CCAC interview with Bongiwe Mba on 2023/02/20 at [Place/Location] - transcript

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

Interviewee name (and acronym): Bongiwe Mba (BM)

Name of translator: Cullen Mackenzie & Buntu Makhedama

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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***.

Mode of interview: In person

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

[START OF AUDIO RECORDING: 0:11:30]

NTM: Alright, now we are starting. How did you become a body-mapping artist?

BM: Mm. I was part of a… what was it? a Memory Box Project which was led by Jonathan at the time. That was 2002 if I'm not mistaken, and then he brought along u… who is this lady, Jane? Then Jane introduced us, you know Jane, by the way…

NTM: Jane Solomon?

BM: Yes, Jane Solomon. She introduced us to this Body Map. She started the journey with us, we did the Body Map together.

NTM: Mmhm.

BM: So that's how I… um…

NTM: Began?

BM: Yes.

NTM: And then can you tell us about how, when and why your artwork was made?

BM: *Yoh* uhm. It might happen that I mix things. It was, we were partners. It would be me and then my partner, then, it was on the thing…

NTM: A cardboard like this?

BM: Yes, something like cardboard but this little thing that you see here (*she points to a piece of hard paper*). So it was this, and then I would lie down and then my partner would sketch my whatchamacallit…?

NTM: The marker?

[TIME OF AUDIO RECORDING: 0:13:33]

BM: Yes yes yes, the marker. And then from there I will do the same to my partner, and then from there, I identify the scars that you have in your bodies. It would be what happened there and why did you have this scar, what happened and you tell the story on the body map. So that's how it was made, we were using the markers, with different kinds of colours of a painting. Yes.

NTM: Why then did you do the body-maps?

BM: I think, uh, uhm, they wanted to know what happened in our bodies. They wanted to know the journey and our identity, because you will remember at the time, some have, at the time of HIV. People used to have these side-effects of, you know these things when they are present, what are they called properly? um I have these lesions, these so uhm… these lesions leave marks here on the body. So they were just wanting to know if these scars like this here were happening on your body. Now that you started this statement and then what is happening in your body?

NTM: If there's somewhere where you want me to say something in isiZulu I will try. How does this artwork speak to the HIV and AIDS epidemic that started in the early nineties, reached its heights in the early two-thousands and is continuous today?

BM: Please explain to me.

NTM: Okay, So, this artwork, this one that you made, how does it relate with the way that HIV was seen, HIV and AIDS were seen, in the 90s, and how that changed in the 2000s and now the way you think about HIV and its stages?

BM: Okay, looking at…

[interruption until 0:16:27]

BM: Okay, uhm, to be honest, what I can say is that there is much that has changed if you look at HIV and uhm, it… what it did, at the time when it was starting, you see the difference now. For me I would say that there is a difference because for me here, in the early nineteen-nineties people used to be afraid even to come out, uh, and talk about their status, even from their own families they would hide.

They were even hiding from their own families, yes. But I think a lot has changed now, because people have come out and they talk openly about HIV, it's no longer an issue if I may call it. It's no longer an epidemic. It's no longer, what shall I say, a shameful thing to have HIV? Yes there are still some who stigmatise but it's not that, it's not the same.

NTM: And then the artwork, how does it speak to HIV as it was an epidemic at that time?

BM: I think that it… it also helps that people know to come out openly. It helped a lot in terms of people coming out openly, and seeing that 'okay, if these people are… they can do this, so what's stopping us from also coming out'. It helped some people. It plays a role that people can come out openly.

NTM: Okay. Please tell us about the first time you received HIV and AIDS treatment, and its impact on your life.

BM: Oh ja, um, I think, uhm, it was, I was diagnosed in 2001, if I still remember, and then I started my treatment in March 2002. At the time, uhm,' what was it called?', my viral load was very very low, and even my body weight. Uhm, I can say I am better than the thing that I was before I started taking the treatment. There is a big difference that it made, that happened. It helped me a lot. It has helped me a lot. Yes.

NTM: Okay. And then, *yho*, no this question is a long one.

BM: How many questions, five questions? Okay, question five.

NTM: No, twenty. We are going to be here a while.

NTM: Okay, so, while understanding that the 2002 Memory 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? Did it help you with your healing process?

BM: Uhm, yes, we did receive counselling. Uhm, before we received the treatment we did receive counselling, informing us about the changes which would occur in our bodies. It was up to you as a person if you would take it or not, and then it was up to you whether you would take it or you would not take it because it was not something open to everyone. One will remember the fact that at the time there were rumours that these, uhm, ARVs are killing people. There were sort of things that were said among us that make people afraid to take the ARVs, but for my part looking at the way the things that it was doing to other people that I knew at the time who had HIV, and they knew they were the people who were helped by the treatment so I told myself uh if they got help, so why can't I not just take it myself. So, I kept going until I reached a point where it became a decision.

[TIME OF AUDIO RECORDING: 0:21:21]

NTM: So, at the time that you were doing the artwork, did you perhaps get counselling from the Memory Box?

BM: Yes, with Memory Box we were part of something like a support group.

NTM: A support group?

BM: Yes, it was a support group, where we were talking about these things, *eh*, talking about disclosing all these things. So, it helped, it really helped us a lot, to deal with all the stigma with all these things that were being said.

NTM: Okay, and then did this project help you destigmatize HIV? You have already started to answer that question, so if it's the case that there's something we ask that you have perhaps answered already then that means that no we can leave it. Did it help you destigmatize HIV in your community and more broadly, and do you think the stigma has changed around HIV?

BM: Yeah, they do say that, yes the stigma has not yet completely ended. Uhm, but there's a difference though. Although there are still things here and there but it's there, it isn't the same as before it's not the same, truly, as before. There aren't people who are still afraid to come out, so, at least things have changed. And that, what will I say, and the media tried to help people by telling them about what happened like Pamodzi, everything, it tried so that support groups played a role—the campaigns they did, they played a role. So it's not the same as before.

[TIME OF AUDIO RECORDING: 0:23:08]

NTM: Indeed. So, the body maps, the ones from 2011, uhm, they are called the Longer Life Body Maps Project. It reflects how you've lived with HIV and AIDs and it advocates for people who test positive to take treatment for a better life. Reflecting back on both artworks, from 2002 and 2011, would you say the state of treatment accessibility has changed?

BM: Mmmm…

NTM: so…

BM: Please explain this one.

NTM: So, I stated that in 2002 you were…

(*overlapping interruptions*)

BM: The first one?

NTM: Yes, and even the Bambanani, the cohort of people who were the first people to receive it back then.

BM: Yes…?

NTM: So that artwork showed that, since I received the treatment, and everything else that I had, these are the things that have changed. Even in 2011 I am demonstrating that I am still alive, you see? So you start by saying that, perhaps if you look at these two works, because I was working towards treatment being made available, you start by saying that treatment is now more available, for people?

BM: For people? Yes, I can say, sister, that it is available in a, it is available widely, like it has changed a lot because firstly in the past it was the case that one obtained treatment accordingly, they would look at your CD4 count and how much it was. But I think now, as soon as you are diagnosed with HIV, that is the point at which they begin putting you on treatment at that time. So it's no longer that thing of it taking time.

[TIME OF AUDIO RECORDING: 0:24:58]

NTM: Yeah.

BM: *Ja*, so, huh, I think that because people were at that time, they would sit and wait for the time until they start with the treatment. Some would wait for over a year until they gave up and died. So I think they saw that and they said ‘no man come, let’s accelerate this process immediately, as we see someone is positive we start them with the treatment straightaway’. So I can say that, what is it, the treatment is easily accessible now? And it is up to the person if they do not. I ask myself if we know a number of people that refuse to be helped, but help itself is there?

NTM: It is there.

BM: Help is there but it occurs that perhaps I don’t want to get help.

NTM: Yeah, indeed. Okay.

NTM: How would you measure the success of sharing your story through the body mapping process? I have heard that you travel?

(*Laughter*)

BM:*Ja*, I was, but I only travelled once myself. I think it was 2012 first, and the last time I left and went overseas with a lady called uRachel. She's also an artist from the UK, so I did that. We did art together there. It was something, it was also some form of body-mapping.

NTM: Yeah.

BM: *Ja*, I can say that it helps people because I can't say I received feedback from it. They were just looking at your thing from afar but they went and exhibited it over there and I can say that it helped them over there.

NTM: *Ja*.

[TIME OF AUDIO RECORDING: 0:26:43]

BM: In all instances I never received feedback saying 'from watching your story these are the people that then got help'. These people, someone said that we were saying that. But then I think there's another exhibition that will be there in February.

NTM: In Paris?

BM: Yes, in Paris or something like that.

NTM: Okay, were you affected by COVID?

BM: No, I wasn't.

NTM: How did you feel about HIV not having an immediate response like what was done with COVID?

BM: Mm… what shall I say, like is it this thing of how quickly it was feared?

NTM: Yeah, whereas with HIV there was a long wait.

BM: It took time.

NTM: You all fought, fighting treatment.

BM: Oh well, what I will say is that each person would, I think it does not sit well that they rushed so much with COVID and given attention, because there's an impression that if HIV had the same attention like it was with COVID, there would have been so many people who would have been helped at that time.

NTM: Yeah. Uhm, okay, and then, what do you think about the fact that people, the youth today, do not care about what happens with HIV, and it doesn't know the history and how people died for the time where the treatment was available, and nobody cares what happened? What do you think about that?

[TIME OF AUDIO RECORDING: 0:28:47]

BM: Like if this lack of care was what?

NTM: Lack of care.

BM: The kind where it's because they don't personally experience it or what?

NTM: Yeah, kind of like that, and then also that they don't care about the fact that, perhaps that we don't care about what, how it happened that we reached a point where it can be said that stigma is not as serious, where you can get treatment. You just see the things that we fought for and that we are here. The youth do not care about that thing.

BM: Well *ja*. The issue with the youth is quite complex, it's, I don't know what it's going to take the thing that young people, because the awareness programmes are being carried out and it has been done on many occasions. There is a discourse about HIV a lot, including on TV. If you open the television, if you open your radio, even here on social networks, there are conversations about these things. But, just you see that they are just numerous. It is being negligent a lot from young people, especially the youth. The youth of today, uhm, there is a great difference compared to our youth. Firstly, I will say that they are irresponsible, young people of this time. They are irresponsible in such a way that, I don't know how I can put it and explain it, what it will take or what needs to be done for them to be responsible, like taking care of the… I would say, for them to become the youth that is responsible. For them to know that when you are intimate you should use condoms and stuff, you see? but these are things that they are unaware of, and the more they don't see it I see that they are greatly enlightened by not caring about the time that we were in at the beginning. When these people are in the light in the way, but the more they are in the light, it's like I can see people that are ignorant. They are very ignorant, so I don't know what it's going to take, the thing of them getting help.I don't know man.

NTM: *Eish*, *ja*.

BM: *Ja*, I don't know.

NTM: It's difficult, *ja*.

[TIME OF AUDIO RECORDING: 0:31:16]

BM: For the fact that they know things, they see them happening even among their friends, within their families, among their relatives. In their families they know that thing that says if you are not infected then you are affected. They know that there are these people in their families. But the more they see and do not do anything about it, they are uncaring. So I don't know because I won't say that nothing is being done. The government is trying all it can, including in the clinics there are condoms put out for people to take. Oh man what can one say for not using them, they discard being safe? Everything is being done, everything to watch out for each other and the situation of HIV.

NTM: Indeed. Okay.

NTM: Looking back at your, um, body map, from 2002, what stands out to you, and how do you feel about the artwork. I put in a copy here to remind you of what it looks like (*laughter*). So what stands out to you, and how do you feel about it now?

BM: Okay, I would think that the most powerful thing is the change in my body weight, like I have said before the thing of how I was when I was forty-six kilograms at the time, when I started on the body-map. Uhm, but now I think I'm sixty-something, so, my body-weight has just changed a lot. And even in my viral load, it's right, because it's undetectable compared to a time when I started my body-mapping. *Ja*.

NTM: Okay, and then what do you think about the artwork as a whole?

BM: Mm… what I can say about this artwork and what I like about it, it's that it has been followed, like how can I put it? When I try to explain it more clearly it is a thing that can help someone outside, who when they see it, they can see it saying something like 'alright, okay, there was a person who was helped by these ARVs which is something that is still happening now, this thing is possible.' I can say that this thing is…

NTM: *Ja*, it is helpful.

BM: Yes.

[TIME OF AUDIO RECORDING: 0:33:54]

NTM: Okay, what did you enjoy about the physical process of making this artwork? And what was most challenging about the whole new painting?

BM: Okay. um the thing I like about this as an artwork is that as I said that we used to do it when there were many of us and we were doing it as a group and you were assigned with your partner.

NTM: *Ja*

BM: So then I would think that we did it and we learned more. You knew more things about your partner which you didn't know like oh you have a scar in a certain place which was where some small thing had happened in your life. So it was nice for that reason. However it was challenging because I'm not an artist (*laughter*), so that was the challenge! *Yho*, a big one, ja.

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

BM: Well, I'm not going to lie.Uh, since I said that I'm not an artist, yes I would love to become one but no, it's just difficult. I do long for it, *ja* I do long for that.

NTM: Okay. What relationships did you form with other artists who were part of the Bambanani Group?

BM: Mm… our relationship I can say that it has grown in terms of knowing each other. Uhm, it doesn't end there, we met back then, when we were doing the body-map. But it continues to grow for those who know each other. We also made the initiative to develop the friendship to a thing which didn't end there but which grew as though I knew them in a different way. Because we were meeting there without knowing each other, like where one lives or we were just meeting each other here in the support groups since we met at the clinic. So then now it ended up building our relationship to a point where you knew who lived where. So-and-so lives here with their brother or their siblings and here is their family and their father there, these things which can be called friendship.

[TIME OF AUDIO RECORDING: 0:36:05]

NTM: Alright. Were you made aware that your artwork was bought by the Constitutional Court Just Artworks Committee to form part of the Constitutional Court Art Collection?

BM: Yes, they told us. They told us, I think, but they told us.

NTM: Yes, early 2000. How did you feel about having your artwork as part of the Constitutional Court Art Collection today?

BM: What shall I say then? I shall say that it feels great that my work is all the way over there, and is seen. I mean for people to know that there is a Bongiwe who exists (*laughter*) *ja*.

NTM: Okay. And then, what does the Court and its Art Collection represent to you?

BM: Uhm, please explain this to me clearly.

NTM: The court, you know, I guess it's a funny thing that you've never been to the court to receive the artworks. So I guess the significant thing about the Court is that there is art there that informs, well, I wouldn't say that it informs, but it is in dialogue with the work of the judges, you see? and remember that these artworks were acquired after that case of the TAC in July 2002 which was heard there in the Court, that treatment should be made available. That you are now owed and have now been heard and that you all did things to advocate for the treatment. So I guess if you look at the Court it fights for Human Rights, but for you this thing of art that is there, what does it mean to you?

BM: Okay, no. I think that it means a great deal. Um, I think that truthfully we are still waiting, and despite that we are still waiting, that still speaks to the idea that the Court advocates for our Human Rights. I think that we are still waiting for this thing, that there will be a cure. When this could happen here, is unknown to me. But I think the fact that they are there, these artworks maybe it can be able to spur them on, that there are people who have taken up the charge here and these people are still waiting. Yes, yes their health status is now right, but it tells a story and we would be rejoicing greatly to find a cure in terms of fact.

NTM: Indeed.

[TIME OF AUDIO RECORDING: 0:39:04]

BM: This is the thing that makes us all engage in this thing of ours, which is to say the cure must spread, that we need the cure—this is the thing we want, *yho* it is urgent.

NTM: *Ja*. Alright then. So, our set of prints there at the Court has been damaged because they didn't frame it well. If I put it like that, do you see? They were even exposed to the sun through the displays that are there. So we reprinted them and I have them here, and then there are others among the artists who have passed away and others that we want to acquire and we have sent them to another company in Kenilworth, DK Conservators. So we will frame them again, and make sure that they are enclosed behind the glass, to make sure that they last for some time. Is there another thing that you can advise us to do now to make sure that they don't get damaged further?

BM: Hmm. No, I know only a little. Uhm, that they stay protected?

NTM: Mm.

BM: No, I don't know, what shall I say, I mean what can I say about how they should be kept so that they stay protected.

NTM: *Ja.*

BM: Perhaps they can be put in something like, what shall I say it? In fact I don't know.

NTM: I'm sure that the just frame will be alright.

BM: The frame should be what? it should be… it should be, but now the glass will break anyway. I don't know man (*laughter*). No, I don't know, I really don't know man.

NTM: No, it's no problem, for me I think that the glass which we will use will be. It will be strong enough because this museum otherwise makes sure that the light doesn't penetrate. Okay, is there perhaps a way that you would like us to present your work?

[TIME OF AUDIO RECORDING: 0:41:28]

BM: Apart from that thing that follows from you that the history is here? Yes if you all are able to, you all can write anyway, so that whatever the whatchamacallit would be enough. You can write about it.

NTM: Okay.

BM: Yes, you can write about it.

NTM: And then, is there anything else that you want us to report in this interview?

BM: Uhm, one thing that I shall want to be recorded is the one about, you know, they can find some way to get a cure, that we find a cure to cure HIV permanently. Yes, the ARVs have helped us so much but in this stage we long for the thing that can find a cure that will end it permanently.

NTM: Once.

BM: Yes, because this thing of constantly taking medicine uhm, I don't know when I started.I started the treatment in 2002, it's been how many years now? 2023. Even now you are expected to…

NTM: Twenty-one years, imagine.

BM: Twenty-one years down the line. So you see this thing that one needs to go to the clinic, you can see that I look after children, and now tomorrow I have to go to the clinic tomorrow. Imagine all these things, they are quite difficult, even for me to find a place to send all of these people's children. You see that there's a need for them, their mothers to go to work, so I look after them and they go to work. Oh what can I do? So then I go and fetch them (medication) and when I get there I find that sometimes I missed the date, it's wrong. And then it's as though I feel it's…

NTM: It's stressful.

BM: Very much so! It's very stressful. So therefore I say if we could get a cure, it would be better in a big way. It would be a big change in our affairs.

[TIME OF AUDIO RECORDING: 0:43:22]

NTM: Yes. Do you live alone?

BM: Yes, I live alone.

NTM: Do you have children?

BM: No, I don't have children. I have my brother. I have a brother who was born in '89. But he doesn't live on this side, he's in the Eastern Cape.

NTM: So then you stay here alone now.

BM: Yes, for most of the time I am alone.

NTM: Oh. Alright then. Thank you very much. Let me stop here. Please can I take a picture. I will take a picture of both of us, you and me.

[END OF AUDIO RECORDING: 0:44:05]