

BOITUMELO'S STORY



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OCCUPATIONAL THERAPY

Prologue

It has been an incredible journey that has brought us here to this consolidated story of Boitumelo. Whilst this narrative originally formed a data set for my PhD, it is relevant for additional analysis and may be useful as an example in teaching and learning. My personal narrative may be an important account, describing what researchers and community workers often experience as they navigate the struggles evident in vulnerable communities. I am aware, however, that others may have reacted differently, and had there been better knowledge and understanding of the context, it may have led to different interventions and outcomes. Please remember that both Judith (my co-researcher) and I did what we thought was best at the time, together with what we were capable of doing, considering our own challenges and the various other roles that we were fulfilling.

And whilst this e-book has an ending, it is not the end of our story with Boitumelo. We are continuing to engage with her and look forward to the next chapter.

Helga E. Lister

Methodological considerations

Please consider the following information when reading this life story:

- This narrative was constructed during five years of engagement with a household in the peri-urban area of Mamelodi, in the East of the City of Tshwane, South Africa, whilst I (Helga, the researcher) was conducting my PhD research – a life history study on the food security of women living with HIV and disability in vulnerable contexts. In the initial phases of the research, myself and my research assistant, Judith, functioned as voluntary community workers. At the beginning of 2019, I became employed at the University of Pretoria’s Occupational Therapy Department, where I coordinate the community-situated work integrated learning (WIL) module, supervising final-year occupational therapy students in Mamelodi. The Occupational Therapy Department at the University of Pretoria (UP) has long-standing relationships in various communities across Tshwane, including Mamelodi. Occupational therapy students participate in various service-learning activities during their WIL module and are embedded within other interprofessional and interdisciplinary projects.
- The methodology followed in constructing this life history narrative is as follows:
 - Informed consent was obtained from the participant (Boitumelo) at the start of the study.
 - Various interviews were conducted in Boitumelo’s home or other sites within the community (as required). Some of these were more formal with a research assistant

(Judith) and translated into Sepedi* in real-time and recorded or translated and transcribed back into English actively during the transcription. Other discussions were more informal and occurred as the relationship continued to develop.

- I reflected on my engagement of these discussions as well as my experiences whilst in Mamelodi through reflexive notes. Photographs, participant observations and hospital records were also obtained. Data collection and interpretation occurred constantly throughout the process, as both Judith (who became a co-researcher in the process) and I tried to make sense of the developing life story being shared.
- The transcriptions were cleaned by focusing on crucial aspects of the story, joining sentences and words where appropriate, rephrasing questions asked by Judith and me as answered statements (for example, “What is your name?” was changed to, “My name is...”) and reflecting on conversations in the researcher narrative.
- Where required, Judith and/or my questions have been inserted as explanatory notes to identify the topic under discussion (as opposed to including the direct quotes of the researcher in the interview). Written in the voice of the researcher, these have been highlighted in light blue, similar to the reflexive notes, to separate it from the voice of the participant.
- Also, if clarification is needed, this has been included in brackets or as footnotes. Even though, at times, the use of the English language may appear incorrect grammatically and technically, it has been written in the way the participant spoke (bearing in mind that English is not the participant’s first language). This has been indicated using brackets [*sic*] where necessary.
- This narrative includes the first layer of interpretation since Judith and I became embedded within the community of Mamelodi and achieved a greater level of understanding through community-based occupational therapy intervention. This process is referred to by Polkinghorne¹ as narrative configuration. Therefore, the process of data collection, analysis and interpretation did not occur in sequence, but concurrently. Also, the life history is not reflected on in a single interview, but rather as the researcher and co-researcher were embedded within the community of Mamelodi for extended periods of time (and the co-researcher also living in Mamelodi at various times), i.e., we were present whilst life events occurred. This is referred to as the narrative mode of analysis, since analysis occurred continuously whilst collecting data and writing up of this coherent narrative.¹
- There were periods of lack of contact with the household due to Judith and my changing circumstances, which made it difficult to maintain ongoing connection to the household. There

* Sepedi is one of the 11 official languages in South Africa, and a vernacular language in the community of Mamelodi

were several times when Judith or I tried to call or visit the household, however, no-one answered (due to phones being unavailable or stolen) or no-one was at home.

- The researcher account, as well as the entire narrative, has been read through by Judith, the co-researcher, who was present for many of the engagements, and with whom much of the reflection was discussed and interrogated. This serves to enhance the authenticity of the story.

Ethical considerations

- The pseudonym, Boitumelo, has been agreed to by the participant.
- The names of all other people in the narrative have been changed.
- Specific names of clinics have been removed to protect Boitumelo's identity.
- There is only one district hospital in Mamelodi, and this hospital's name has been retained (Mamelodi Regional Hospital). The community refer to the hospital as 'Dagga' (pronounced "da-ga"), from its previous name, the Mamelodi Day Hospital.
- Specific dates of discussions and reflexive notes have been removed.
- Photos have been taken and published with permission. To protect the identity of the participant, her face has been blurred.

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Reference

1. Polkinghorne DE. Narrative configuration in qualitative analysis. *International Journal of Qualitative Studies in Education*. 1995; 8(1):5-23. doi:10.1080/0951839950080103



Image above: Helga and Boitumelo

LIFE STORY – BOITUMELO

Discussion: April 2018

I'm Boitumelo and I was born in Mamelodi [be]cause I stayed there; I grew up there. We grew up with [my] granny. My mother was not looking after us. Our grandmother is the one who raised us. I did my primary and my high school there in Mamelodi West. I did not finish my high school; I did not finish my matric^a. I stopped at grade 11 due to... I think it was a sight problem, I don't know. Then I dropped out from school, and I tried to further my studies, but every time when I tried to further my studies I would drop out. I went, I tried to work and do computer ICDL^b, I dropped out. Everything that I do I just drop out. I don't know what is the problem here.

I worked at Superspar^c in Elardus Park^d for a year. I stopped [be]cause they were not paying very well. It was R1800. I was working just for transport. It was hectic for me. At the time my mom was not working. I was the only one working and I was supporting my family, my mom and my siblings. We were all living in the house together.

I have one older sister, one older brother; I'm the third one and I have three siblings. Two young brothers and one young sister. We're six. My older sister is married. She stays at her house with her kids and her husband, so she's looking after her family. And my older brother was staying my mother's house at Extension 5 with a girlfriend and I was the older [be]cause my older sister and my older brother, they were not staying with us. I was looking after my younger sisters, my young brother and my mom. They were still at school, and I was buying schoolbooks, I was looking after them. I was making sure that everything is okay with their schools and that we eat. My mother doesn't earn any[thing], but sometimes she was getting piece jobs^e, for example in the kitchens, domestic working as relief for those who are on leave. My father died in 2008 and he was not staying with us, [be]cause him [sic] and my mother were divorced, when I was very, very young. My mother had other boyfriends, because my other siblings we're not from the same father. My older brother is working piece jobs and the other three siblings are now working. At least they finished matric, they finished school. All of them, they're working. My younger brother, he's working, but he's not working well, he's not earning much, but he's trying. And then my younger sister is not working and then my mother's last born, my younger brother, is working. I think that one, at least he's working well. He's earning much better. It's not much, but it's better. They all now live in Extension

^a The last grade in High School which is known as Grade 12

^b International Computer Driving License, which is a syllabus designed to cover the key concepts of computing

^c A retailer in South Africa, selling mostly food items

^d A residential suburb in the city of Pretoria

^e This type of work is common in the community of Mamelodi – many unemployed persons engage in work that is paid for a fixed-rate per completion of what has been required (for example sweeping the yard)

5 at the family house. My younger brother, he stays outside at the boy's rooms. He's eating alone, he has everything alone in his room and my younger sister stays in the house with my brother, the girlfriend and the child. My younger brother, the one that comes after me, [also] stays with my mom still, he's working but he does not work well. My mother was the one who, when my granny died, had to move out of her house and went home and look after my granny's house. She had to leave her house and come where we are, where we grew up with the granny.

I was on the list for RDP^f housing since 2011. I moved into my house in the middle of 2017.

I lose [sic] my vision in 2010 due to meningitis and HIV^g. I got HIV in 2008, but then I was not taking my medication. I was staying with this boyfriend. The guy I was serious with him, and I was staying with the guy full-time. I moved in with him at his place. Then there was a time he wanted a break, then I went back home. So while I was there at my home, he just called [be]cause, at his workplace, they wanted to test them, eyes and all that. So they took some blood and they found out while he was at work that there were doctors, he found out there that he's HIV positive. Then he called me immediately. I don't know immediately or after a day [be]cause, maybe, he called me one day after a day or so. I don't know. He did not tell me when he made the tests; [he] just told me that, "I had took [sic] some tests at work and they told me that I'm HIV positive. I think you must go to the clinic and check." I found out that I was positive. We were not using protection. We did not know our status, both of us, [be]cause we stayed for long time.

In 2010 I got meningitis and I lose [sic] my vision. My left eye is totally blind, and the right eye is partially blind. I started taking medication [ARVs^h] then. I take medication for depression, and I also take medication for meningitis. I don't take it to [sic] the same clinic. The ARVs I take it to this clinic and the meningitis I take it to Dagga [Mamelodi hospital] [sic]. I don't take it from the same place, because I defaulted. When the headache stopped, I felt 100% better, then I stopped taking the medication for the meningitis and ARVs. I'm a born-again Christian, then I was exercising my faith that God heals and I think [be]cause I'm a believer in God and knowing that God heals, I think that I'm healed, man. I won't take these things anymore cause I believe that I'm healed and I was exercising my faith at the same time. And before I go there [Mamelodi hospita], then I think in 2015 or so, I don't remember very clearly, I defaulted my ARVs for a month, just a month, one month, and I got sick. And I think me getting sick, it was because I did not take my meningitis pillsⁱ and ARVs for a month and I went to hospital and I got sick and I was diagnosed with anaemia. I was anaemic. Then I was taking my ARVs at Mamelodi clinic. Then I had to start again going back to taking my pills for meningitis and I had to go where I started taking those pills and where I started it was in Mamelodi hospital, that's why I have different clinics.

^f This refers to a Reconstruction and Development Programme (RDP) house. RDP houses are provided free of charge by the government to beneficiaries.

^g Human immunodeficiency virus

^h Antiretroviral medication

ⁱ Medication

I defaulted on my ARVs [be]cause then I started hearing voices and I think the voice said, “No, stop taking these things. You’re healed you don’t have that thing.” And I said yeah. I also said yeah, maybe it’s a good thing [be]cause now I’m a born-again Christian, I won’t take these, and it was part of exercising of faith. I took it as those like the first pills, the meningitis pills, I took it as like I’m exercising my faith. But, at the same time, I heard a voice speaking to me and I started having problems with my teeth, then I went to a dentist, then they checked and they prescribed medication, then I went to the pharmacy. I bought those medications, then I was starting to be sick, then I said, “Let me go back to using the pills, I can’t be this weak”. Even though I took these pills, I got sick with anaemia until I was admitted in the hospital. I was very, very weak and they took me to hospital; [the] ambulance came to my place and took me to the clinic, and they transferred me to Dagga, to Mamelodi hospital. They said “No, you’re not a patient from here. This is serious. You have to go to Dagga, to Mamelodi hospital”. I went there. They admitted me I think it was two or three weeks. They were putting a blood transfusion. Then after that I came back. I was taking all the medications, my ARVs, medication for blood, still I was sick. Then I went to Steve Biko. Then I was admitted to Steve Biko, I don’t know for how long, I think for a month. They did not know what was the matter. There came professors [sic], all sorts of doctors, they did not find what was... something was drinking my blood. They did not find out what was it. I had a bone marrow what-what, I don’t know what was that, my blood cannot produce itself[sic]. So only to find that the medication, the ARVs that I’m taking, they don’t work for me anymore [be]cause I defaulted and I was not even taking the pills for meningitis, I think so. So I defaulted, they started to want the medication that can fit for me and make me better, so they struggled for a long time to find the medication. They even went overseas to find medication for me that can stop this so that my blood can produce itself [be]cause every time they had to transfuse blood. It was hectic. That was very, very serious. I was thinking that I’m going to die, so fortunately, by the grace of God, I got help. They gave me medication, then that medication started to work, then they discharged me.

Hearing voice [sic] became very serious, I think it was last year. The voices was [sic] talking too much with me and for me it was becoming normal, [be]cause it’s something like they’re keeping me busy and sometimes I will laugh alone [be]cause, like, I have a friend that I speak to and that friend is the voices. So last year I started becoming aggressive, angry, I’ll beat myself, I’ll be so angry, I’ll pull things, I’ll always cry, sometimes I’ll laugh, I’ll get so depressed, I don’t know, I’ll not sleep at night, and I’ll come from one room to another. Then I was staying at my mother’s house at Extension 5. Everybody was becoming worried that “Boitumelo you don’t sleep. What’s wrong? You wake up night, you open doors, you go to the room outside the house, you come back inside the house, you switch on the TV. We don’t understand what’s wrong with you”. So, then it becomes depressing; it was so sad for me.

I then got an advice to some lady from the church [sic]. I told her my problem. I said, “No, this maybe I have to share this with somebody. I cannot keep this alone, [be]cause it harms me. I will scratch myself – I had long hair by then – I will pull my hair, I will injure myself.” So I told this woman my problem cause

she was seeing that “Boitumelo you’re losing weight, you’re becoming ugly, you’re not yourself. What’s wrong?” I said I don’t know. I don’t know what’s the matter. Then she said to me “I think you must find a psychologist. This is serious [be]cause even in the church you don’t stay at one chair”. I will move from this chair, go to that chair and everybody’s looking “what is the matter with you?” I’d say I couldn’t sit still. It was like something was piercing me. They’ll say, “If it’s nails, just try and sit still”. I will be uncomfortable where I’m seated. I will move from one chair to another chair. So, the voice came again, said to me, “No, don’t go there. You don’t need psychologists. You must go to church.” So, I said yeah I’m not going there. I don’t have a problem. I don’t have a psychological problem.

So, until early this year, I was having my radio. I was listening to the radio then sometimes my moods were okay. I was not angry, I was singing, dancing, it was okay for me. So, one day I opened the radio [sic], I switched on the radio and I heard this lady giving a testimony [be]cause I only listen to Christian [radio stations], it was Impact Radio^j. The lady said she went to psychiatrists, so the things that she was speaking, they asked her how this started, “How were you feeling when you realised that you had depression?” Then she started, “I was having 1 2 3 4 5”. I said, “This is what I’m going through, maybe this is what I need.” So I went to Mamelodi clinic, to Dagga. I wanted a psychologist. I told myself that there was where I got advice that I must go to a psychologist, maybe I need a psychologist, maybe there’s a problem with me then, maybe I might die. I will die with this problem and maybe there’s help out there and I’m staying in this house.

Nobody knows my problem, but Kelebogile. [She] was the one that I was speaking to. I was telling her my problem, “Friend I broke some things, I’m angry.” Even the radio, I put it in the fridge. The stove, this is the second stove that I’m using. The first one I broke it. I was breaking things in the house, so I went to Dagga. So when I arrived, I said “I’m looking for the psychiatrist.” Then the lady said no, because she knows me, she’s a sister there. She said “Boitumelo, you know people who see psychiatrists, they’re people who are not well, so I don’t think you need a psychiatrist”. I was ashamed. I feel shame. I said no, maybe they’ll think I’m crazy. So, I said, “Okay I don’t need a psychiatrist, I need a psychologist.” And she said, “Let me lead you to a psychologist clinic.” So, I went there to a psychologist, then I started to see a psychologist. We had a session, sessions, and that’s where she said, “No, but I think you need also [sic] a psychiatrist. This is serious, so I must make an appointment for you to see a psychiatrist.” Then [we] went to a psychiatrist’s office, then she made an appointment for me and she said to me, “When you come to a psychiatrist please make sure that you come to my office and you have a session, then we speak. This is serious, I cannot leave you like this. I must go further with you. You must see a psychiatrist and come to me also.” I said, “Okay”. And then I started going to a psychiatrist, then I told him my problem. He took bloods and he took it to the lab. Then that’s when I started going there and he gave me medication, then I go there and take my medication. Sometimes I go and see the psychiatrist and I go to the psychologist.

^j A local Christian-content radio station

It helps. The voices are much better. I can't hear voices, I don't hear voices anymore and I don't see the things that I was seeing, [be]cause I'm partially blind and I was seeing even things. I was seeing snakes and all sorts of things. The psychiatrist told me that those pills will help me not see those things and I will not hear voices anymore. The anger is much better, [be]cause now I'm spending much time with friends. I'm not all alone. I think the medication is helping. I take my medication every day, but when I don't have food, like today I don't have food, so the lady that came here said I must come to her place and drink tea with bread, so that I can have my medication. The pill that I'm having they call it Epilim^k. They did not really tell me the diagnosis I have.

So, I have run out of money more than five times in the last 30 days to buy food. I have sometimes, maybe, if I eat three times a day, then I will eat two times [be]cause of the lack of food. I will say, "No, I eat in the morning and at night, so that I can save food". But I love food. Sometimes I don't realise, but usually I eat four slices of bread, but sometimes, [be]cause I don't have enough food, I'll take three slices. I'll take smaller [sic]. Sometimes I'm just eating pap^l, that's what I don't like. Like maize meal, those are basics. Sometimes I don't buy veggies [vegetables], because I have, maybe, maize meal and I have tin fish. I will eat pap. Sometimes the whole month I won't even eat veggies, but potatoes when I buy it; I buy a full bag [be]cause I love chips [fried potatoes]. I cook pap and mash on the side and eat it as sishebo^m.



Image Above: Boitumelo with a takeaway that she bought

^k Psychiatric medication

^l A South African dish of white maize meal

^m A relish of Africa descent

When I get my grant moneyⁿ, I buy my groceries. I'll buy my maize meal, my meal, rice and tin fishes [sic] and things to clean the house, maybe tin fishes [sic] and baked beans and sugar beans. Sometimes, but I don't usually buy them, I buy some potatoes, a bag of potatoes, soups, stock cubes, Rajah^o, and maybe tomatoes and onions, maybe carrots. Those are the veggies that I have in the beginning of the month, because I have money. I only buy them in the beginning of the money when I have money, [be]cause here we don't have fridges. I know if I have them for a long time, they will rot, they'll be rotten. I make sure that I buy lots of them for the sake of the fridge. And I buy my cleaning things, maybe Domestos^p, Handy Andy^q, Sunlight liquid^r and floor polish and tissues and my toiletries, maybe like washing soap, bath soap. I'll buy my Dawn^s, my roll-on, my toothpaste.

I use my solar for lights and for charging phones. I bought it from the man who give me the gas. I must fill the gas. It's a 9kg. He fills it for me and, when I don't have money – it's R200 every month – he fills it for me. When I don't have money, he gives me a full bottle and I give him an empty one, then I give him his R200 at the end of the month. The solar, I just bought it last month, so I paid half-half. I give him R200, it's R600, so I give him R200. If I don't have R200, he said R100 is okay until I finish the R600. The solar helps because I can charge my phone and I'm partially blind, I'm not totally blind, [so] sometimes I need light to see some things, but even though I was trained to walk inside the house [and] I know things, but sometimes I really need a little bit of light. Sometimes the gas finishes in the middle of the month and I'll call the man and he refills it and I give him money at the end of the month.

If I run out of food, I don't really beg, but I have friends, like Kelebogile. Sometimes, when she doesn't have food, she comes to my place and tells me she doesn't have food, I'll cook for her and her kids. Sometimes, when I don't have food, I go to her and tell her I don't have food and find, that time, she has food [so] I eat too in her place. Or the lady who's putting the fridges in my house stays here in my front opposite. I go to her and tell her I don't have anything. Then she'll give me bread. And the lady that was here, she asked if I had eaten anything [be]cause it was time to take my medication, [be]cause she knows I drink medication. I told her I had not eaten [be]cause I have nothing, I haven't bought food yet. She said, "Come to my place to have some bread."

I take my pills twice a day, eight in the morning and eight in the evening. My disability keeps me busy and I manage by the grace of God. I love to do some house chores and every day, when I wake up in the morning, I just go to the bathroom, I brush my teeth and I wash my face and I make breakfast for taking medication. After that I clean, I do my bed and I clean, sometimes I just sweep outside and I clean outside

ⁿ Meaning here the South Africa disability grant which is a social protection programme from the government

^o A producer of a range of spices

^p Disinfectant

^q Multipurpose Antibacterial Cleaner Spray

^r Dishwashing liquid

^s Body lotion

the house. When I come back in the house, I take a bath, sometimes, maybe in the afternoons I take a bath.

When I came to live on my own, in the beginning it was not easy to learn where everything was, but I was with my mom. She helped me for about a month. She was staying with me. She was helping me with everything and making me to get used to the place. She was helping me to clean, to cook and to do some other things [be]cause I used to do that at home [be]cause I'm partially sighted, I can see just a bit that this is a door, I can go this side and when I get into the bathroom, here is a toilet, the basin and the bath.



Image Above: Boitumelo's bath, with the bucket she uses to wash her clothes

Very often I feel tired. These nowadays, I'm even lazy to wake up. It's hard for me to wake up. I was waking up around 7 o'clock, but now I set up the alarm for 8 o'clock for my medication. My alarm will ring and I'll be in the bed, I'll even be lazy to wake up. It'll be very, very hard. Sometimes, I'll even take my pills late, because it's hard to wake up. But it's been long now since I slept during the day. Sometimes, when I have time, I sleep, [be]cause most of my time now I have too many friends, I think, so when I want to take some nap [sic], they just knock. Sometimes, you'll find that maybe I remembered something and I have to go and talk to Kelebogile and remind her about the disability forum things, then I just go to her and when I get to her place, she doesn't want me to come back here. "Hey sit. Don't go, just wait a little bit." So I don't get my time to sleep during the day. Sometimes I feel like I don't want to do anything. Like, I will

feel like the house is dirty, or some people are coming, and I must just clean the house. I sweep, I use my mop, I put water to scrub [sic], and sometimes I put on [floor] polish and I brush it so that it'll be, like, shining in the house. And the bathroom, I clean it thoroughly. I use Handy Andy to clean the bath and the basin and, sometimes, I use Domestos, I need to use Domestos, and I put on Domestos inside the toilet, because of the hygiene. I just love a clean house. I hate dirty things. I just love to stay in a clean house.

Sometimes, I get excited to see my friends. Most of the time, I like to be alone. It's just that friends come and I cannot say, "Go! Go! I want to be alone!". I just love my time. I just love to think too much, I think and I just listen to my radio, I love radio. Like, right now, when you were calling, I was listening to my radio. I was listening to Impact Radio. I listen to motivational speakers and all that, and I love music and, sometimes, when I'm busy, maybe I'm not sleeping, I will just dance in the house. I just love that [be]cause I love music.

I'm independent in the community. I know how [to travel] with the taxi and by now I'm used to the area and I just take my walking stick. Like when I get a taxi, I just do [travel] locally, and then I tell the taxi driver where I'm going exactly, [be]cause they know the areas, they know the places. They're taxi drivers and I'll tell them that I'm going to this place, and they put me exactly where I'm going. [Be]cause I can't see where I'm going, I just tell them, [be]cause they're seeing that I'm partially blind. If they don't know, I tell them that I can't see clearly, please help me. I don't know the place, or I want to go to this place, and they put me [sic]. I take a taxi to the Disability Forum. I don't feel scared when I go out of the house. I'm okay [be]cause I was taught how to use the walking stick, how to be independent, how to walk around and how to cross the roads and how to ask for help while I'm in the roads [sic]. There was this woman from [the] National Council for the Blind who taught me. Her name was Anna. Around the house they tell me not to use the stick. I must feel this is my house. I must know my way to walk around the house.

We tried to get some more information about when she started experiencing depressed mood.

Whilst I was working at the Spar, I was not partially blind, and I was not taking medicine for depression or even taking ARVs. I only started hearing the voices after I stopped working. When I started taking ARVs I started seeing things.

Before the depression medication, I had too much anger and I was being angry and moody. But now I'm okay, but I still see those things, but I think they're getting better; even the voices I don't hear them that much. The things that I hear, sometimes, they tell me what to do. I might say like, "Clean the house! Why don't you clean the house?" Then I will clean it, but then they will tell me, "Why don't you kill yourself?" and I'll think there are better things for me to die, then I will just take my ARVs and try to commit suicide, but now that doesn't happen anymore. It's been long since that happened. You know, these voices, sometimes they tell me negative things, but sometimes I'll just remember. I don't think it's remembering or it's voices. Maybe, sometimes, I can't differentiate or maybe I don't understand, I don't know, but sometimes they come so negatively to say "Do this!" "Why don't you do something?" "Take this radio and

break it!” “You understand?”. But I can’t understand, sometimes, what is happening. Whilst I was hearing the voices, I did not have friends. I was most of my time at home. I think my friends were busy, they were working, they were living their lives and they did not [have] time, really, for me, because we’re grown-ups. Some have children and some are working, so they don’t have time to come and see me, but when they have got time they come. They just stay for maybe for some few hours or spend the day with me and they go, but not more often.



Image above: Boitumelo indicates that she is able to move around her community independently

I would sleep when I feel tired, but, when I wake up, I will feel like I want to do some things in the house. Maybe I will bath, I will brush my teeth, I will wash my face, take breakfast and clean, sweep the house and all that. Where I wouldn’t clean properly, my mom would come after me – I can’t see clearly – and my mom will come and do [sic]. She’d help me to do properly and after that, when I feel tired, I would just sleep. I would take a nap.

The anger started while I was staying with my mom. Let me just be specific, it started two years back. I was not angered from the beginning of my time when I started taking ARVs, it started two years back while I defaulted those pills for meningitis and ARVs, I think.

The anger influenced my relationship with my boyfriend. My boyfriend was scared of me, [be]cause we were fighting a lot and I was beating him. It was depressing me a lot. I found myself that I was more

depressed while I was with him than when I was alone, [be]cause he made me to shout [sic] the whole day. I would shout at him like a child. I think he was very careless and he did not really understand me and he did not respect me. I fought with him and, one day, we were fighting and he did something stupid. I was fighting with him, and I just took a knife, a table knife, I just stabbed him. It was just a little bit of a scratch. It was not something big. He was scared and my mom even came and said “No! Boitumelo, you don’t do that”. He told my parents that I’m dangerous, he’s scared of me. I started taking medication for depression this year^t [be]cause we fought this year January when I stabbed him with a knife and after that I saw that this is serious and I think it was the same January when I started going to a psychiatrist.

I was together with him for two years. I think I started breaking up with him this year. He did not want to come out of my life. He was just coming, not understanding that I didn’t want him anymore. We would fight and I’d ask him to leave. He left and didn’t come for months and when he came back, I’d chase him, “Go!”, and tell him I don’t want him anymore. But he refused to go and stay[ed] in my life. Before I came into this house, he’d come to my mother’s house and spend a day there. When I came to this house he used to come and sleep here for a day or two and refused to go, and I ended [up] calling the police and told them he was troubling me. Until last month, he came, and I told him that I moved on, [and] “I don’t want you anymore in my life”. I think maybe now he took me seriously, [be]cause every time when I break up with him, he did not take me seriously. He will just come even though I told him that I don’t want him in my life anymore.

I would support him by buying him food, [be]cause when he comes here, he would eat my food. And I buy limited food, my food won’t last for a month while he’s here, [be]cause I know when I cook today, I will eat for today and tomorrow. So, when he’s here I have to cook with big pots. He was a little bit of a burden for me, [be]cause I support him. But, sometimes, when he has money, maybe when he gets a piece job, he will come with the money. But, when he has money, he doesn’t buy real food. He’ll buy pizza, KFC^u, things that you eat right there and then and they’ll be finished. So I ran out of money quicker and went hungry quicker.

I now have a boyfriend who stays around Mamelodi. We just started dating, it’s now two months. He’s not working, he’s disabled. He’s totally blind. I met him last year December. We were at a Christmas party. They were doing [sic] us a disability Christmas party, that’s when we met.

I like the guy and I think I understand him and what he’s going through, [be]cause I’m in the same situation. And [be]cause, even though it was not for a long time for me, [be]cause my right [eye] can see, the left eye can’t see at all; the right one sees partially, and this is totally blind. Before I was like this, before I saw partially, I was totally blind. I think I understand him much better. I’m attached to his situation. He is not

^t Referring to the year that this incident occurred

^u Fast-food restaurant company that stands for Kentucky Fried Chicken

able to go around the community independently. He's afraid to go around, more especially alone. He needs assistance. Usually we see each other at his place. He supports himself.

I tell both of them about my status. I don't want to be in a relationship while a person doesn't know about my status. We're using protection.



Image above: Boitumelo cooking food on her gas stove

Discussion: April 2018

When we came to Boitumelo the next time, she was very upset.

I had up and downs. I'm just broke[n]^v. I'm just broke[n]. I'm just drinking my wine this early morning. I'm just stressed. My boyfriend, he's engaged another lady. He called me and he told me over the phone. This weekend he spent the whole weekend here. And on Monday he called me and says he is engaged. And he engaged the lady on the same Monday. And then the funny thing, he slept here. The night before he was engaged, he was here.

^v Meaning devastated and hurt

I know the lady. Not physically. He tell[s] me about her. Before we started dating, he told me that he had somebody else, but things are complicated with her. Things were not well between them. He told me, like, he doesn't want the lady anymore and things are not well between them. Because I loved the guy. It was love at first sight. That's why I gave him chance. I loved him before he showed me he is interested.

I was always insecure thinking, maybe, he was with another girl and all that. He's a man of a women [sic], he loves women. I was always insecure. He would tell me that he is going to the group with the lady, I must not phone him. And it hurt me, it hurt me so much. He doesn't consider my feelings. When he was with this lady, he will call me, "Don't call me today – I'm with Christina". Like, it hurts. How can a man, what kind of a man does that? He doesn't consider my feelings, he doesn't respect me. I saw this. She doesn't know about me. I think she knows a little bit, he chatting with someone called Boitumelo. Because, by the time she asked, "Who [is] this Boitumelo? Boitumelo calls more often and he calls late at night. What's going on?"



Image Above: Boitumelo sharing with us during one of our visits

Maybe, because he doesn't see what he has in me because he's blind.

I miss him. I was thinking about him early this morning. Every morning he calls me and we talk. But that is not happening anymore. I'm feeling pity for the lady. They are not going anywhere. You cannot spend the night with another woman and then say next day, "Baby, will you marry me?" You cannot do that. I pray, I ask God to heal my heart. I was so hurt. I don't deserve this guy. But, deep down in my heart I know that I love the guy. Deep down I cannot lie about it. But I'm telling myself, "No, I don't deserve the guy". But I need him. The way I'm feeling vulnerable. I'm afraid. That scares me. That I will bump into this guy again,

I will go back to him again, give him another chance. He's everything that I need in a man. The qualities that he has, he's intelligent, he's more informed, he's matured, he is caring, loving. I cannot tell that much. But he is very, very much caring. And he's supportive. He's ancestral worship [sic]. But, when you tell him about God, he listens. And he prays. And he's catholic, Methodist church^w. But at the same time, he worships ancestors, like sangoma^x, he does those things, traditional things. But when we were dating, last time, I saw he was wearing things, "What is this for?" And he says, "It's for protection". I said, "Protection? How can you be protected by this, while God he is the one who protects us?" You understand? I should have got it there. Maybe I was too blind, or too ignorant. Because, when you tell him about God, he listens. I cannot say he is a God-fearing man, but he fears God. You understand? He listens to you. One gospel, he prays, and he knows scriptures here and there. And when you tell him about scriptures, he listens. Just a little bit, he knows about God. He was the best, he was. He was there for me.

According to his tradition, he's allowed to marry two women. Polygamy. I break up [sic] with the guy when he told me he is engaged and I thought it is over between me and him. The Holy Spirit said, "I'm proud of you. I'm proud of you." But yesterday I was thinking to call my psychologist and saying I want to come and see her before my appointment, because it was killing me. Because, even Kelebogile, she was scared that I would do something stupid in the house, like breaking thing[s]. I said, "No, by grace I can control myself". I'm in that level where I can control myself. Because, yesterday I was angry with myself, I wanted to just beat myself. And I held myself and I cried instead of beating myself. And I cried. I cried. I was thinking that to make an early appointment with my psychologist.

Discussion: May 2018

Boitumelo's friend, Kelebogile, told us that Boitumelo was not well. She was very concerned about her, because, according to her, Boitumelo had flushed her medication. We went to visit Boitumelo the day after we heard this. The Boitumelo we saw this time was very different to the one we had previously met. It was difficult to understand her, she was incoherent at times, and avoidant. We tried to convince her to return to the psychiatrist and psychologist, so that she could get assistance. We also worked with her to receive additional support, and to speak with her family (specifically her mother), for support. Finally, she told us that she still loved her ex-boyfriend, and he was helping her get additional food through his disability organisation. It appeared though, that he was trying to control her and we asked her what the reasons for this could be? There are many concerns about the way that he is treating her.

^w Boitumelo appeared unsure of what denomination he was from

^x A traditional healer, who diagnoses, prescribes and performs rituals to aid in a person's physical, mental, emotional or spiritual healing

The night before, I just flushed the pills, ne^y. There's a thing that happened. I just heard a voice, again. And that voice said to me, "Go and sleep at the mattress, on the floor." So I refused. "No, I won't do that. What is it in this bed? I'm going to sleep here." So that thing keep on pushing, and it tried to make me do things that I don't want to do. It tried to control me, "Do this, do this, do this". Like, sometimes, it will make me to pray [sic]. Of which, yes, it's a good thing. But it makes me to pray like, uhm, even though I don't feel like doing it. And another thing, it makes me to go somewhere, go to Kelebogile, and sometimes I'll go to Kelebogile, I'll find Kelebogile she's not there. And I'll be offended. Eish^z, this voice, it makes me to go somewhere, and I find that that person is not there. I'll be angry. I went there and I did not feel like going there. I get offended, like, this thing, what is this thing that controls me so much? And I hate it, [be]cause of [sic] it makes me to do things that I don't want to do. I had two, three, four days not taking those pills. But, the voice didn't make me flush the medication. I guess it was I [who] decided to do so. So, it said to me, [be]cause I had maybe two days, three days not taking those pills. Even when I was taking the medication, I was hearing it. It [be]came too much. It was, like, loud. I tried to sleep, I couldn't sleep, and I was feeling so disturbed, like something was irritating me. I felt so irritated. So, I cried. And I prayed, "God, why this, why things are happening like this?" I started questioning God. And after that, I tried to sleep, and even when I tried to sleep, I couldn't sleep. This thing keep [sic] on irritating me, I feel irritated, I feel like things are entering in my body, something like that. So after that, that thing said, drink your pills. I said, "Never. I will never do that." He said, "How can you leave your pills? You must live with these things." I said, "You're the devil, you're an enemy."

I thought, I was thinking, ne, [be]cause I was in [sic] this medication, I was taking Diflucan^{aa}, they're for meningitis. There was a time I stopped taking those pills. Then I got sick. Then, I did not know what was the matter. [Be]cause I was every time [sic] so upset, confused, so angered and whatever. I was acting strange. Until one day I remembered that there was [sic] pills that I was taking. And I left those pills for two years. Then I went back to the hospital, and I told them that I left those pills for two years. And that this is what is happening to me and I want to take my medication back. Then that doctor, she prescribed them again, and I went to the chemist and took my pills. So I was thinking that, maybe, because of I was not taking those pills, they weren't for meningitis. And then they were long-life pills, I was not supposed to leave those pills. So I was... now I'm thinking that maybe if I just stick on my Diflucans [sic], and I stop these ones, maybe things will get better, with time.

And another thing that made me so upset, that made me to think that these pills were not right for me, it was the same voice, the very same voice, that said to me, "How can you leave your pills? You know you must take your pills." It's the very voice that told me to leave my ARVs. That was the time that I did not take my medication. So, it's confusing. How can this thing tell me to leave my ARVs? And those pills are

^y A parenthesis, which for Boitumelo, is used meaning "that is so", or "are you still following"

^z A South African word used to express exasperation or disbelief

^{aa} Diflucan is typically prescribed for Diflucan as an antifungal medicine

serious. And now they want me to take these ones? What is it with this? Is it that that thing hates me so much, that the pills that I know I will die if I don't drink them, it told me to leave them. And these ones, maybe these ones they're not right. This thing wants to kill me. You, see? So maybe that's why it push me [sic] to drink these pills. Maybe these...me, I'm just assuming, this thing, maybe, it hates me that much, that it want[s] to hurt me. It want[s] to destroy me. It want[s] to kill me. What is wrong with these pills that it pushes me, and it speaks with like, the voice when I hear it, it's like, "You Know You Must Drink Thing, How Can You Leave These Pills?!" And so, I was, like, "How dare you? Who do you think you are? You are a[n] enemy, you hate me! I won't take these things, [be]cause maybe these things are not good for me."

The good things, it doesn't tell me to do. It leads me to destruction. I'm trying to resist that. But sometimes, I can't. Sometimes I don't. Sometimes, when I don't do what it tells me to do, I feel guilty.

And the funny part of this, ne, it's not funny, [but] my mom, she doesn't know. I've never told my mom what is happening with me. [Be]cause last time, like, they know I was okay. So, they knew that last year I had problems, [be]cause they were seeing me, physically, I was, like, affected, I was not okay. How [do you] know what a person is like when they're ill, right? You get slim, you change, and you lose weight. It showed that I had some stress. They did not really know what's happening to me. I dunno [sic] why I don't tell them. Maybe I feel ashamed? Or, I feel like they'll judge me...I feel like my mom... I don't know. It's not my fault, but I think like, this thing... two years back I was okay, and all of a sudden, things are like this, and what went wrong, what's wrong? I'm still going to decide who do I [sic] trust in my family.

And the other thing that disturbs me is that the medication that I'm taking are too many. It depresses me for me to take such [sic] many medications every day.

Maybe, I must tell myself that I've been on my own for a long time. I had no-one to talk to, I was feeling good, I was feeling happy when I just listening to television, ne? I will watch my Christian channels, where pastors preaches [sic]. I will feel happy when I listen to my gospel music, and just lock myself inside the house. So, another thing that I was thinking is that, maybe, I've been on my own for such a long time that, maybe, I need something to do, something that may keep me busy every day. That will take my mind out [sic] of things. If my mind, maybe, explores, I just do something that I like. I'm thinking, I was just thinking, that maybe that thing will make me happy. That thing that will make me not to think too much. Unlike, to be on my own every day. I just go outside once, and maybe I go just to see Kelebogile for an hour, and I just come back, I'm on my own. So, ja^{bb}, I was just thinking that if I find that [sic] I can do, that I can like, people that I can be with, maybe socialise a lot, or maybe go out a lot with friends.

The one, my boyfriend, my ex-boyfriend, I don't know what to call him, he just call[ed] me. He called me, it was when, on Saturday night. He told me that there are food-parcel people. So, he's in this Disability

^{bb} Meaning "yes"

Forum support group. The other one, not the one that we go to, it's the other one, it's a what-what, I don't know the name. And so, it's their own organisation. So, he put my name there when they wanted the blind people, they want to support them with groceries, and he asked for me. He asked, "People, could you also please add Boitumelo?" And they said, "No, Boitumelo she's not in, she's not with us, she's not in our organisation, there's no way we can take Boitumelo." And he insisted. We are going to Joburg, they're organising transport, the taxi. The taxi will take us here. It's me, him, and the other blind people. At their organisation.

When he calls, I feel satisfied. I feel so comfortable and, like, when I hear his voice, I'll think, like, I miss this, I miss speaking with him, the conversation that we had. [Be]cause he was calling everyday day, like, that's what I missed. And I feel comfortable and happy. [Be]cause we had not really talked, even though I don't know what we would talk [about]. I don't know what is it that I want to hear. But, I see a little bit of hope. When we're speaking like this, ne, I'm telling myself that okay, before we got involved, he told me that he has a girlfriend, there's a girlfriend, ja. So, I'm telling myself that I knew he that had a girlfriend and, I was in the relationship knowing that he has a girlfriend, and I'm asking myself that... I don't know... I was comfortable with dating a man who has a girlfriend.

Oh, okay, like, I was thinking that I don't need this guy, I can't live with this kind of guy. I have to move on. But deep down in my heart I know that I still love him. Maybe it's not easy. And, another thing that made me to love him even more is that he considered me in that organisation, that thing of theirs. But, it might be for other reasons.

Because, I'm thinking, [be]cause he told me this week, "I will come to your place. I don't want to be told what to do. I don't want somebody [to] tell me what to do. And, I do whatever I want, exactly when I want to do it, and in the way that I feel like doing it." He said, even at my place, "I'll come". He will come when he wants to come at whatever time he feels like coming. And nobody is going to tell him when to come and when not to come. He try [sic] to control my life.

Reflexive Note: May 2018

Judith and I reflected on what had happened, as we tried to make sense what was happening. Judith wrote, *"As I reflect on Boitumelo, I then realise that she is frustrated and broken. When I compared her with the women of her age with disability in the community she's living in, she is far much [sic] better; all she needs is just a push and motivation. The fact that she uses men as a coping mechanism in her life really worries me; I'm not sure if she is hiding her illness and disability behind changing men. Boitumelo confirmed to me that she [would] rather date a guy who cheats on her as long as she loves the guy. I tried to reason with her that she should put herself first, [but] all she said was "ke a morata" – I love him. I wonder if you can love a guy who sleeps at your house [the] whole weekend and [on] Monday morning, he calls you [to tell you] that "I'm engaging someone. Please don't call me, I will call you". That confirms*

that Boitumelo does not put herself first, as she still insists that she is going on with the guy. Is it low self-esteem? Is it poverty-related issues? Is it because she never received love from her childhood? Is it maybe she is trying to make herself feel loved and proving a point that she is cable of dating?

Do we blame parenting, do we blame lack of resources that can advise her, do we blame lack of job opportunities in our country, do we blame our system that does not support our disabled people, or do we blame Boitumelo for not being responsible? I can't judge any of this; as I get to know her, I will find out. This problem is not only on [sic] Boitumelo; [a] few of the ladies that are disabled who I worked close[ly] with have some of the issues mentioned above.

What upsets me so much, [is that] Boitumelo is not telling us [the] same stories. Every visit has a new story that contradicts the previous story. The highlight of them all in Boitumelo's life is the fact that she does not want her family to know about her illness; it worries me too much. I feel the reason why most people are not getting better, healthwise [sic], is because the family support system is not so strong."

Judith, currently living in Mamelodi and working as a community worker, wrestles with the realities that are around her. We try and make sense of what we are seeing, whilst remaining true to Boitumelo telling her story. It is a difficult place to be in.

Discussion: May 2018

Judith went with Boitumelo to the hospital to make sure that she received the necessary intervention. There, they administered an injection to assist her. After this, we visited her again and she was doing much better. We were concerned that she was getting involved with various men in this time because of her vulnerability.

I don't hear the voices at all now. Since that day after that day that I told you I heard the voices, I must drink the pills — I never heard. The doctors, they're given me a medication [sic]. I'm feeling okay. It's normal...

But since I've gone back with Judith, they say I experience this because I defaulted on the medication. I started on the ARVs, and then I stopped with ARVs, because the voices was telling me not to take them?

But the doctor said I got HIV and I didn't take the medication then. But, before I was not hearing the voices. But, maybe, I don't recall, but my CD4 count was never up. Always was down [sic]. It was recently, I think it was last year, when my CD4 got so high. I was, like, surprised.

I'm not keeping men, no. I'm okay alone. [Be]cause I saw my psychologist yesterday. And he said I must be on my own, I must heal, I must not just bump into another person... [be]cause before I got to this relationship, I was in another relationship, I told you guys ne? And I never had my own time, I never had a break. And then now, I'm out of this one, and then I'll bump into another one again. That's not normal.

I'm getting there... but I told myself that I don't want any boyfriend now. I'm okay on my own, I must have my me-time, where I might realise things that I like about myself. That's what my psychologist said. Maybe I can realise new hobbies and all that, if I'm on my own.

I love reading. Unfortunately, I can't read. Maybe that's why I must find something that I like now, maybe without my eyes, that I can do without seeing. I liked... fixing, [be]cause I wanted to be an electronics, electric engineer. That's what I like to do now. What I also like to do is watch TV, it's listening to music, my pastors. I love cooking with all my heart, [be]cause I was a chef before I got blind, and I can cook even when I can't see. I can cook, ja. I've got a radio, but it's broken yesterday. The day before yesterday, it fell. So, I don't have a radio anymore. And I have got books. But the thing is, I don't have an audio, it on a USB. I don't think the radio is going to be fixed... I think I must buy another one. But I'll try and find somebody who can fix [it]. If it doesn't get fixed, then I'll buy another one.

Discussion: June 2018

We came again to see Boitumelo two weeks later. I had gotten a stress fracture whilst running the Comrades Marathon^{cc}, was using crutches, and was unable to drive. Judith had fetched me to take me to Mamelodi. I had not been able to accompany Boitumelo to her follow up appointment with the psychiatrist, which had been scheduled the day before our visit. Boitumelo seemed to be doing well, but said she had been discharged from her medication. This was contrary to what the psychiatrist had told Judith, that the medication was strong, and that Boitumelo should continue taking it. Boitumelo also said she was seeing her ex-boyfriend again.

Yesterday I went to psychiatrist, and he said I'm discharged. I must stop the medication and I must drink my ARVs accordingly. Then I'll be okay automatically, because I cannot drink those pills and ARV. They are strong, both [of] them. There is no way I can drink, you know – he told you – I cannot drink ARVs and those pillies^{dd}. The previous doctor lady, she is no more [sic] at Dagga. The one that I spoke to is the one that is in charge; he is the one that discharge [me] now. He's not a new doctor. There were three doctors. He was in charge. What I heard is he has been there at Dagga [for a] long time, he is just new to me. I told him I was still hearing voices, but I haven't heard voices since discharge. I still see things.

The man, we are still talking, he is around. He was here last weekend. I don't know when he is getting married, maybe I must ask him that. But, if he hurt me again, I will be broken. I think I'm going to die if he does whatever he does again. And, he is about to be married. My mum doesn't know; my sisters know. I

^{cc} The Comrades Marathon is an ultramarathon, run annually between Pietermaritzburg and Durban. It is approximately 89km, and is the world's oldest and largest ultramarathon race.

^{dd} A colloquial term for medication

love the guy. I'm not sure if he loves me back, because he can say he loves me, but I'm not sure. But I cannot be okay with him having a number one woman. He is not rich. I am not fine with polygamy.

That is why I want something to do, that I can do, that can keep me busy. I want to take my mind out of [sic] many things, maybe I won't think of him then that much. I cannot start a vegetable garden, I don't have the rich soil. I think that at my back, there is something – cement thing, concrete. I'm afraid to plant my vegetables here in front, ne. It won't look nice. I'm thinking to do them there at my back. But there is a dog there. That dog there, they don't watch it.

She kept on finding reasons why she would not plant a vegetable garden. Judith explained the situation, "The mentality here in my community is, in the front its flowers, in the back its vegetables. The only person that I know in the communities who planted vegetables in the front is my granny, because she also doesn't mind what people say. Because, most of the people, they want nice flowers in front."

I don't think this water is free. The people, they say so. But we will see when the rent comes, the bill. It will be thousands, I think so. I don't think its free water. There is a meter box. When we came into our houses, they opened there, they opened the taps here, so that we may operate inside.



Image above: The area where Boitumelo had considered starting a garden

Reflexive Note: June 2018

It was another exhausting day in Mamelodi. Today I fetched Boitumelo and we went to the hospital so that I could speak with the psychiatrist, to find out what her diagnosis is. It seems to be a lady who has

only been there once before, and who does not really know Boitumelo. We explained the situation and Boitumelo said she was confused, because, after the last session, the psychiatrist told her that he was going to discharge her and she did not have to continue with the medication. But then Boitumelo told me that, only last night, she was still hearing voices. She seems to think that the auditory hallucinations are related to stress. She feels that she needs to let her boyfriend go, because he is not being good to her. She says that he does not treat her well. He says he will phone and then he doesn't.

The psychiatrist says that they do not know what the cause of the psychosis could be. It could have been caused by the HIV, or by the ARVs, or as secondary to depression. However, she says that it will still be treated in the same way. She says that this is life-long medication, so I can't understand why they previously said that she should go off it. Then she mentioned things like a brain scan, and the side-effects of some medication, which completely freaked Boitumelo out. She is so worried now about the medication, and I could see that she was thinking of not taking it. I had to reassure her that it's not this medication, and that it is better to take it, even with side effects.

We then went to see the psychologist who had also discharged Boitumelo in March. I told her what I thought Boitumelo needed help with and then the two of them discussed things together. I said she needs constructive use of free time and help with working through what decision she wants to make regarding her boyfriend who has a fiancé. Also, that she needs to learn about managing her medication, because they said that she should be discharged from the psychiatrist. The psychologist wanted to talk alone with Boitumelo, so I waited until they were done. Boitumelo says the session was very fruitful and she is glad she did it.



Image Above: Boitumelo indicating the boundary between her house and her neighbour's house

Boitumelo is now getting food from the church. She has taken some of it to her mother, because her mother also doesn't have an income. She is good at sharing, even though she goes hungry herself. She says that she gets a disability grant as well as a grant in aid^{ee}. This should be enough money for her, so I'm not sure where the money goes?

I was able to review Boitumelo's hospital records. Some of the information seemed different from what Boitumelo had told me, however, I'm not sure that it impacts her life story to a great extent, except that she has had many problems passing at school, and therefore there may have been other reasons for her failing her grades before.

The earliest notes are from 2011.03.11. There it notes she has "loss of vision, both eyes, since last year October (complete blindness) – occurred when patient was admitted for cryptococcus meningitis. She has been on HAART since November 2010." The following entry is 2014.11.18. Here, it seems she had been admitted to hospital for the anaemia (with chronic ds ?ERT). The notes say that she "feels very weak and tired and dizzy, with generalised body pains." She had to receive transfusions. There is another entry on 2015.01.12. Here, the notes say she is a "known patient with optic atrophy. Her pupils were dilated, and her optic disc had (unreadable)." It says, "explained condition to patient."

The next entries are from 2017 (exact date not clear): "Failed grade 10, she passed, the(n) she failed grade 11 then she dropped the school. She wasn't doing well in the school. After that she worked in SuperSpar for 3 years. Then she left the job 2007. Then she was home doing nothing. Then she went back to school but she dropped out again. Late childhood, she drink with her friends, no legal problems. Suicidal ideation; she wanted to take RVD^{ff} treatment, but she stopped herself because she did not want to die. She was angry. Delusions – last year she was thinking that people were following her, stalking her, but now she doesn't feel that way. Perception, hallucinations – Pt hearing voices, the voices were telling you to be a witch, kill yourself, they say she is a prostitute. She thought a snake going out of her body – that happened 2015 when she was at church. Cognition – patient is alert, orientated, memory good, intellectual average. Insight – not good, she things she is not well. Judgement – good. Temporal epilepsy? Depression with psychotic features. Medication – Epilim 500mg bid; Citalopram (10mg). RBV, UDRL, PHA, TSH, Liver function, Beta HCG."

The next input is from 2017.02.13: "No auditory hallucinations, visual hallucinations (snakes)." The next entry is from 2018.01.16, indicating that the original file was lost. "Encephalitis, on lifelong treatment." It noted that she moved out of the house she was living in with her mother, due to a strained relationship. She reports that she has been seeing snakes coming in and out of her body and she hears voices telling her to kill herself and witch people. She often gets angry and breaks things and hits her boyfriend. She came to psychologist on January. The psychologist made her appointment for 23 January, but she did not

^{ee} Social protection offered from the government, given to a carer who looks after someone requiring full time care

^{ff} Meaning retroviral disease (AIDS); therefore, receiving antiretroviral medication (ARVs)

have money for transport. So she came today. She says since she spoke with the psychologist, she is acting better and her anger has released. She is on Fluconazole, tab daily, Zovilam, twice a day and other tablets that she doesn't remember.

2018.02.13: "Alcohol sometimes, usually on Christmas, 1 or 2 glass, smoking none, drugs none. No mental illness in the rest of the family. Younger brothers use marijuana. She was molested when she was 5 years. The man want her to touch her private parts. She was doing okay in the school. She failed grade 1. She did well until grade 7. Previous PTB⁸⁸, Cryptococcal meningitis."

It has become such a worry to me to read what is written in the hospital file, and to be able to see things from the other side. It just shows that the information we gather when a patient is admitted only tells us one side of the story – there is so much more that is going on, and so any other influencing factors. How can we ensure that we work preventatively and prevent the things that are happening with Boitumelo? How could one, way back when she was abused, have intervened and ensured that she was able to deal with the trauma? What about not being able to pass her grades? What caused her to have unprotected sex in the beginning? Etc... There is so much to think about.

⁸⁸ Pulmonary tuberculosis

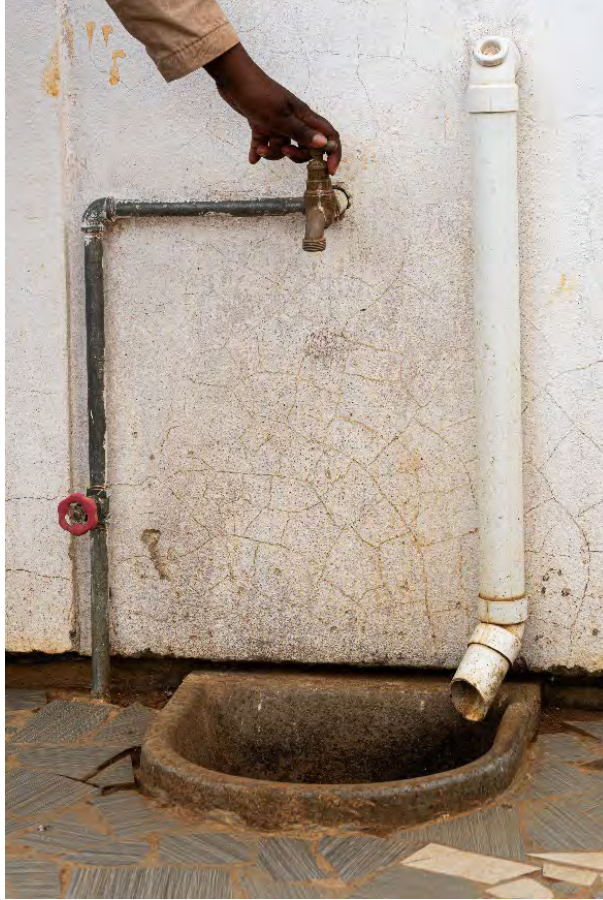


Image Above: The outside water tap

Discussion: July 2018

During the next visit, I became very aware of the network that has been created within this small area in Mamelodi. Since the various women with disabilities we have been engaging with know each other, I have to be so careful to maintain confidentiality and to keep a trusting relationship. We almost breached that today. When we were chatting with Kelebogile, she had wanted to tell us some things. Then, Judith indicated we needed to leave to be able to take Boitumelo to Social Development. I couldn't fully understand, but it sounded like she was saying something about the training course. Boitumelo said to us on the way to Social Development, that we must please not talk about her. She does not want people to know about her applying for the training course. Kelebogile thinks that Boitumelo is on her team to try and apply for another company that can then apply for tenders. I am concerned that they have no business experience. Kelebogile suggests that they want to get the tenders (assuming because of their disability status), and then outsource other companies to do the work.

We went through the form to apply for the basic computer literacy skills training through a college for the Blind. It was a very long form, and there were many aspects we had to explain to her. It also required her

to get certified copies of her parents' ID and proof of parents' income. Her mother doesn't get a grant and her father is deceased. The form said that if the parents are unemployed, she has to get an affidavit saying that they have no income. So, Judith explained this to Boitumelo that she must get this for herself and her mother from the police station. Additionally, she requires proof of her SASSA grant income (for the disability grant), as well as the grant in aid that she is getting for someone to assist her. Additionally, Boitumelo says she can get the death certificate from her father's mother, who lives on the other side of Mamelodi. I read all the information accompanying it, and am just wondering how someone would fill this in if they didn't have support, did not have access to resources, could not go and drop the form off? How would they be able to guarantee that the postal application will arrive, and then be returned to them? I do not really know anything about this course, as I read about it, and it says that it will be full time. Boitumelo must decide whether she is going to stay there, and the financial assistance that we are applying for gives money for the cost of the course, as well as accommodation. I feel hopeful, but at the same time almost feel as if this is a long shot. Can it really work?

I'm not sure why this information has never been shared with Boitumelo? I know that her previous or current boyfriend spoke to her about it. But it seems that nothing happened after this. It is also unclear to why the Disability Forum that they belong to does not share this information? Like Boitumelo says, she is bored, and she is desperate to do something. However, she does not know how and she does not know what.

Being able to get training, unfortunately is only one of the battles won. There are so many other And people talk, and they make you think that it will all be so easy, when it's not! There are so many confounding factor. The employer will need to offer reasonable accommodation, transport will need to be arranged. And, what about the cost of the transport versus the potential current income.

Boitumelo is young and vibrant. I really wish for her to be able to live a full life. Except that she is living in poverty and has numerous disadvantages and discriminations that she needs to overcome. And this changes everything for her.

Reflexive Note: July 2018

Judith sent me her reflection about our interactions with Boitumelo. She said, *"Boitumelo told us that she depends only on disability grants. For almost half a year Boitumelo had expectations that we were going to give food parcels. Until we started intervening, helping her with her application to study at the school for the blind, she then revealed that she has an extra income from social grants. That really made me angry, because we paid for Boitumelo's transport to hospital. I once took Boitumelo to hospital, then she asked money for food, and I gave Boitumelo money to buy bread. Why would you not have money if you earn about R2 000 staying alone? I thought Boitumelo maybe gives the men money, because they visit on [the] weekend, and I once asked when we were queueing at the hospital, "What did he bring?" She*

confirmed that they don't bring anything. She said, "That is why I sometimes fight them [sic], [the] other one I even stabbed with the knife."

Money issues is a problem to me, as it also creates expectations to us [sic]. First thing after we filled [in] school forms, Boitumelo said to me we should have helped her drive around to get all the required documents. A week ago, she said she went to get food parcels from Johannesburg, I then asked myself, "Do you take advantage of us because you think we have money and petrol?" What worried me is that I told her that Helga is in pain, but still [she] ask[ed] me to help with documents. To date Boitumelo did not call and check or update us with the progress of the school. We put too much energy in[to] this intervention, [while] she was so relaxed, take[ing] time to report back to me. I waited at hospital for Boitumelo, [but] she told me, 'No let's do it tomorrow'. [She] lied first that she has everything. All that really [does] [is] make me not [want] to help her, because Boitumelo is not honest with some of the issues."

I can see how Judith is wrestling with this situation. She herself, has previously not had money to buy food. Currently, whilst she is being paid as a research assistant, it is not a sustainable source of funds. Whilst I am trying to assist with my income to support our work, Judith is using from her own funds too. This is not sustainable, and I am unsure what to do.

After a short while, we went to get all the required documentation from Boitumelo and then to the college for the blind to drop off the application documents. By what feels a miracle, she was accepted for training.

Discussion: September 2018

We visited Boitumelo again in September at the college for the blind during her lunch. She was very happy.

I share everything that we do with my family. When I phone home, they ask what were you doing, then I tell her and she says, "I'm jealous, I want to come to school." It's nice here. I've got friends. Those three ladies and this guy. One is from Northern cape, the other one is from Limpopo and the other one from Eastern Cape – currently, she stays at Johannesburg, but, originally, she is from Eastern Cape. We talk English, and tried to learn one another's language.

I'm enjoying the learning. It's hectic, but it's hard work – too much! I even do extra classes after four. Maybe at six o'clock I will just go for an hour, just to do some extra classes. I do computer training, what you do during the day. I do also braille on Tuesdays and Thursdays. It's okay, but it is hard. But what we [are] learning, we [are] learning how to read it. It's difficult to read those dots, dots, dots. I did work with a computer before, but, JAWS^{hh}, I never did it. I'm using JAWS. It is very hard. You have to know every key to know what you are doing, when to cut, to paste. There are keys that you are using. You don't see, you have to listen, you have to write by keys. But, I like it, it's interesting. I'm very happy here. My family

^{hh} An acronym for Job Access With Speech, which is a screen reader

are happy for me. My mum, she's even proud. She said I must say thank-you; she really appreciates what you have done for me.

We bump into each other, yohⁱⁱ, every time, because we cannot see another. When we come out the door, we bump into one another. Those that are partially blind, we help one another. Others will be lost to go to classes, we take them to classes.

I just felt how ironic it was that here we were visiting Boitumelo, who we had originally met because she had a disability and was food insecure, and here we were getting hot dogs where she was studying. Management at the college had invited us to join her for lunch and everyone was very friendly. Like Judith said, "Now Boitumelo is serving us lunch."

I was still using a wheelchair. It had been three months since my injury, and I was on medication hoping that my stress fracture would heal. The empathy I received from the participants in my study was incredible. Boitumelo said, "Kelebogile's neighbour says there was a white lady here who walk [sic] with a wheelchair. 'Boitumelo, who's that woman?' She came to Kelebogile's place. I said, 'Who?' And I did not know and I asked Kelebogile, 'I heard there was a white lady who came in a wheelchair, who's that?' Ei, Helga. No, you are lying. Ah, I almost cried. I thought maybe, something worse happened."

All of my medication, I'm taking. I'm going again to the clinic on the 20th of this month. I will tell them the day before. Maybe after class, I go home, and then after clinic the following day, the day after, I go back. They told us, we did an induction, so I asked them questions, they say we can apply for next year.

There are a lot of other partially sighted people. The teachers, they are good. They are great. And they communicate to us, and they make us be friend [sic]. They want us to be friends. My facilitator, he is partially blind. The other one is totally blind, and there is the one, he can see. There is the cricket [sic] for guys, but they do it in other schools. They come Saturdays, they fetch them for the transport, they go and practice and bring them back again. Nothing for the girls. But they ask the ladies what do you want to do for fun. And others they suggested, we can have a Miss College.

There is a TV room, and there is a gym. After classes, I go to the gym. The mission is to make everybody independent. They told us in the induction that, "We want everyone to be independent". And, even those who cannot use the walking stick, they teach them. We sleep in our own rooms. The only thing that we share is a bathroom. I have a roommate, but we share only a bathroom, not a bed. We do everything by ourselves. Another thing, they wash our clothes. Asking me, we wash our underwear. They know how to mark the clothes. But if you can't find something you ask the neighbour or somebody and they will bring to you. They will say, no, this is not mine.

ⁱⁱ A South African word used to express awe or surprise

I won't go home every weekend. It costs 30 rands to go there and back – 15 rand to go, 15 to come [to Mamelodi]. I take [a] taxi; t is cheap.

I thought maybe you will bring me some snacks. As long it is not alcohol – that is what they don't allow at school. But snacks, cooldrinks, whatever they allow.

As much as the excitement is there that Boitumelo has the opportunity to change things in her life by learning and taking ownership, it seems that she still does not take responsibility for herself and relies on us to do things for her. It is very tricky, knowing that I belong to the 'have's', whereas Judith does not have anything, to think that there is this requirement or expectation that we will bring, we will contribute, we will give. Although I do feel that this is a success story, where does the intervention end? Up until what point does one continue the relationship with the person or is there, maybe, no end, because we are ones that keep on growing, changing or developing.

Judith sent me a reflection afterwards, as well, *“As we managed to assist Boitumelo to get into the college for the blind, I was disappointed that she could not inform us.. Moving forward, it excites me that we made to success [sic]. Boitumelo has better future ahead, and that brings change to the community. How does this change our lives? What we achieved as researchers? This type of progress gives positivity to community to work with researchers, we created [a] great opportunity for the next researcher to learn to work with community people, though it can also create expectations from the next researcher.*

As we visited Boitumelo at the school, it really gave me a great pride and I was happy to see her excitement and [how she was] enjoying herself. Her willingness to learn more, it showed that she is happy to receive the opportunity. Helga mentions a get-together for us and Boitumelo's family to host a braai^{jj} day at [the] school as a celebration. It is a good idea, yes. But knowing some community members and how they think about us researchers, I found it skeptical [sic] to initiate the braai. I think is good if Boitumelo's family initiate[s] the process and we follow. We don't have to take lead on everything, some of the things family can lead, we follow. We suggested it. I think we should wait to hear from them.

I still think we should be careful about giving in the community. We should also learn to prioritise with Boitumelo and others, [as] the intervention process has consume[d] of our time, [more] than the research time.”

It was valuable what Judith thought, and we, therefore, never arranged the braai ourselves, nor were we invited to one arranged by Boitumelo's family.

^{jj} A South African barbecue

Reflexive note: March 2020

When it was announced that South Africa would go into lockdown and we had three days, I was worried about my research participant's potential food insecurity during and quickly drove to Mamelodi, not knowing what the future would hold. Boitumelo was doing well and living in her home. She did not have work and had finished the courses at college for the blind. She was using her disability grant for her monthly expenditures and was happy. She had really enjoyed her time at college for the blind, however, did not yet have a job.

Note: During 2021, the researcher experienced significant events and therefore was unable to visit Boitumelo to continue engagements.

Reflexive note: May 2022

I was thinking about Boitumelo and wondering how she was doing, when suddenly, out of the blue, I received a message from her. She was inquiring whether I knew of any jobs that were available for persons who are visually impaired or blind. I had accidentally sent her vacancy adverts for our department a few months before, and she was wondering whether I had anything available for her. We exchanged voice notes and I asked how she was doing. She indicated that she completed the Business Management course after the Introduction to Computers course at college for the blind and has been trying to find work since then. However, it has been very difficult. Otherwise, she said, her life is good. But she really wanted a job to keep herself busy. I also asked her whether she had a man in her life, and she said that she had a man that was living with her, and everything was good, by the grace of God.

Reflexive note: May 2022

A week later I heard from Boitumelo again. She told me that she was hearing voices again. She said they were "making her mad" and she was going to the psychologist, and they were trying to help her. She said she was still suffering from the same problem she had previously. She was stressed and unhappy, her house was beautiful, her fiancé proposed, but the voices are trying to destroy her relationship. She wanted to share this about what she was going through, and maybe "God will help her one day". I asked her to urgently see the doctor, and that she may need to be admitted to hospital. She said that she was under psychiatric care, and she would be speaking to the doctors for guidance.

Reflexive note: June 2022

A few days later, Boitumelo confirmed that she had been admitted to hospital. She was in a private psychiatric unit. I could not quite understand what was going on.

I wanted to come and visit her, but she said that visitors were not allowed to the hospital, because of COVID regulations. I asked her whether she would allow me to share information about her history with the psychiatrist, considering it may assist with her support and intervention. She agreed and I gave her my contact details. Unfortunately, I did not hear from the psychiatrist. She then gave me her psychiatrist's contact details, but I did not receive a reply to my email. I told Boitumelo, and asked her to follow up with her psychiatrist, but never heard anything.

Boitumelo and I continued communicating whilst she was in hospital. I asked whether there were occupational therapists working at the facility, and she said yes. I didn't know the facility, and I was wondering how I should best try and speak to the team. Boitumelo said to me that she really needed a job to keep herself busy. She said that whilst she was studying at college for the blind, she was okay and did not hear the voices, but when she is unoccupied, then she would hear the voices. I know how difficult it is to obtain employment currently, however, I wished that those who were working with her every day would concentrate their energies on trying to find her supported employment.

After two weeks in the hospital, Boitumelo was discharged. I asked her how she is doing and whether she was feeling better. She indicated that she was.

Discussion: June 2022

Judith and I met Boitumelo in Mamelodi at the end of the month. She had been at a shopping centre, so she joined us in the car where we could talk and catch up. She was looking so well, and we were very excited to see her. She had gained weight since the early days, and arrived with a bag of shopping from Woolworths^{kk}. It seemed to me that she had additional disposable income. What transpired was that her fiancé was working for the public service, and he had added Boitumelo onto his medical aid as a dependent. This is how she had been able to access private medical care and been admitted to the private psychiatric unit. He was funding her various expenditures, for example clothing and food. But it did not sound as if he was always treating her well. She was alluding to some things that were really concerning for us.

^{kk} Woolworths is an upmarket chain store in South Africa for both clothing and groceries.

Sometimes I want to be by myself. I see myself, like, I can do it without a man. I just want to live my life, I want to work on myself, I just want to have my space and my time. More especially, even though I'm engaged, I still wish to be a single woman. Men are so controlling sometimes.

Judith asked what she has done to live independently up to now. Considering her fiancé is supporting her, she was wondering what Boitumelo had done up until now to live an independent life. For example, she went to school, which contributed to her wanting to change her life.

I was trying to find a job and I was opening my own company to do the tendering things. I opened a certificate for [a] company, and I did everything that was needed. I was marketing myself [the company] to supply. And fortunate[ly] enough, I was supposed to get this tender. So, unfortunately, it failed because people were saying – they were fighting – “How can Boitumelo get that? She's disabled, she's a woman.” Like many men, they were fighting. They stopped [the] subcontract. I was supposed to be a subcontractor, so they stopped that, because many people were complaining. They were fighting the CLOs [community liaison officers] in our communities. So, they tried to stop them, so they cancel[led] everything. Okay, no tendering. Only people who are going to labour, working with their hands. That is the only work they have. That is when everything failed. This was in my area. It was for the electricity, they are busy putting in electricity.

I am so thrilled that after all this time of there not being electricity for all these RDP houses, they will finally get some.

It's been years. Gosh.

Judith asked whether she was using what she studied at the college for the blind in terms of business administration.

I am using that as well, and I got a laptop from school, as well. I am using it as a device. Maybe [if I] get a job and they don't have devices for the blind people, I do have my equipment. I only have a laptop that has the JAWS.

Judith tried to again clarify whether she cannot apply for a post with the municipality and offer her skills to train other blind persons.

I can do that. That is what the social worker said to me. She said she will take me to the Social Development people and empower you and give you some skills and empower others.

Judith is trying to ensure that Boitumelo does not wait for us to try and find work. If she tries to share what she can do with prospective employers, in a small way, perhaps she can share her knowledge. Judith is concerned that Boitumelo's life revolved around having a man, and she would end up committing in this relationship when he was not treating her well. Judith was emphasising that marriage is a big thing, and, even though they may love each other, she has to understand that. Judith said, “The men are coming

into your life, you are comfortable, you are relaxed, and then they're taking care of you. You don't look at the other side. It is time you put yourself first and do your things, be independent of men."

I think now I can do what I need to be independent. That is why I am looking for a job. After coming from college for the blind, I went to Tshwane North College. I registered by myself and I did generic management. This was for a year. It was supposed to be three years, but I did one year. I didn't cope with the other two. There was a reason I did not complete. The COVID, and I could not find my device. I was supposed to get them, I was supposed to get a scanner, they were supposed to come from Hong Kong, the way they import. It was COVID. So, they couldn't find the devices for me – everything was so slow for me, because I was the only blind person.

We are concerned that Boitumelo has started something that she has not finished. Judith previously mentioned that we have seen this a number of times with her. I asked Boitumelo whether she thinks she can finish the next two years.

If I have the devices, I did [pass the first year]. But, it was frustrating. It was the first year of COVID. It was 2020. Everything was like, eish, I couldn't cope. Due to the fact it was not a high mark pass. It was luck that I passed the first year. I enjoyed [it], I had friends, they were taking me seriously, they saw potential. I was going there every day from Mamelodi. With COVID I was going there at arranged days.

The social worker from the hospital said he will arrange for the people from Social Development to help me. He didn't keep his promise. But it is well. I will try to just go.

I try and suggest that when Boitumelo meets with the social worker at her next appointment, she finds out who the person was that he wanted to refer her to, so that she can contact them and find out about the opportunities. I confirm that she is on medical aid and she has been given a diagnosis that they are trying to get registered as PMB¹¹. Boitumelo confirms she is taking her ARVs every day and that she is eating healthily. She agrees that she should get counselling with her fiancé, because there appears to be something wrong, since he is too aggressive and controlling. However, her pastor indicated that he will not do the counselling with them, unless her fiancé has paid lobola. Boitumelo was intending to speak to her counsellor at the private psychiatric unit to see whether they can arrange couples counselling. Her fiancé has two children (insert ages). He is 45 years old and Boitumelo is 37. Judith asks whether her fiancé is aware of Boitumelo's status.

He knows everything, and he is HIV negative. He's taking... I don't know. He just goes for testing every three months. He is negative, negative, negative, even now. He said his blood is "O". He was renting in

¹¹ Prescribed Minimum Benefits (PMBs) are a set of defined benefits which ensures that all medical scheme members have access to certain minimum health services (for specific illnesses or disabilities), regardless of the benefit option they have selected

Mamelodi, and he has moved in with me. It is a home. If you could come and see my house, it has changed, it is very nice.

We would love to go and visit her in her home to see. Boitumelo said to us that she has changed since going to college for the blind.

It unlocked everything. It gave me nice perspective of things, to see life differently. I wish I could go to that place again, if I could. I now [think] out of the box. There is life out there, I can live for myself, I can work for myself, I don't need anybody to do anything. I just need me. I just need to have confidence. I think this came through everything and everybody that was surrounding me. And the lecturers, as well. And seeing other people, "Ooh, life is not like this, there is better life out there." I had some of the blind people who were working in government and they were there at school, so I gained hope, if they can work. The blind people are so wise. So, there are many of them that are so wise. And they are so able – disabled, but with special abilities.

We wonder whether she could not get a job at college for the blind.

I don't know? They said they will find jobs for us. So, they took our CVs, they photocopy our certificates.

I remember the lady from college for the blind who taught her and came to Mamelodi to teach Boitumelo initially about orientation. I wonder whether Boitumelo could not do that kind of work?

She worked in [the] other department where they are selling devices. I will try and look for a job there as well. I will call them.

Judith then asked whether she has met her boyfriend's children.

I have met them, the first born. The other two I haven't met. They are staying in Mpumalanga and the older one is staying in Jo'burg. They don't see their father regularly, they talk to him over the phone. And you know how children are, they only call when they need money, most of the time. But it's their dad. We are intending to have one child [together]. He was not married before. The first child, he has his mother, and the [other] two, they have their own mother. So, he didn't marry any of them. But, he was supposed to marry the last one, but she was cheeky and all that.

We ask her if she is happy.

I am happy. My life is fine. Except, what I need now is a job. It was on Friday, I went to some guy, I heard they need people living with disability, I heard they had a post for them. I went there looking for a job. In Ford. They said if there is anything, they will call me. I gave them my number.

We try and find out whether she is still going to two clinics to get her medication?

I take all my medication from Mamelodi clinic. I love this one, because I'm used to it. Everything has moved here, my ARVs. I am only taking the mental health medication from the private hospital.

We ask whether she cannot get her psychiatric medication from the government clinic.

It's very expensive medication, I don't think they will give it. I will try ask my psychiatrist, but I don't think so, because it's very, very... It cost me 1.5 [rand]. They said I have to take the medication for six months; we will see how it works. I will go to my regular check-ups once a month. Every month I have to buy. I got it from Clicks^{mm}.

I try and ask whether they do not have a generic option and explain that this will be a cheaper one, if it is available. Judith says she can send them an email and ask.

They give me exactly what the prescription was.

Judith asks Boitumelo whether she loves herself better than before.

I love myself much better now. Because, what can I say, I see life differently, and I am taking charge of my life. I do things, like the things that I think to do, I do them. Like when I want to go and look for a job, I do it. I don't just stay and do nothing.

We congratulate her on her efforts, and how wonderful it is to see her. We are unsure about what the future holds, and Judith explains that she is also looking for a permanent job.

I just hope it is in Pretoria, because I love you guys.

We say goodbye to Boitumelo, as she goes to get a taxi to return home.

Reflexive note: September 2022

We hoped to check the synopsis of Boitumelo's story with her, that I had written for the article as part of my PhD. I knew that member-checking was an important aspect of the qualitative research process. I had also hoped to be able to go through this entire e-book with her, and to double check everything that was written. Boitumelo was in agreement. She asked whether we would allow her to put it on her laptop, so that she could use her JAWS programme to read it to her.

What proceeded was a lot of back and forth, between trying to organise the University to assist with uploading the license key again (Boitumelo said it stopped working after she took her laptop to an IT technician to fix it). The University was not able to work on private laptops, so we considered downloading JAWS onto a university laptop in the computer labs, so that Boitumelo could use that space. However, the

^{mm} A health and wellness retailer, including a pharmacy

computer labs on Mamelodi campus were unavailable for this, because they were being used by students for lectures.

Eventually, I went back to college for the blind to ask them whether they could assist with the laptop, considering Boitumelo had gotten the laptop from them. They agreed and asked me to get Boitumelo's ID number and which year she received her laptop.

I realised it was probably best if I went to fetch Boitumelo's laptop to take it to college for the blind to see if they could fix it. I also asked Boitumelo whether we could come and take some photos of her for the e-book, and she agreed.

Kirstin, who was going to take the photos, met me in Mamelodi, and we drove together to Boitumelo. When we arrived at her house, I could not believe the change that has occurred! She now has a large flat screen TV, sound system, and a fridge. Together with this, she has a bigger solar system to be able to watch TV and listen to music. Additionally, they have built a veranda with two large pillars at the entrance, and inserted a glass sliding door. There is even a beautiful red rose plant at the entrance.

Boitumelo was happy to pose for us throughout the house and outside, signifying important areas in her home that we had previously spoken about. It was a wonderful time together, we laughed and were amazed at the change. It really is remarkable to see the difference, from when we first met her five years ago.

She gave me her laptop to see whether I could sort it out. She said then she did not get the laptop from college for the blind, instead she got it from an organisation in Johannesburg. It was only JAWS that she had gotten through college for the blind. I switched on her laptop at home, and it looked like she had version 14 of the programme. The college for the blind IT staff said that, unfortunately, this was an old copy of JAWS, and that we should instead try and download a different open-source screen reader, NVDA. He said that although one has to undergo a learning curve until one knows how it works, it does have a really excellent user guide as part of the documentation. I was so confused. I'm not sure that Boitumelo would be able to learn how to use this new screen reader at short notice?

Reflexive note: September 2022 (the next day)

The next day I called Boitumelo, and she said that she actually did have version 20. She then said she did not get JAWS from college for the blind, instead she got it from Accessible Solutions, a shop in Centurion. She said possibly the person who fixed her laptop previously added an old version onto the laptop again. She would send me the license key she had in her emails. At college for the blind, they sent me the link to be able to reinstall JAWS. Since the laptop had not been issued by them, and it had been so long since Boitumelo had been with them, I would have to pay if I were to bring Boitumelo's laptop to them. They were happy to assist via email, though, and to see whether I could do it. I downloaded the new version of

JAWS and used the license key to activate it. I added the synopsis of her story onto the laptop, so that she could read through it. Judith came to fetch the laptop to take it back to Boitumelo.

Reflexive note: September 2022

Judith brought Boitumelo the laptop. However, when Boitumelo tried to use the laptop with the JAWS programme, she was really struggling to do so. It does not make sense to me why she was having difficulties, when she had been trained in using it? Eventually, Judith read through the synopsis with her and translated every aspect. As she was reading it, Boitumelo became upset. She started asking Judith to change certain aspects of the story, for example, she wanted us to change the part about her previous relationships, where her boyfriend became engaged to another woman. She said that is that it was hurtful for her to look back again.

I did not know what to do. We continued discussing with her the value of her story, and tried to reflect with her that it is difficult when one looks back and remembers things, but that she can look back on her life and see the growth. I reinforced that the story will be anonymous, so she won't be identifiable, and how others can benefit from what she had shared, especially regarding the different kinds of illnesses and the complexity that exists in this. I also said that we can change aspects in the story that she wants to have changed.

She indicated that she does understand, and that she appreciates what we can do for other people. She sent me a voice note, saying, "Thank-you very much for what you are doing. It doesn't only help people, you guys helped me a lot through my situation, for me to get the academic, college for the blind, and some stuff, you helped me. Even Judith went with me many times to the hospitals. You've been there for me, I appreciate you as well. You did a great job. It's not nice for looking back at things, it's sad sometimes, my heart was so painful, I was hurting when Judith was reading that article for me. But I have to move on and help others with my situation. Thank-you guys."

Reflexive note: September 2022

We went to visit Boitumelo to follow up on how she was doing, and whether she had managed to sort out her medication. She was at her mother's house. We had previously visited her at her mother's house, when she had allowed us to discuss her illness with her mother, so that they could support her. Since Boitumelo does not have electricity at her own house, she does laundry at her mother's house and frequently visits her.

Boitumelo told us that had not taken her medication again from when we had seen her in 2018, until May 2022. She said that she went to Mamelodi hospital to see her psychologist in May, since she was not doing well. The psychologist there said that, since she now has private medical aid, she should access the private

psychologist in Pretoria East. This psychologist then referred her to the private hospital. This is how she came to be admitted. Here, she was prescribed new medication by the psychiatrist. But unfortunately, her medical aid has since depleted, and the medication is so costly. She only took the medication for two months. Apparently, the psychiatrist requested a PMB for her medication, but according to her, the medical aid did not approve this for her diagnosis of depression. It does not make sense to us that she has been diagnosed with depression. I feel frustrated that the medical team did not take her medical aid and socio-economic status into consideration when prescribing the medication. Judith and I advised her that she should go to the public hospital, so that she can get the medication for free. We are concerned that, according to Boitumelo, the psychiatrist at the private hospital was aware that Boitumelo's medical aid was exhausted. According to her, the psychiatrist says she did not have resources to refer Boitumelo to Mamelodi. This points to the disconnect that exists between the private and public health systems.

She then said that her fiancé called to speak to the psychologist, but they did not ask him how he is coping or provide any information about Boitumelo's illness, they only wanted to know more about how Boitumelo was living at home. Boitumelo says she experiences a lot of anger. When this happens, she wants to scream, and it makes her tired. She says that when she was taking her medication, she was sleeping well. However, she does not feel that she was assisted properly in the private hospital on how to cope with her illness.

We asked if she still hears voices. She mentioned that she does hear voices, coming in the form of God, telling her not to go to hospital to get medication. She says that the voices sometimes tell her that her boyfriend is cheating on her and then she starts getting angry at her boyfriend. Judith asked Boitumelo if she gets angry at everyone when hearing voices, or only at boyfriend. Boitumelo said she only gets angry with her boyfriend, she does not get angry with her family, because her family understands her.

Yoh ousⁿⁿ [sister] Judith, it is surprising that I was not aware. The voices make me angry only at my boyfriends. [I] never had this with family or friends.

Judith tried to problem-solve this with Boitumelo, asking whether she may be needing to "work on her jealousy". She asked Boitumelo if she was "using your voice as an excuse to cover your jealousy, because you get upset when your boyfriend goes out with friends." Boitumelo said that perhaps, as a result of her disability, she feels insecure. This could create anger in her.

Judith suggested that Boitumelo joins a support group. It seems that the private facility did not consider Boitumelo's home context upon discharge. She should have been referred to an institution for care from home.

ⁿⁿ This word comes from the Afrikaans term "ou sis" which means "older sister". It is used as a term of respect for a slightly older woman

Boitumelo then stated that she volunteers at a workshop for the blind. She said that they call them to come and help when there is a need for extra hands at the organisation. It was not exactly clear what volunteering this was.

We brought up her synopsis again, as well as the e-book. We discussed with her that we did not want to make it painful for her by going through the e-book with her again. We realised after last time when Judith discussed the synopsis with her, that it was too traumatic. She does not have to look back, she can look forward now, into a happy future. Judith also discussed with her those elements that she had wanted to change. She said that we did not have to change them. She said that it was emotional for her, but she understands the value of sharing the story with other people.

One of the things we wanted to clarify, however, was regarding the work she had done at Spar. Why did she say that her salary had been “decreasing”, and why did she leave. She explained that they were taking money from her income to pay for the cash short fall from her cash register. Therefore, her income was getting less. According to her, she was not stealing the money, and was, therefore, upset about what occurred and decided to leave. It could have been that Boitumelo did not calculate the change accurately or made mistakes. But, it seems that the manger did not explain what was happening to her, they just took off the money from her salary. It is unfortunate that other avenues in the store weren’t offered to her. Perhaps she could have moved from being a teller to being a packer. There may have been some resolution that could have occurred.

We tried to encourage Boitumelo to urgently go to Dagga to resume sessions with the psychologists and psychiatrist. She said that, “I’m going to go Monday, this time serious, I’m going to make sure that after my boyfriend leaves for work I will get ready and go.”

Reflexive note: October 2022

We have been in communication with Boitumelo. She said she went to Dagga to see the psychologist to try and make an appointment, however, the psychologist was on leave. They took her number and said that they would ask her to call Boitumelo.

Reflexive note: November 2022

Boitumelo has a job! I called her to find out what happened, and she explained that she is working for a workshop for the blind. According to her, a fellow disabled person in her area told her about it. They then called her, and she started working there. She is enjoying it a lot. They package items including pens, fertilizer, assemble wine boxes, etc. She says she has a friend called Tshego. There are a number of people with disabilities – some are blind, some are deaf, others have various physical disabilities. There are, according to her, also “normal people”. She said she has been doing this for about a year, since last

February. I remember her talking about volunteering at a workshop for the blind, but I didn't realise that she was working there. I am so glad to hear this! She is unsure of how long this particular contract will last, but she is hoping it will go onto December. They work from the morning until 15:30 in the afternoon, and then she takes the taxi to go home.

I was so excited. I asked whether I could come and visit. It was between where I work and Mamelodi, so I drove there that afternoon. She had gotten permission from the supervisor that I could come. There, Boitumelo introduced me to her supervisor and co-workers as, "my occupational therapist and my friend". I smiled hearing her say this. I am so grateful that we have become friends. After short introductions she said she wanted to go back to do her work; she did not want to fall behind. Her supervisor showed me around the assembly points. Boitumelo was very proud of the work she was doing. She demonstrated how she has to put the fertilizer pieces into the plastic containers, and how they then get sealed. She also has a friend, who sits with her at her table.



Image above: Boitumelo sorting the fertilizer and packaging it

The supervisor says they are hoping this contract will last until January or February next year. The items get sent overseas and are sold there. Unfortunately, they can only employ people as contracts come in. There are about 22 disabled permanent employees, and another 22 contract staff with disabilities, who they phone when work comes in.



Image above: Some of the fertilizer, before it is sorted



Image above 1: The end product

She said she was happy and she was enjoying it. She said, at least she was working and not “sitting at home doing nothing”. I am so thrilled, and just wish that she could get permanent employment somewhere.

There is still much to be done. We need to ensure that her healthcare between the private and public facilities are coordinated. We also need to ensure that the medication she receives is affordable, so that she does not discontinue using it. I am hoping to have a meeting with her psychiatrist and psychologist to take this further.

But there definitely is hope...



Image above: Boitumelo enjoying working



Image Above: Boitumelo with a new rose bush that she was given as a present