CCAC interview with Thobani Ncapei on 2023/02/20 at Thobani's home in Khayelitsha - transcript (English)

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Interviewer name (and acronym): Thina Miya (NTM)

Interviewee name (and acronym): Thobani Ncapei (TN)

Name of translator: Cullen Mackenzie & Buntu Makhedama

Name of transcriber: Cullen Mackenzie & Buntu Makhedama

Notes on access and use, if applicable: The English translation of each answer is written in **bold** under the vernacular version of the answer. If the phrase was said in English, the text is incorporated into the original vernacular text in ***bold italics***.

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List of acronyms: NTM (Thina Miya), HIV (human immunodeficiency virus), AIDS (acquired immunodeficiency syndrome), TB (Tuberculosis), MSF (Médecins Sans Frontières)

[START OF AUDIO RECORDING: 0:01:23]

NTM: So, how did you become a body-mapping artist?

TN: Eh, I was working for TAC, Treatment Action Campaign.

NTM: Okay.

TN: *Ja*, in short I think they call it TAC. *Ja*, it was because I worked for TAC from 1999. TAC was founded in 1998, and then I worked for TAC in 1999. At that time I was the first patient for MSF, because I was about to start ARVs when MSF managed to get the medication, *ja*. And then I was working around the clinics in Khayelitsha, because there were only three HIV clinics around Khayelitsha at that time. It was here in Site A, and also in Site B, and then in Michael Maphongwane, that is Maphongwane in Harare. TAC's offices were in Site B and then the guys who were working for body-maps, they were coming from ASRU, the AIDS and Society Research Unit in UCT. They visited all of those three clinics where there are HIV clinics. Uhm, because we were running support groups at that time. For people who were HIV-positive, they gathered in support groups where they advised each other. Then those guys came to the support group in Site C. Because I was here, I was taking my medication in Site C. And then they told us about this plan of trying to start body-maps.

NTM: Okay

TN: *Ja*, uhm, I decided to join them, no matter I was busy at TAC, because I was a district organiser at TAC. And we were fighting with Manto and Thabo Mbeki at that time, in order to get ARVs medication, and then I joined them. Unfortunately I was the only man (*laughs*) in that group. I was the only man. They were mostly women. You know men? They always drag their feet when it comes to something like this. That's how I became a body mapping artist.

NTM: Okay. Can you tell us more about how, when and why your artwork, the AIDS bodies, was made?

TN: My art-body map was made but not yet finished, that's because as I have mentioned, I was busy at TAC at the time. I used to attend and not attend, and then when I'd attend I found out that other people were far but the time came when the body-maps must be released and then I told myself "no man, there's nothing wrong with this body map, because it shows how to start a body-map, rather than the other body-maps". Because other body-maps, people when they look at them, they don't know how we started to do the body-maps. Because mine shows how we started, because when the first person has to lie down, and then the other one draws that person, and the other one lies on top of that drawing, and then you fit them.

[TIME ON AUDIO RECORDING: 0:05:41]

NTM: Oh that's beautiful. How do you think this artwork..? (I inserted a picture of it here, just to remind yourself). How do you think that this artwork speaks to HIV and AIDS speaks to the HIV and AIDS epidemic that started in the early 1990s and reached its height in the 2000s, and speaks to its continuance now?

TN: I think at that time, in the 90s, most of us didn't have information about HIV and AIDS. The only thing that we knew was that once it said you are HIV-positive, we know that a person has AIDS, we hadn't heard this thing that if one was HIV-positive, in fact one had AIDS, as soon as there was that thing with HIV in it, they said we are dying, because that means wherever there was AIDS one will die. Because, like, the way I was told, because I was diagnosed HIV-positive, it was in March 1997, I was in the Eastern Cape at that time, in Matatiele at one of the hospitals there. At that time, 1997, there were the nurses who were in charge, they were sisters in charge. Sister-in-charge called me early in the morning because I was admitted and in hospital. She said to me, "you can sit on the table", and then I just sat on the table and then I was climbing up onto one of those tables from before, the wooden ones, which used to be in schools at that time in the early '80s. And then in that room where we were sitting, for me, I was afraid of it and I had only just encountered it. There were three charts talking about people who had arrived with *ikhwasha* (or disease) there on the wall. On which were pictures of AIDS outbreaks. And then she told me "you have AIDS?" Then, I asked "no, what do you mean when you say that I have AIDS?" She said "you have AIDS, and there's nothing we can do." And then she said "go back to your bed and sleep, and wait for your day (to die)."

NTM: Oh my gosh!

TN: Yes, just like that.

NTM: No way.

TN: Then I got up and I climbed into bed. In fact I didn't know about this because people were ignorant about this AIDS thing. I said to myself, about the information I received, she should have sat down with me and told me that "listen here, you have AIDS, and when you have AIDS it's like this and like that." So I want to say that at that time, we did not know much, in the early nineties. We started to get information in the early 2000s. It was the time when these NGOs were around, which were working on HIV.

[TIME ON AUDIO RECORDING: 0:08:38]

NTM: Like the TAC

TN: Like the TAC, Love Life, and others, *ja*. And now, with this new gang, I don't think the youth who are around are aware of this thing of what HIV means, because they know that there are people who are HIV-positive. There are people who have success (stories) of being HIV-positive. A child who does whatever they think of doing, because you will find out that most of them don't prevent when they have intercourse. A child tells you this thing of "no I will survive because there are others and the ARVs are here." They have been told this thing that the ARVs are here, and how might they have arrived they care little about that.

NTM: I don't know.

TN: They don't care, these children, because they don't know how things used to be.

NTM: And how things were fought for? *Yoh*. Please tell us about the first time you received HIV/AIDS treatment and its impact on your life?

TN: When I first received my ARVs, it was MSF at that time. It was in 2001 and I remember it was the 11th of June.

NTM: *Yoh*, after such a long time!

TN: Yeah, since 2001. And then, at that time, the doctor who was there, Dr Hermann Roodt, the one who had moved from where he used to be at Lusikisiki. He had an HIV clinic at Lusikisiki. Dr Hermann Roodt it's like, within the time when we were going to Site C, because the clinic wasn't named at that time, it was a bungalow, attached to the clinic, whereby whenever a person attended the clinic they would stop to see if they were not seen by anyone before entering the clinic. When you've entered, you exit with your urine. And we had a support group. We attended a support group, each and every day, and then Dr Hermann Roodt was a people person at that time. Because at that time, when the ARV medication started, he would sit down with you and he would tell you this, that "if you start the medication, ARVs, what will happen is this and this, and then you have to look out that you follow these. And then there are conditions which you will be given". And then at that time there was a counsellor, who followed him, who would start by going to see your home situation before you were given the ARVs. The ARVs were not just things that were given out like today. They would firstly look at your home situation and who you live with at home. This home that you were staying in, this person that you live with, will they be able to care for and support you? That is what they called the treatment "support".

[TIME ON AUDIO RECORDING: 0:11:22]

NTM: Mmh..

TN: And then, it would be the person that you live with who would then come to the clinic to sign for your ARVs. But before you are given the ARVs, there would be a meeting with doctors. In Khayelitsha, the person who was in charge was Dr August. He would look at the records that were presented by your doctor to determine whether this person should start taking the ARVs. At that time they would pay attention to your CD4 count before you could take the ARVs. It wasn't the same as now. Now you are HIV-positive and are given ARVs. At that time they looked at your CD4 count and what it was, and then they looked at the medication which you would be prescribed. Because it would not be given like any medication at that time.

NTM: *Ja*.

TN: So mine before I started my CD4 count was at 1, it was at 164. My CD4 count was at 164. My viral load which made it so that I took the ARVs, it was at 240 000.

NTM: *Ja*, it was too high.

TN: *Ja*, it was very high. So many people at that time, it wasn't easy for them to start taking ARVs, because there was the pamphlet, I don't know where it came from but it said the ARVs are being tested on guinea-pigs.

[TIME ON AUDIO RECORDING: 0:12:54]

NTM: No way!

TN: There was that pamphlet that was doing the rounds. It said that people were taking ARVs…

NTM: They wanted to get them revoked!

TN: Yeah, they wanted to get them turned away. So then the doctor showed us the pamphlet and asked us that even though you have seen this thing, do you still wish to take the ARVs? And then it was my choice that I want to take the ARVs. This was in 2001, and then I was the first person in Khayelitsha to start ARVs.

NTM: Nice!

TN: *Ja*, I think it was Matthew Damane, it was me,and then it was Vuyani Jacobs, the late Vuyani Jacobs. At that time, after we started to take the ARVs, that's when I decided that I should be open about my status. I was open and public,because at that time I had had three months since starting the ARVs. I remember I had my picture appear in the Mail and the Guardian. *Ja*, I told my story of when I started with ARVs. And that's how I started with ARVs.

NTM: I love that. And did they help, at the point where you…?

TN: *Ja*, they helped me a lot.

NTM: Okay. This question is long, you know? Normally I repeat it twice. Um, while understanding that the 2002 Memory Box Long Life Project was focused at advocating for wider access to Antiretroviral Treatment, and Nevirapine, it must have been a very personally revealing thing to do. Was there counselling involved during the process of making the artwork, and how did you feel when making this artwork and did it help your healing process?

TN: No, we did not receive counselling by the time we were doing the Memory Box, because most of the time we would be coming out of the support group. Then in the support group that's where we had our counsellor. We would find ourselves there and sit with them, you would arrive and express any feelings there to them.

[TIME ON AUDIO RECORDING: 0:15:07]

NTM: *Ja*

TN: Another thing that I noticed that we enjoyed doing the Memory Box, because it was where a person would express scars that they had on their body, through HIV. Because some of them had lost children, and others were the first with TB, and TB mostly leaves stripes, it comes and leaves striped scars. So a person would show the scars they had got at the time when one started to say they had HIV.

NTM: Okay, and did this project help you destigmatize HIV in your community and more broadly? Do you think the stigma around HIV has changed?

TN: Uh, at that time, the stigma was widespread in the community because the t-shirt which had "HIV-positive" because what TAC was trying to introduce was t-shirts written "HIV Positive". With those t-shirts, it's not that they were only given to HIV Positive people, but to people who were supporting those who were HIV Positive, and people who had lost family through HIV. So the stigma was very widespread in the communities in which we were living, because the moment you wore that t-shirt, you were seen by passersby, they would point out this thing that you were HIV-positive. So the Memory Box, I think it reduced stigma. It reduced it a lot.

NTM: And then now, do you think that…?

TN: No, now I don't think, I'm not sure whether stigma still exists or it doesn't because as I have mentioned that these children do not care, and they do not care about anything. What I have noticed is that if a parent has a child that is sick at home, and they suspect that the child might be HIV positive, that parent does not waste any time, they come to me and say, "Thobani look please come speak to this person at my house as I am suspecting something". They say that "at least they will not be ashamed if you do that because perhaps they will be able to open up to you about the problem that they are facing." People understand that HIV is part of our reality. There's no point in stigmatising someone else because you will point at a person outside that they have HIV not knowing that you have someone positive within your household. So we have conquered the stigma now. There's nobody who still cares for it, and so on. I think the other thing that played a big role in this issue of stigma was those programmes which were made on tv, like Siyanqoba.

[TIME ON AUDIO RECORDING: 0:18:12]

NTM: Siyanqoba. Were you also on that?

TN: Yeah, I was there.

NTM: Wow.

TN: On that programme of Siyanqoba. I was also there.

NTM: Oh nice!

TN: So those were some of the programmes which I think played a big role in this issue, because you would hear a person say "no, Siyanqoba starts at a certain time" and then would run off to go home and watch the tv.

NTM: Oh that's nice. I want to ask, did the support groups have like their unique names for them, or was it just an HIV Support Group?

TN: No , it's like, there were names because you would find that there were a lot of us at the clinic. So you would find that at one time maybe in each group there are 20 people and so on and so on in their different ways. For my part I remember one of the support groups that I was in, we called it Madiba.

NTM: Madiba?

TN: Yes, We called it the Madiba Support Group

NTM: Because, why?

TN: Uhm, It's like, the only person that highlighted the fact that he supports the issue of HIV was Tata Mandela. Either than the other political leaders who were in government at that time.

[TIME ON AUDIO RECORDING: 0:19:17]

NTM: And then, just a question, sometimes the community would call you in, just so you could talk to their kids. So, do you think in that role you have become like a community leader in that specific area of HIV and AIDS, in advocating for that or some sort of counsellor, you know?

TN: *Ja* I played a huge role in the community in which I was living. I was living here in Site C at that time, I was at B there up on that side of taxi rank. And then, because there was the thing we were using, it's like at that time at the TAC, the TAC had branches who went in there. Since I was staying in Site C, there was a branch of TAC there. When we would have a meeting, one would request a hall there at the school, and it would be on Fridays. We would invite everybody, so that we could do education about HIV and AIDS, so then we would educate. And then we would sometimes have events, and then we request the funding from the TAC, we would go door-to-door, we would hand out pamphlets and then a person would come to you and say "I have such and such a problem", and then you would explain it. If you couldn't, you would transfer them to the office.

NTM: Okay, so clearly you were educating.

TN: We were teaching about this thing that we were doing. It was education.

NTM: So, in 2011, uhm, you guys participated in the Longer Life Body-Maps Project. Were you a part of it?

TN: Yes?

NTM: It's the second Body Map.

TN: Oh. Yes.

NTM: Yes. So the 2011 Longer Life Body Map Project reflected how you've lived with HIV and AIDS, and advocates for people who test positive to take treatment, for a better life. Reflecting back on both artworks, would you say the state of treatment accessibility has changed?

[TIME ON AUDIO RECORDING: 0:21:20]

TN: Uhm, *ja* it has changed. It has changed a lot because at that time the medication was dispensed by MSF. MSF had their own doctors, and their doctors were caring. But now if you go to the clinic, there are doctors who I do not really know whether they are municipal and they are from the government or they are from the City of Cape Town. There are doctors from the City of Cape Town. They don't have any interest in paying careful attention to a person, because I remember at the clinic I had since I was taking the medication at that point my doctor had a graph that he would make. Everytime I went to see him he would present the graph and show me where I was in terms of health and where I am currently. That made me determined to take the medication because you would see the changes as well. As I continue to take this medication it is putting me in this good position. For them, at the same time they would make us aware of things like alcohol. It is not that you should not drink it but when you do, you must know the position that you are in. You should not compare yourself with people who do not know their statuses.

NTM: Yeah, and obviously alcohol is not right.

(Thina and Thoban laugh.)

NTM: How would you measure the success of sharing your story through the body-mapping process?

TN: Uhm,I think my story played a big role, because, more especially the one of the body-map. In my life I had never thought that I would travel to London. So it was the body-map, because it was 2011, 2012 when we flew to London with Nondumiso and Bongiwe. *Ja*, we were three together. At first it was me and Nondumiso, and then we stayed for 8 weeks, and then we came back. We repeatedly went again to London, this time it was myself, and Nondumiso and Bongiwe. Yes both Nondumiso and Bongiwe. Because at that time we were doing the artworks with Rachel Gadsden. *Ja*, she had seen Nondumiso's bodymap from the Constitutional Court, in London.

NTM: Really?

TN: And then she tried to contact us and she was able to reach Nondumiso. Then Nondumiso referred her to Jane, and then she came to South Africa for a whole month. We ended up meeting together and we had a meeting with her and we did the visual work. *Ja*, and then we went to England so that we could present our Body-Maps.

[TIME ON AUDIO RECORDING: 0:24:25]

NTM: That's beautiful. You say it's Rachel who?

TN: Gadsden.

NTM: Gadstone.

TN: You can find her if you google her name.

NTM: Okay, that is beautiful. Oh, sister Nondumiso was also saying that she travelled to so many places.

TN: Yeah she travelled many places with her body map, *ja*.

NTM: Were you affected by COVID, and how did you feel about HIV not having an immediate response like was done in COVID?

TN: Ah, no. I think I was lucky. I was never affected by COVID. Yes, everyone had some worry, more especially since you know these things of being on chronic medication. There was a worry when this thing arrived and started taking these big guys, the ones with access to all things. But I never got infected. And then, I think the thing that played a role in it not affecting me was that I would always stick to the medication because the ARVs are strong. If you stick to the ARVs it makes sure that the immune system is strong, but not so much that you have no worry of being infected with anything.

NTM: Now, how did you feel about HIV not having an immediate response like that was done in COVID?

TN: I don't know what to say because really that is true the way they responded to COVID is very different from the way they responded to HIV, because if you look at HIV in the early 2000s, we lost plus minus 20 000 young people every day, all over South Africa. But they never responded, because it was Manto Tshabalala that told people that we must eat garlic and beetroot. And then Thabo Mbheki said he had never seen a person with HIV, but he was the president.

[TIME ON AUDIO RECORDING: 0:26:49]

NTM: Wow! Where was he living?

TN: So the way they responded to COVID, they responded more swiftly than to HIV. For HIV they never responded to HIV at all. If ever these NGOs weren't around like these Treatment Action Campaign and MSF perhaps it wouldn't have been the case that they do this thing of us ending up getting the ARVs.

NTM: Yes, indeed. *Yoh*. What do you think about the youth? I think you have already answered this so you can choose to skip it. What do you think of the youth and people unaware of the gravity of the HIV and AIDS crisis and its history that they need to know about today?

TN: *Ja*. I think this youth, the one of the 2000s, they are careless. In their carelessness it is what will lead to them consuming ARVs while they are young. When they start having families they will have families that they would have made while they are on medication of ARVs. Because they are so careless, they do not care. Because you don't see someone with HIV today more especially because everyone can take the ARVs. You'll never see someone with HIV.

NTM: True.

TN: *Ja*, it's a serious thing, to protect yourself through your own actions.

NTM: Okay. And then, looking back at your artwork, Art-Body from 2002, what stands out to you, and how do you feel about the artwork now? Is there one there? You can page through it, here it is.

TN: Um, *Ja* it's like when I see it I realise that I come from far. When you look at the position you were in and now, and where I am now? Looking back I see in myself that this is a long road I have walked, from 2000 to 2020, and now to 2022. This is a long road that I have walked, and if ever I was the man who would drag his feet and be reluctant to find out about things that were done, perhaps I wouldn't be where I am today.

[TIME ON AUDIO RECORDING: 0:29:49]

NTM: True.

TN: I wouldn't be where I am now. So the body map played a big role in my life. It played a big role in my life because when I disclosed my status, nothing else ever made me fearful.

NTM: And that's the beauty of it, because I guess now that you have disclosed, you're like "what did I have to lose in my life? literally.

TN: The moment that I disclosed, I didn't do it for people to know that I have HIV. I disclosed for people to know and be aware that there is HIV out there, that there are people who are HIV positive. So then people should try to protect themselves.

NTM: Okay. And then, what did you enjoy about the physical? You've already touched on this, so you can just skip if you want. What did you enjoy about the physical process of making this artwork, and what was most challenging about the drawing and painting process?

TN: Ah, I think the challenge is that drawing was not my thing. We just grew up in that time, we went to school in the 80s, where there was no such thing as drawing (*chuckles*). There was no art, it wasn't done at school, just as there was no sculpture.

NTM: True.

TN: So, when it came to conversations about drawing, no man! you realised that they were speaking about something foreign (*laughs*). We only knew how to mould a cow from clay, or to make a wire car and put it there. Those were the only things that we knew. When it comes to drawing, it wasn't something that we knew. But anyway, because when you did something you weren't judged, they encouraged you to do it the way you see fit. I ended up enjoying that drawing process, because it was that part where I could express my feelings. There were times where you would realise that you things that you want to express but you yearned for the ability to take them out so that they could be visible, *ja*.

[TIME ON AUDIO RECORDING: 0:32:05]

NTM: Okay. Did the Memory Box Long-Life Project inspire you to continue making art?

TN: Uhm, ja it didi inspire me. It did inspire me just that in terms of time I was always busy. Then I ended up getting full time at UCT for research. So I am always on site but from time to time I will be at the office or sometimes I work from home. Sometimes it depends on the students research, what it focuses on or where their study is focussed on. And then if they were doing the research about rural areas, I have to take the students to the rural areas.

NTM: Oh nice. So to be clear you work as a researcher too?

TN: I am an assistant. I research, that is, I assist the students who are studying in these departments. It depends on what the student is researching about, and then this is the research we do together. Then I go and recruit people, then I do the research and then they find the information. And then if they do follow-up-interviews, the following year, I seek the people out again. If people have moved from that place, we have to follow them to where they are.

NTM: You are doing my job then. What relationship did you form with other artists who were and are still part of the Bambanani Group?

TN: Ah, we have a strong relationship because our relationship we met through the body map. As we met during the body map process, all along we were HIV positive. And then now our language was the same. No matter that they were women but we were able to speak one single language, even though I was male. They would respect me as someone who is the same as them.

NTM: Okay, that’s beautiful. Were you made aware that your artwork was bought by the Constitutional Court Trust Artworks Committee, to form part of our collection?

TN: Uhm, yes, Jane reports about everything to us.

NTM: Okay. How do you feel about having your work as part of the CCAC, today? Additionally, what does the collection represent to you?

[TIME ON AUDIO RECORDING: 0:34:35]

TN: Uhm, I don't know how I can put it but the thing that I heard from Jane, I said to Jane is that no matter the time comes when I leave the earth and go below, my reputation will clearly not be abandoned. My children will be left with something that when they look at it they will say that this is dad's thing, that is dad. Even if the child is young at that time they will be able to say that "no man, dad was doing noble work." And then a child might go on and follow that thing, and continue with it.

NTM: True. Okay, this one is a very long one: The Long-Life Memory Box Body-Map prints have degraded over time. They've been exposed to environmental factors partly due to the dibond hanging system. We've reproduced the artworks by artists who are still alive and accessible, while some are being restored by DK Conservators. The artworks will be archivally framed behind glass according to museum standards. Do you have any further specific recommendations on the preservation of these works to ensure their longevity?

TN: Uhm, no, I think they will be safe if they will be placed there over the glass, so that there will be something whereby everyone who passes there may look and see that this was done by that person. And then another person may perhaps be able to say that when they think of their children that 'no man', these children worry themselves by stressing out after finding out that they are HIV-positive. Here are stories of people who are HIV positive, here are people who lived a long life after discovering that they were HIV-positive at the age of 27 years but they lived to be 50 plus years . So the most important thing is accepting your status.

NTM: Acceptance. Okay, do you have any recommendations on how we present the artwork?

TN: No, ah-ah.

NTM: Is there anything else that you would like to be added to this interview?

TN: No, I think we covered everything.

NTM: We covered everything.

TN: So if ever there is something, as you are typing it out that you realise you need a follow up on, it's fine you can call me.

NTM: Okay, let me stop the recording and I ask additional…

[END OF AUDIO RECORDING: 0:37:32]