by a specialist centre. At that stage there were a number of specialist centres treating adults living with HIV but the Mildmay Centre was one of the first really dealing with children at adolescence living with HIV and making sure that you know the issues around sort of long term treatment with antiretrovirals are documented because it's not, it really is not just a question of you know taking the ARV's and you know hoping that things, that's it. I think that one of the things that we did at the Mildmay Centre which are even pertinent now is around the support that living with HIV need to manage their lives around HIV and it really is dealing with emotional issues, the physiological issues, the spiritual issues and the symptoms that are around pain and other symptoms that you know the ARV's don't necessarily sort out. I remember actually one of the things was some of the side effects of some of the ARV's themselves. For instance Stavudine now which you know is obviously being replaced but you know some of the side effects around the pins and needles that were given in people's feet and agh it was yea managing HIV is interesting but just working with the patient and their family...

LM: Yes because not exclusive.

CS: No it's not, it's not at all exclusive and one of the things I know is that at least in the Ugandan context where for a long time HIV was sort of managed by the community rather than sort of; and then by the time it got to the tertiary level with specialists at least the community was able and receptive although of course stigma did exist but there was a lot of support that needed to be provided in the communities themselves. So when I came to South Africa in, when I returned back to South Africa in 2000 at that stage interestingly enough when I was at the Mildmay Centre the then Minister of Health Manto Tshabalala-Msimang actually came to the Mildmay Centre in Uganda for a visit and she came with a few of her MEC's for health from the provinces and they came to Uganda to do a study tour to see you know how Uganda was managing the epidemic.



LM: And I see in 1998 you guys already had antiretrovirals being rolled out in Uganda?

CS: We had them but I wouldn't say it was a National Programme it was still very much in treatments, a few treatment centres mainly around the Capital around Kampala and so there like 5 treatment centres. Some of them, some in private mission hospitals, one in the Government public sector and some in NGO's so it was a mix and it was basically trying to ensure that everybody whether if you could pay you paid and if you couldn't that there would you know some access to it. So by then the negotiations of the prices had actually also come down so then we were talking about \$one000 a year as opposed to \$10,000 a year. So yes she came and she, I think she learnt she visited some of the community based organisations, she visited us and I think it was a model that certainly could have replicated in South Africa. So when I then joined the United Nations I joined, my station was in Pretoria here where I am and the work then was at a different level it was around advocacy and policy and that time of the era you called the era of denialism was quite an interesting time but very stressful I think. But I think that it was also a process that has led this country to where it is now to be honest. I don't think it's a lost decade I think there's a lot of things that happened during that time particularly one things that other countries could learn particularly around for instance the fact that it's although Government it's Governments responsibility for a lot of things that actually AIDS is everybody's business and particularly around I think the civil society activism and advocacy that happened around that time and involvement of the judiciary and the judicial was things that other African countries were beginning to learn here from the first time. It was sort of like 'hey you mean we can sort of you know push the agenda you mean you know you can take things to court you know you can have a constitution that you know protects the rights of individuals' so I like to think of it as a positive time that even though obviously there were things that could have moved a lot quicker you know and I think that as some people would say 'okay lives lost during that time if we had done it earlier maybe you know so and so would be alive' but you know with history I think that you know history is there so that we learn on things that can take forward, that we can take forward on a positive note. So yes it was interesting times, I remember the Nevirapine saga and remember Uganda had been doing all those trials and the Nevirapine around mother to child transmission. But I remember the constitutional court cases and I remember TAC, at that time I was at the regional level and I was part of the team as UNAIDS that actually documented some of the activism that was taking



place around access to ARV's and in South Africa it was really the civil society movement and you know the way of working that TAC and other activists took forward around the community media stations the treatment literacy programmes and you know what other countries learnt during that time in, you know what treatment literacy is about, what does it mean you know so we can't just you know as civil society or as beneficiaries we don't need to just rely on Government to give us the pill but we also need to be part of the treatment programmes so that we all live and our quality of lives is improved.

LM: And make things work!

CS: And make things work!

LM: Let's go back a bit...

CS: Sorry I told you I could talk forever.

LM: I love it that's how it's supposed to be. So what would you say stood out for you about your first encounter in working or rather during the process of documenting the rolling out of ARV's in South Africa and the rest of the world because you said the moment it you stepped into UNAIDS you started your part of the team that documented it?

CS: Yes, yes, yes, yes. I think the thing that stood out were that different countries were at different stages and the different players particularly the roles of Governments because remember Governments were being pushed, there had been the UN Declaration of Commitment signed in 2001 where Heads of States sign on behalf of member states that this is, these are the things that they will be able to achieve you know and we're going up to 2015 now and we're still on that journey and all the time we have to keep reminding states that this is what we promised, this is what we promised. So there was that angle of the Governments role and I know that you know different Governments played it had, were at different stages you know I think we documented a case for South Africa where we focus on the civil society action which was very different to other countries. We documented Botswana which for instance had commitment from a very high level very early on about sort of you know put a 100% going for universal access for every Botswanan to be on ARV's and then we had the Ugandan story where you know although there was political commitment they



didn't have the resources but the community based organisations were still you know pushing and making sure that HIV testing and counseling and the PLHIV's support groups were the you know the bar you know the mainstay of the AIDS response. So there were different responses at different times depending on the resources, depending on the political wheel and commitment and depending on all the other players that were there at that time.

LM: If you can recall, what were then the challenges for South Africa?

CS: The main challenges I think for South Africa were that whole what we called political commitment. I remember being at the World AIDS Conference in 2000 that's even before I joined the UN actually. I came as a you know working for Mildmay and I came and presented papers on what we you know what we can do and that sort of thing and I remember President Mbeki came and I remember Nkosi Johnson at the event in the evening standing there trying to read and President Mbeki getting up and walking out and I remember thinking 'gosh how, what is this I mean how' did he walk out on purpose or is it really he's got another appointment or you just, I can just remember that whole debate and dialog at that time and coming from the outside coming into the country I couldn't understand, I couldn't understand this whole conversation 'does HIV cause AIDS' and you know and I thought ooh maybe they've got it wrong or maybe they misinterpreted what him and his administration really meant and because it was there in your face it was quite clear. So for South Africa I think that element was, was missing but I was also very impressed by the fact that people did not give up you know and particularly not only, not only civil society in the broadest sense but even people working for the Government themselves, I mean they were individuals who were caught in between you know they knew what needed to be done and they could see people. They knew family, they knew relatives, they saw it on a day to day basis and so they were having to juggle this, the political statement visa vie what they knew they themselves actually thought so I thought it was an interesting time. There was really a lot of vigour and had to keep on top of it and had to feedback and you know jostle with what is the next move. I don't think people slept during that time actually really. But I do think thought that in spite of everything that even during that time that this country even had a strategic plan I mean they don't call it a strategic plan, I don't know what they called it.

LM: The National AIDS Plan!



CS: I think it was the National AIDS Plan but even then that there was still efforts to, you know in spite of the fact that it okay hadn't, there was a political tension that you know the technocrats or the technicians and the programme managers the people who were in touch with the general populace knew that HIV causes AIDS and this is what's happening to our people so this is the plan, we will treat it as this so you know it's not as if that nothing had been done until the new administration came on. Now I really think it's important that that is documented that the efforts that were made. They may not have to the level at which everybody thought South Africa should be at particularly South Africans themselves but they were not quiet people, were not quiet.

LM: Yes I can see, you would think that people did not sleep because of voice activism in the background.

CS: People were not quiet. I don't think they slept, yes not even in the background in the forefront I mean you know the conversations were there and I know that people working for Government were torn between what you know the principles say and what the political arena, you know conversation is visa vie what they know in their professional lives and as family members you know.

LM: So I think also what got since civil society and every other person involved is that the courage of conviction you know when it came to a personal level you said 'I cannot ignore it'.

CS: Yea, yea, yea, yea.

LM: So would you think what was happening in South Africa was exceptional compared to other countries, particularly the African countries?

CS: I think the movement and because I guess South Africa is South Africa. You know economic wise and you know the historically and socially globally South Africa is in a different place to most of the other countries so of course you know the, you've got a pretty active media here and the media outside everybody would want to know what is happening around South Africa and think civil society made a point made sure that took place but also the Government was keen to also reflect its points of views. So there was this dialog which would be interpreted by different media houses differently, so yes I would say that is exceptional because in some of the countries and I won't name



any civil society were not able to act like that you know you had no voice. You had no voice and freedom of expression and all that business about taking Government to court well it was like 'hey what' and so how can you do that and does our constitution allow for that and will the Government even allow it, will they allow even 2 or 3 people to congregate around a street corner and demonstrate on anything, do you see what I mean so yea I think the environment was quite exceptional. And I remember you know it was all you know from TAC they formed this, what did they call it, the International Treatment Preparedness, it's the Africa Wide one equivalent of which have quite a lot of vocal activists and who would speak now trying to get the agenda much more Africa Wide rather than South Africa and I think it was also then it would be a little bit difficult for some of the other Africans to be as vocal but of course they were but you know could probably be more vocal outside their countries than in yea, yea because the way things would work would be very different to here.

LM: And you've got the constitution...

CS: Yes, yes, yes, yes.

LM: So let's reflect back about treatment. What challenges were faced in whatever experiences you've come across to get treatment to people?

CS: Ooh goodness. Well the first thing was really making sure that those who needed to be on treatment were identified you know so that whole element of you know 'am I ready to go for HIV testing' and even if I go for HIV testing 'am I ready to accept my results and what they mean'? So you know and you can only do that in an environment where people feel safe if they go for a test that there will be confidentiality around the test and that the results will only come to me and then I'll be counseled to be able to disclose to somebody to help me, either my sexual partner, my partner who I'm having sex with but also maybe somebody else whom I'm not having sex with but who will be there to give me emotional support. It doesn't have to be in the house it could be somewhere in the church or you know somebody I'm close to. Once that whole; I think there's, we still have a challenge around HIV testing and counseling because I think, I think there's a focus a lot of focus on the HIV testing itself but the acceptance of what that test result means to you and to you know I think that the level of, the emphasis on that process has been minimized to just getting the numbers out and



getting people tested, 'here's your result here is'. I'm hoping that people will then act in an appropriate manner with that result whether it's negative or whether it's positive. Now once people then know what their result is if they then are able to sort of get a facility where they can find a healthcare worker who can then explain what the implications of that test are and what needs to happen from now on. So this is even before we get to the ARV itself, it's really for the counseling and the information that needs to be given to me who is going to be able, who is going to make the decision whether I'm going to swallow those tablets or not.

LM: And if you'll believe that the test is true or not?

CS: Absolutely you know and if I believe that these medicines actually if I do, because you know give, you have to live positively, eat well, do exercise dud, dud, dud and you will be well you know and having to really must do that. Actually this is for life it's a decision, it's not that I'm going to have an option to sort of check out at some stage. So the whole buy-in from you as an individual is so key around sort of I think from my experience anyway in really some, a person taking onboard that's what they're making a contract to do and this is for an adult. For an adolescent and a child it's a completely and I don't even, I haven't even started that conversation. But when then we got to the stage where somebody has accepted and the ARV's are on the shelves, they're there and you know you, apart from having to think about; in the old days it was 'oh can you afford it'. I mean that dialog was so difficult. How much, can you afford this, how much it will cost! Once you've been to the counseling and you're given the information and then it's sort of 'but doctor how much is it going to cost him', so that's why we had you know apart from bring your family, bring the guardian, who's going to pay, dud, dud, dud.

LM: So it was quite intense!

CS: That's if they haven't had an opportunist infection that's made them sick so in those days we used to say 'okay let's get you better without antiretrovirals, start you on medicines that will take away whatever the infection is' and then we would have to have a conversation and we'd have to have a start and it was really quite rigorous and even at that stage I remember at the Mildmay in '98 the monitoring was done by nurses, the initiation was done by doctors but the monitoring was done by nurses and it would be monitoring not only just whether you've taken your tablet but how you're



feeling, you spirituality your sych, you know your emotional issues and everything to do with just getting to be in that space and being comfortable about it and with yourself as you move forward. So for me that journey, I really don't think that journey has changed, I mean that whole thing I think that I don't hear much about it anymore. There's this, I feel in my own self that there's a assumption that because we've got ARV's now, they're much cheaper that it's really about get the HIV test if you're positive, do your CB for count, if you're eligible start you ARV's and you're on it for life. Heaven help you what happens for that journey and that's adults! For adolescents I think the, it's even trickier you know and for children who obviously get started on you know decisions are made by their guardians or their parents as they grow, hey you know what it's like when, you get inquisitive if you ask and there's so many issues around children on, with HIV that I feel you know are still not dealt with by the families and communities let alone the healthcare workers in a way that you would think you know, this is the way to go so that's my perception around ARV's. I think of course you know they're important definitely, they're life saving but they're not the bee all and end all and I think that even the symptoms some of the chronic symptoms that give people living with HIV and treatment pain are still there but we don't, we don't talk about them we don't you know, we don't prioritize them so it's about you know Septrin and ARV's when in fact I still might be getting pins and needles in my feet, still not being able to walk properly you know yea. Will I still be able to go and do what I was doing before you know the, yea so it's quality of life at the end of the day and then with the fact that I have to take pills now every single day, how does that change everything that I do around me? In an environment maybe where not everybody you know knows about you know my blue pills and my green. I mean I still hear stories of where people get their ARV's and they put them in their Panadol yea containers you know and they're in a relationship an intimate relationship and the other partner doesn't know, so you can see we've got a long way to go. It's not, it's not as if we there if I have my, if I'm diabetic and I have my insulin injection, 'ooh funny I've forgotten to do my jab you know just draw it up for my and phew you know'.

LM: What do you think; it has become less for priority?

CS: I don't know, I, I'm hoping that maybe I mean out of touch with what's happening at the real you know of the reality level but I know that certainly for my experience in my family and with my friends that that's the feedback I'm getting that it's really very much about the ARV's. I think that



maybe, maybe there is also some general fatigue about hearing about HIV now we've so well about saying 'it's ARV's' you know 'for chronic illness get out there and manage it' you know you manage it like I heard an advert will be out there saying 'it's like having the flu' my goodness. Yes manage it like you've got you know and I thought ok well maybe but I think that you know they're missing the boat a bit and I think that even those who've been on ARV's for a very long time, there's some people who've really done well. I've got friends who've been on it you know the length of time that I started in Uganda 12/13/14 years and doing very well but they've managed to have a very supportive network, been able to deal with it with their families and you know and they've been open and they'll courageously come out and everything but not everybody has that same journey and I think even when I was at Mildmay in Uganda I remember, I'd only been there 2 years and people were already talking about drug holidays. You used to get patients coming in and saying 'oh can I have, is it possible I could just have a month or 2 off' and of course you know research was undergoing, was taking place in the States then which obviously showed that no it's not a good idea because resistant develops and so then you have to sort of, but it just showed you that you had to work with you know with the person concerned and sort of the support that here is support and that's why I think more around that support network and groups even if they're not formal structures but your network in you know dealing with that day to day management is key mainly because you know the stigma around HIV is still very prevalent. Unfortunately one of the things I think is that, that has not helped and I would like to see a lot more is around the support from the faith based organisations, the institutions that we, a lot of people interact with on a weekly basis and I think that a lot of that discrimination still persists still even to this day.

LM: Sort of the stigma of how you...

CS: How did you get it?

LM: how did you get it?

CS: I've been to, went to a funeral last year where you know the Pastor conducted, I had to walk away because it was just too you know still going on about you know 'who did this' and the person had died you know it was sort of 'who did you sleep with and people you mustn't' you know it was still judgmental and you still hear and maybe they're not stories maybe they're true of people



stopping their treatment because they've been told they've been healed, they've been cured, take this, take that so there's still a lot of funny stuff going on around which you would have thought 30 years on that you know we'd all be the cleverer for it. But there's always that hope that 'oh no maybe I didn't get it like this, I didn't misbehave, somebody's judging me' you know this whole judge, 'how did I behave, who did I sleep with, how many times, what have I done, who brought it, where did you get it from, who did you give it to' you know.

LM: I mean we look at I can't recall exactly the sad part of, it's very unfortunate during blood transfusions, that's how some people got it.

CS: Yea, yea.

LM: Some it's through just some other occurrences of contact with blood without being very cautious and it doesn't occur to other people that you don't only get HIV although it may be the highest medium through with people get it is during sexual intercourse and so on but it's not the only way.

CS: It's not the only way but still even if you have got it through sexual intercourse, it should still not be judged because you don't know you know and women don't go out there looking for HIV I mean you know or men for that matter you know but you know so it's this finger pointing that has really made the virus survive big time because it deals with human beings being nasty to each other and that's how it sort of just propagates itself and because people are you know are always wanting, 'so who did I get it from' and you're looking and you're trying to chase your sexual network and all the rest of it instead of focusing on you who is here now, you who has got children, you who has got a partner you know so those, those discussions on where did I get it from you know tend to be very negative in sort of really helping us to top AIDS and so the stigma and discrimination I wish, I think we need to put more into it. I don't think it needs money because we will say 'oh but we don't have money to do this and this'. I think we as people as human beings need to really reflect on what it is around our own humanity. What makes you judge somebody else and not have 4 others with 3 fingers pointing out at you.



LM: And I mean also you just look at the dynamic surrounding us dealing with the disease. Sometimes whether it's at a personal level or organisational or even national level, do we stand and reflect that are we responding accordingly to this disease that we're not just pocketing into sizes and say 'economically do we have the money, yes or no'? Socially are we having conversations with the right people, yes or no? Instead of looking at how it integrates.

CS: With life!

LM: With life!

CS: Because we're living in a world of HIV. It's here and it's going to be here for a while longer.

LM: It hasn't come out and make bumping...

CS: No, no, no, no you're right you're right. So then that it sort of, that's when people send, because it's sort of out there standing, 'oh no let the doctors get on with it'.

LM: Exactly and then if...

CS: Let the Minister of Health deal with it, let the you know, health, health, health when in fact if it's around us fully it's to do with everybody and everything around us.

LM: And I think the power, the triumphant spirit came about, we then recognized that you know what 'we each have to do something about it'.

CS: Yea, yea and it's everybody's business.

LM: It's everybody's business, you can't say 'Government you're not' although you play a key role with this, how are we then supporting and how is that relationship?

CS: Yea you're right and that we as citizens have a role to play and it's not just the Minister of Health will put the drugs on the shelf, yea the drugs are on the shelf now but are the people getting there and if they come out do they feel safe to talk about it? If I reveal to my husband, in fact we were, last week we launched a photo exhibition "Not Me, Not Mine" it's showing at Constitution



Hill at the moment and you should read the stories powerful stuff. The violence when women reveal yes to their spouses.

LM: or partner.

CS: Yea beaten up, chased away, you know and you think ‘hang on a minute, but you and I you know we had a thing, what’s up?’

LM: I remember I think it was Prof McIntyre who was sharing about the women’s rights that then makes them into HIV because that now comes into play that you know women also have rights but you know those rights have not, there’s no justice around those rights because the moment the woman says ‘guess what I have, you’re the only partner that I have but it seems that I’ve got HIV’ not seems like, ‘I do’ then the violence that erupts out of that.

CS: Yea, yea.

LM: And the denialism who think you know that there’s also at family level that there’s denial and then it just rolls out because now we’re looking at also from national level it also transcends sometimes downwards to say the moment a national leader says ‘I don’t believe’ and people listen. If a national leader says ‘I don’t believe’ and I’m like ‘well he’s right he knows what he’s doing’ but look at a person who’s less fortunate to reason who’s less fortunate to think at high levels, what then?

CS: That’s why they say leadership is very key but you can have leadership at different levels hey! Head of Government but the Head of your Church you know the Pastor the Reverend whomever sits in the, stands in the pulpit every Sunday and tells you ‘dee, dee, dee, dee’. The teacher, the Head Mistress at the school, the Head of the Police Station you know so if you get, so if you get violated because you’ve told your husband you know ‘I went to the clinic’ you know ‘number one I had a hard time at the clinic but the health worker told me take your test, your test is positive’ then I go home and I get whoosh a beating. Then I go to the police station and police don’t want anything to do with me, they tell you ‘but your husband loves you go back’ so you see it’s a...

LM: Just a cycle in a web...



CS: It's, yea it's entrenched and you're right I think that the burden of the epidemic of course on this continent is around women, women and girls. Not only around their vulnerabilities as girls in schools, girls in homes places where they should be safe is where actually they're violated and then when things happen the partners who they, you know somebody was telling me 'but AIDS is a disease of love' because this person, I say 'I love you' and he said "I love you' back and virus is, and the minute I disclose he beats me up or chases me away. But it's not only him his family may do the same thing so the women will be pointing fingers 'so you were seen with so and so' you've got nowhere to go. You go to the police report a violation, nothing's followed up, the justice system is slow, if you do manage to get through 5 years waiting so yea it's, we've got a long way to go to gender equality that's for sure but this virus is not waiting.

LM: Exactly it's not going to be put on hold it doesn't go on holiday.

CS: No, no it doesn't go on holiday, it doesn't go on holiday.

LM: So what do you think makes it much more challenging apart from that I'm assuming that you know what; we get stories documented about how Africa is dealing with the disease and how somewhat in other ways it appears that the west has been able to have less challenges than we are because really it's, the notion comes only at, with the role of media because what you read and what is being published is what you think is but necessarily is true because if right now we look at it, it seems like sorry to say but the Caucasians are not having as much difficulty with women violence in the west when a wife has to disclose to their husband that I've got the virus. You come, now African context it becomes a big thing.

CS: You've asked a very difficult question, I don't know, I don't know. I don't know whether it's just African and I know this is being recorded and I'm sure it will be the one thing that's got to come out, I'm shall be this woe to the same war, you, you, you the things you should say and this I'm saying in my personal context is that actually it's not just Africans and I don't know whether there's an issue around, it's a, because if you look around you know if you got to the US for instance who's got HIV? It's the African Americans. If you go to South America, who's got HIV, yes, yes, I don't know what it is but I think that they're issues to do with sort of that's why it's not a health issue it's around the social economic issues and the gender relations within those cultures that allow men and



women to either be or not be apart with each other. Believe me violence, gender based violence actually occurs very much around in Caucasians as well.

LM: Yes that we've...

CS: The early, you know there is no discrimination around that and I actually I haven't actually seen anywhere where it's been documented that you know for Caucasians when they disclose there's less violence and maybe what happens is people just walk away because people do walk away. Maybe it may not be a fist in your face but it's just 'bye bye you're on your own, I'm off' maybe that's what needs to be done. I haven't seen the study and maybe that is there but I do know that the stigma around HIV is real it cuts across whether you're African, African American, Brazilian, Fijian you know and it has that same whole moral judgment you know and it's really around 'are you gay, are you straight, are you a woman or are you a man, are you injecting drugs, are you not injecting' you know...

LM: It's got no favourites.

CS: It's got no favourites but people will always want to put it in a, put you in a category and we just need to get better at really humanizing you know, humanizing everything. I'm talking too much what time is it?

LM: No you're not talking too much I'm just concerned about your time because you have to be out of here by a quarter past.

CS: Yea, yea, yes.

LM: So we'll say we've got exactly 5 minutes or less.

CS: Okay, okay.

LM: It should be safe so that you don't miss your next appointment.

CS: Yes thank you, thank you.

LM: So are there any other stories that really touched your heart and still resonate in your mind?



CS: The one which I had started talking about at the beginning which is really around children and adolescence. I think that there's, there's, I know a lot of attempt has been made now to sort of you know put children at the forefront. Then this big group one0 to one9 year old who they're not adults and they cease to be children but you know they're living with HIV and they're also going through adolescence and you and I have been through adolescence we know what the issues are you know dealing with your own sexuality, dealing with your you know, you being you but you've got this...

LM: don't know how to make decisions...

CS: Yea but you've got this virus which all your other peers do not have right! You've got medication which you have to take which everybody else does not have to take you know and you've probably, and you read you know what HIV is, you hear the stigma, you hear the, you know you're sort of taking in a lot of stuff and I'm not convinced that the support mechanisms or the you know the safety net for adolescence is there, out there yet. It will come later like how you know adults usually cater for themselves. All these guidelines came up for adults, we forgot there were children and so we're very emotional around babies and young children because 'oh no it wasn't their fault, they didn't get it' and then 10 to 19 there's a fallout somewhere and that really, that is a, that really pains me I think. No it does pain me because I don't know what the solution is and I think if, in maybe the west they've got the ideal models but in Africa where the countries are struggling anyway with their health budgets and this budget and that budget and healthcare workers, number of staff whether they're there or not, I feel that it's so easy, adolescence just fall off, they stop taking their medications and they die and it's just another, do you see what I mean? It's, it's painful. I do know that we're making strides around eliminating HIV in children but those who are alive now and there will be those who come through with it you know and those who get violated in schools by older men, you know we know that it's sort of that whole intergenerational sex because of social economic reasons and all the rest of it. What happens to them? I remember when I was at Mildmay in Uganda because we had this adolescent, we actually set up this adolescent club of adolescent's living with HIV and at that stage they're probably, they're only about 15 or 16 and they were you know and all of them number one was stunted because you know they were shorted than their peers you know they'd had HIV for a while and they, but they survived you know and then they all started on ARV's



got better, responded very nicely very quickly and then you know the hormones started kicking in. Just have to disclose how you tell an adolescent they're living with HIV how do explain, how do you start and then they started you know wanting, you know the usual. You know you find, you've got a crush on so and so or so and so, so and how do you deal with HIV transmission? One of my favourite patients was called Molly, she actually just said 'doc I'm stopping my treatment, I'm tired'.

LM: How old was she?

CS: She was 14 and she stopped and she died, she died about one8 months later. She said 'I'm fed up, up to here, it's okay I'm tired'.

LM: And did the parents take that?

CS: Her parents had both died so she was living with a carer, yea, yea.

LM: Do you see its initial damage people without HIV?

CS: Ooh must do otherwise I wouldn't wake up every morning to go to work.

LM: Because that's what you do...

CS: That's what I deal with day to day but you know I deal with it from a distance. A lot of things I told you I started off saying 'I was a clinician' I used to be a doctor face to face and after a while I just got burn out I really did actually you know those stories and the you know it just got a point, so now the level I'm dealing with is Advocacy and Policy it's kind of removed from the reality and most of my relatives are ARV's.

LM: Interesting that quite alarming because if you're working with Advocacy and Policy, the policies informed by what is happening on the ground.

CS: On the ground yea, yea. It is alarming but for me I think it's a safe, it's to protect myself you know because it's I've got a family, this is my reason for actually leaving my clinical medicine it was sort of like I've had it 24 hours a day you know it was sort of not and I was psychologically I think quite scared but I thought if I can do anything now it's really sort of to push the agenda because I know what needs to be done and I feel I need I can. Luckily I mean most of my relatives are all on



antiretrovirals and my friends are so I know what the possibilities of but I also know that for instance one of the most painful things was a friend of mine who were activists with and she must be coming up to her late 50's now, she's been an activist for a long time and then she revealed to me that her daughter was HIV positive. Now these are kids we grew up with, these are our children and you're an activist da, da, da you're sort of really you know and that within your own home, do you see what I mean it's hard, it's hard. It's hard I think but so that's why I'm saying is that sometimes you feel you're removing yourself from the reality but actually you're not because HIV is about your daily you know you interact with people on a daily basis. So that's why I'm able to say that 'oh no okay around children and adolescence we haven't got it right yet'. We've got a few specialist centres good but in the communities no.

LM: Before I chuck into some of your time because we could really, now you understand...

CS: No I'm not doing the Shaun Mellors.

LM: Now you understand how it could easily be an hour, it could easily be an hour.

CS: It's brought back a lot of memories.

LM: Thank you so much, thank you.

