

ANNA'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 Anna. 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 Anna and her household. 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, became employed at the University of Pretoria's (UP) 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 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 UP Community Oriented Primary Care (COPC) Research Unit was established in 2015 by the Department of Family Medicine. The Community Oriented Substance Use Programme (COSUP) is a collaborative effort between the COPC Research Unit and the City of Tshwane (CoT) to offer a harm reduction programme for people who use illicit substances in Tshwane. There are currently 17 sites situated in communities across Tshwane. Each site has a core team made up of a clinical associate, a social worker, a peer educator, a community health worker (CHW) and an information

officer. A medical doctor makes weekly site visits. Some COSUP sites also have psychology and social work interns working there for periods of time, as well as community engagement activities from various Faculties at the University of Pretoria. Occupational Therapy students facilitate group therapy sessions at several COSUP sites.

- The methodology followed in constructing this life history narrative is as follows:
 - Informed consent was obtained from the participant (Anna) at the start of the study.
 - Various interviews were conducted in Anna’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^a 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 sequences, but concurrently. Also, the life history is not reflected on in a single

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

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 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 household's pseudonyms have been chosen by Anna and her daughter.
- The names of other people in the narrative have been changed.
- Specific names of clinics and COSUP sites have been removed to protect the household's identity.
- Names of staff in COSUP have also been removed to protect their 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 participants, their faces have been blurred.

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Acronym

- COSUP: Community Oriented Substance Use Programme

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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: Anna and I during one of the most recent visits

LIFE STORY - ANNA MKHIZE

Discussion: February 2018

My name is Anna. I am 51 years old and am originally from Springs. I moved to Mamelodi as a young lady and met the father of my three sons. We had a very nice relationship. Then I moved to come and stay here in this area. I am a churchgoer - on Sundays, when you come here, you can't find me, I am always at church. I have four children – David, Andries, Bule, and Precious. The first son [David] was born in 1989. The second one [Andries] was born in 1992 and the last one [Bule] was born in 1994. The older one stays in a dumping site^a. He doesn't come to visit me. The two [younger] boys, they stay here. They sleep here and then in the morning they leave. They are not working. The last one is my daughter [Precious] born in 2000. She is the one who gave me HIV – my daughter's father [meaning Anna got HIV from Precious' father]. My daughter is in grade 10.

My kids [the three sons], they were behaving well, and I was working several jobs at Spur^b. Then their father moved on. If you have sons, you sometimes don't want your son to be dating a certain woman. The [partner's] family didn't like me and wanted him to marry someone else. Then he got a girlfriend. They liked the girlfriend that he was dating and [then] we were fighting. Then we started fighting amongst each other for the man.

I kept on working at Spur and raising them. They were behaving very well, but as time goes, they started to change. My sons do not drink alcohol, but they started smoking nyaope^c. I don't even know the smell of nyaope. They say nyaope, you mix it with cigarettes. They smoke it in their shacks in the back room. They sell my things to get money. You turn that other side, you see they have sold the bricks, they have sold the roof zinc. The zinc is an old zinc, I used to have a shack here, I dismantled it and packed the zinc there. They broke in here [a cabinet with glass] and took the glasses and plates. They have taken everything, cutlery... they sell it to a woman of my age, and they [the women] don't mind, they buy [sic] even a cup that has been used. You see this one has been used. They buy it from them – mothers and old men. I'm trying right before God takes me so that I can build a home. But they take the same thing that I want to build a home with and sell them.

Then I met a friend in 2000; it's a boyfriend. Yeah, I made a friend and then he gave me HIV. The infidelity started when I was breastfeeding my daughter. Because culturally when you start breastfeeding you stop

^a One of Tshwane's dumping sites is in Mamelodi, called Hatherley. This is a large open area for depositing refuse. There are several people who live here and collect the waste for recycling. Most of these individuals are substance users

^b This is a restaurant chain in South Africa

^c A heroin-containing street drug

having sex, in my culture. When I started interacting with him sexually, I started seeing myself losing weight. The clinic didn't pick up anything. They picked it up at Steve Biko [Academic Hospital] in 2003. They told me you are like this, then I got very scared. Immediately when I find [sic] out, I chased him away. I told him "You brought this sickness to me". He is not staying far. He is staying just a few blocks away from here. I don't want my daughter even to have contact with him, because seeing him is hurting me so much. I took time to accept my condition. I stayed three weeks at Steve Biko^d. When I found out that I was sick, I took time to accept. Even my kids don't know that I'm HIV positive. Even the youngest doesn't know and I'm worried that once she knows she might also get upset that her mother is going to die from HIV. I kept the secret from my children.

I got very scared, very scared, and it took me a year. I didn't even believe that it was me. Because people, they were dying then, and then I thought about my daughter, my child, and I thought she is going to be an orphan. Then when I went to the clinic, they told me the same story. They gave me two weeks and they kept on giving me teaching and counselling. I took my child to be tested and then they found out she is negative. As time went by, I accepted my condition, and I started taking my medication. I was aware that I was losing weight and was becoming very weak. Immediately I started recovering. But then I worked whilst continuing in this situation. Then I got stressed

I don't have a disability, but sometimes I struggle to do things that I want to do. My stress can sometimes lead me to not do anything. Just to sit and do nothing. Even if someone is knocking, I'm not even hearing the noise. I have had this stress since I've been having HIV.

I then started going to work stressed and then one day I was in an accident, hit by the car. It was a hit and run. I stayed long in the hospital and then I stayed at home, because now I was very sick, and I was not working. Then, when I went back to work, they chased me away and they said they don't need me anymore. This was in 2003. Then I used to get piece jobs^e, I just got piece jobs here and there as a domestic worker. In Willow[s], Faerie Glen, Garsfontein, Glenwood^f.

I worked as a domestic worker the year before last. I went to work just for a month. As I was working at that house, I worked for a month. I asked for...I asked my employer that I need to go to the clinic, and I take a day off [sic], and the employer said "Why are you going to the clinic? I know you people, you people always have HIV, you might be sick, and you don't want to tell me". Since then, I'm not working. I wanted to take her to court, but when I got there, she was already moved. I think it's the apartments, the flats

^d Steve Biko Academic Hospital is a tertiary-level public hospital in Tshwane

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

^f These are suburbs in Pretoria East, Tshwane.

that she stays in. Why must she say I don't have to work for her? Because I will infect her children with HIV?

I borrow money to go to the clinic. It's R20. What happens is they give me medication for two months. So I skip (a month). Every two months I go to the clinic. They give the big supply and then I come back (after two months). With their procedure, I don't see a doctor every time. I collect the pills and then they give us very far [sic] to check the CD4 count and all that.

I rely on a child grant and my daughter was thinking maybe the money is already paid in and she wanted the money. She wants money so she can go and buy the pants. That is why I was saying we are fighting. Next year they are cutting the child grant. I don't know what I can do for myself.

I get the grant on the first [of the month]. They [Department of Social Development] can do an advance in child grant. [With] Social Development, you can go and borrow money in advance. They give you R240, and then they deduct money in advance. After getting the child grant, I buy food and then it is automatically done after buying several basic things. After getting the money from Shoprite^g I just go inside the store and buy basic things. Immediately it's going to be finished. I'm left with R10 to come back. I take only a spoon [of food] sometimes to save. I sometimes go up to two weeks and then I just rely on fasting. Every now and then I cut food so that it can expand [meaning the food can last longer].

When I wake up, because I'm not going anywhere, I wake up a little bit later like 10:00 or 11:00 and I eat yesterday's pap. I eat it, it's like a brunch. Then also in the evening, for supper, I eat a little bit. Same pap with a little vegetable. What they told me is that I must eat before I drink my medication.

Now, because it is towards month-end, what happens, as time goes, the food is going to go off. I depend also on vegetables, I get plants, the grains. I get the plants that are growing in the bushes or next to the dumping site^h. It's the grass there. Most of the people they use it as spinach. It's an African traditional dish. Mfino, it's like a spinach when it is growing. The vegetables I have to go and pick it in the bushes. I walk around the bushes. So, I don't get it at the same place. I pick a bigger bunch so that I can go every now and then [not daily]. I cook it and then I save it. Today it's already finished.

Yes, I have gone hungry in the past because there wasn't enough food. I don't have anything. Even now you can open the cupboards, it's nothing [sic]. In the fridge there is nothing, it's just empty. Ever since I stopped working, I can stay a week without food. And now I'm drinking medications. People, when you ask them for food, they keep on getting irritated with me. They [the neighbours] are irritated – when they see me, they will start talking and say here she comes. And then I just ask for water. Where I come from, they just give me alcohol, they don't give me food. I will go hungry because there is no food in the house.

^g Shoprite is a budget-friendly supermarket chain in South Africa

^h This is an area where rubbish is left (in the community)

My daughter eats at the feeding schemeⁱ. She doesn't eat pap and mfino. She will just go out [leave the house] and come back and sleep. She's got boyfriends and she is also eating at school. She has one boyfriend, he is seventeen. I don't know. I don't want to know him.



Image above: At another visit, Anna showing her mfino that she had cooked

When I smoke [cigarettes] I feel much better. I take cigarettes from my boys. They buy them with their own small change. I ask them, they don't give me. But I ask them to give me. And then they will say, "No Mama, we can't give you cigarettes." Then I say, "It's only 50c, give me." I smoke the cheap ones. Only when I had something to eat, I smoke. If I didn't eat, I don't smoke. I smoke when I've eaten, when I'm going to bed, and in the morning. Otherwise, I don't smoke.

Alcohol, I'm not addicted. I'm just drinking. Yeah, I just drink it if it's there. If there is sugar or tea, I just drink. When I drink alcohol, I think it's making my condition worse, because every time after drinking alcohol my sickness becomes worse.

When I am upset, I do not want to talk to anyone, even my kids, because I get so upset and angry. I sometimes stay without food and my daughter will come back from school and ask whether I want food and then I will just bang the door and get angry because I don't want anything. No, I am suffering. I do not even have energy to work.

ⁱ This refers to the National School Nutrition Programme (NSNP), which is a national school feeding scheme where learners receive a meal at school.

I'm staying alone. Right now, I am very happy, I don't need a man, I don't need anything. When I sleep with a man, actually when I have a man, I don't need money, I just need love. I don't care about the money. I just care about what you give. The world is amazing when you're doing stuff for yourself and being independent. Once you have become dependent, you become unable to do things for yourself, it's difficult.



Image above: The home where Anna Mkhize and her children live

Reflexive Note: February 2018

I do not exactly know how to process what I am feeling. I know that I need to write it down, because this is an integral part of the research process – the self-reflection. Going through my own emotions and feelings of being in an interview setting, doing life history research and trying to understand other people's stories better. It is a co-construction. My reality. Their reality. Our reality. And where does that leave us?

I have just come from interviewing a woman in the community for my research. I have been desperately looking for participants for almost a year now. I'm at my wit's end. This morning, I was, anyway, in a foul mood. I was tired after the weekend and the last thing I felt like doing was going to try and find potential participants, only to again realise that they did not fulfil the inclusion criteria for my research, and thus putting me further into a desperate situation of not knowing what to do regarding my research. I arrived to meet the community health workers (CHWs) and find out who was going to take me to the homes. Two

CHWs came with us, and, as we were leaving, I asked them to tell me a little bit about the participants we were going to be seeing. They said they have HIV and are vulnerable. I said, what kind of disability do they have? They said, no, they do not have a disability. My heart sank again. I could not believe that another list we had gotten would again prove to be a fruitless exercise. We stopped the car and asked the CHW who had been coordinating the list to come and chat with us. She realised that the CHW with me had misunderstood what we had been looking for. They did however say that the one lady had a disability – she had been in a car accident. I thought, okay, let's go to the house and see.

Since they normally walk to the house, it was a bit difficult finding it because of not knowing which exact roads to take [by car]. By now I was concerned about visiting Mamelodi because of a previous experience we had of being robbed. They wanted us to drive down a dirt road but did not know whether we would be able to turn around or what the road would become like. I decided to take the chance, anyway, not wanting to leave my car somewhere where it could be stolen. It turned out that the dirt road moved into a tar road again and we found the house rather quickly.

The yard was a brick house with a zinc roof. There were pieces of tiles that had been cemented onto the entrance step leading into the one-roomed house. It was subdivided by a blanket and had a dining table in the middle with four chairs around it. There were two single seater couches, a fridge, a TV, a cupboard, a small table with a stove on top of it.

As we entered the property, two men left the house. They looked very ragged, thin, almost sinister... I hardly wanted to meet their eyes, so I looked away. We walked into the home and there was a woman shuffling around the room. She looked elderly and slightly frazzled at our visit. I was not sure whether she was someone else or whether this was the person we had come to see. My first thought was, please let there be someone else who has a disability. And then, when I realised it was her that we were going to interview, I thought "oh no, she does not have a disability – what am I going to do". The house smells of smoke. There are stompies^j on the table. Judith later says that the participant smelt strongly of alcohol.

But then she started crying and saying that her sons were just in here and she had a big argument with them. They are smoking nyaope and have sold some of her things to get money for this. She is angry with them. Whilst Judith comforts her, I feel paralysed. I just sit there and make sympathetic sounds, gestures, eye glances. The other two CHWs also just sit down. Judith says something in Sepedi, and I wait to see what will happen. My heart is just feeling so upset because all I can think about is that she does not fulfil my inclusion criteria and there is no one else on the list for today and what am I going to do. And then it comes to me, maybe she has depression. That would fit a disability and then she would qualify. I cannot lose this moment. I have to talk with her today. But can I even do this without having a formal diagnosis?

^j A South African colloquial word for cigarette butts

I start talking. I say to her, I can see that she is sad. Sometimes, however, it helps to be able to talk to someone about what one is going through. It might make her feel better. We do not want to intrude and if she does not want us to stay, then we will leave. But we are here for her and we care for her.

Judith translates for me. She seems to relax slightly. I ask her, does she want coffee? I had seen a kettle in the house. Does she have water? I have some coffee in the car. She looks hopeful. I ask her if she has milk and sugar. She says no. I ask whether there is a shop somewhere close by, then I will go and buy some milk and sugar, maybe someone can come with me. The CHW says she will go. I take out thirty rand and give it to her.

I explain to her that before we talk, however, I need to go through a research process to ensure that she stays protected. I think to myself, "Stupid research process. Stupid ethics". How can I, in this situation, not just have a conversation with her and write down what I remember afterwards. Why do I have to get permission from her to have a conversation first? This will break the moment. This will make everything formal, instead of intimate. I look at my form and how it is written.

"It is a pleasure to meet you and I am hoping that after I have read through this document, and if you agree to participate to the study, that we will be able to establish a good relationship. I am looking forward to getting to know you better."

This is not going to work. I take each sentence and slightly rephrase it to make it more conversational. I had already tried to do this when I prepared for ethics committee, however, now what I had written appears stiff, unnatural, forced. As I try my best to get the message across, she nods in agreement, and Judith translates again, with five sentences instead of one, even though she has the previously translated document in her hand. I do not know what she is saying, but I know she is trying to make it as clear as possible what we are doing and why we are doing it. I talk about her confidentiality. That she does not need to continue if she does not want to. How am I meant to read that she can contact Ms. XXX on xxx if she has any questions about the research. I later find out she does not have money for airtime. She does not have email. She probably does not even know how a computer works. Yes, she has a cellphone. But essentially, it is purposeless.

I say that this research is about women who have HIV and a disability and have problems with food, who go hungry. I know that she is thinking her disability is that she had a car accident. That she struggles to walk. (She does not really on my observation) I know she does not think about her depression. Or "stress" as people in the community call it. But maybe I can discern whether she appears to have a diagnosable depression or anxiety.

I ask her whether she wants to disclose her identity. She says no. I ask her what name she would choose to represent herself. She does not mind. I ask her, what about Anna. She laughs, "yes, that is perfect". I

do not even know why I chose that name. What does it mean again? I think it means 'woman' or 'lady'. I later check and it is 'lady'. But some translations say 'virgin'.

And so, she gives us her permission and the necessary signature, and we switch on the voice recorder.

The CHW has come back with the sugar and Cremora. She says the Cremorak was cheaper than the milk. I go to the car to fetch the coffee. I look in the boot and see my husband's old clothes that he is not wearing anymore, which I wanted to give to our church (they support the homeless in the area). Three suits, shirts, shorts, caps, belts, etc. Should I give some to Anna to sell? Or for her sons? Maybe they can try and find work. Or maybe they will use that to steal? I've heard of people dressed in suits going into estates pretending to be homeowners there. It all feels like a far-fetched story.

The story continues about where she was born, her four children, her accident, her HIV, her incredible "stress". She talks about her lack of food, what she eats, when she goes hungry, her daughter who wants to have the grant money to buy herself some pants.

She tells us that her eldest son lives at the rubbish dump. Before I can help myself, I blurt out, that maybe he knows the person who stole my phone^l. I feel so guilty. She misunderstands me and says that she will show us a photo of him the next time we come to the house [in case it was him]. Judith and I both say, no, she must not worry. We do not think it was him; we do not want to know.

The interview draws to a close and I think I cannot just leave her like this. I try and explain to her why I will continue to see her, and why depression can be seen as a disability. That there is help out there, and she needs to see whether she can go and get some medication. I do not even know whether I am allowed to do this as researcher, but I cannot not do anything.

The CHW takes out a referral form and wants to fill it in. But then everything happens at the same time. Judith suddenly takes out money and asks the CHW to buy some food for Anna. I feel obligated to also contribute, and think I know that I said that I would somehow contribute back to my participants in my ethics application, so I am sure that this is fine. Judith seems anxious to leave. The CHW leaves to buy food and we talk about going to see the doctor. We need to go and the other CHW says she is going to come with us. She will fill out the form tomorrow. I tell Anna that I will leave the coffee, sugar and Cremora here. When we come on Thursday, we will have some more. She must make sure that the sons do not steal and sell the coffee. Its expensive coffee. Yes, that coffee costs more than a quarter of the money that she has for a whole month.

^k A type of white powder which is added to coffee or tea instead of milk. It is commonly used in the community where electricity shortages, lack of a refrigerator or poverty may prevent a person from having fresh milk.

^l At the beginning of 2018, whilst Judith and I were driving on our way to a clinic, we were following the GPS which took us on the road going past the dump site. On the way, we were stopped by some people, who then proceeded to steal my cellphone.

As we drive off, the CHWs say that Anna is always crying when they go and visit her. I cannot understand what the CHWs have done thus far. Were the symptoms not clear about her potential depression? Have they been trained in assessment and treatment? That perhaps Anna will be able to feel better? Do they just go and visit her and chat? I will talk with them later to find out more about Anna's history. But for now, Judith and I agree that she should go and see a doctor as soon as she can.

Judith tells me why she suddenly wanted to leave so urgently. She saw that there were people who were starting to come closer, and it looked as if there was more interest in our visit than Judith felt comfortable with. She also thinks we need to double check the information which Anna gave us today, just to make sure that it is the same story again. Sometimes people have outsiders come in and they make things appear worse than what they are, so that they can somehow get help. I wonder about that potatoes and oil which she had asked for when we said we would buy her some food. I wanted the CHW to buy vegetables, but then Anna suddenly said please potatoes so that she can make chips. This is not the most nutritious food available, though potatoes are a good filler.

I ask Judith to try and get the translations for different words related to depression. Sadness, stress, anxiety/anxious, anger, frustration, livid, depressed, are there even Sepedi words for this? Or how will she explain the difference between them? Is it something that can just be described through a facial expression?

I think about all the research that has been conducted over the years with vulnerable people. No wonder there is such negativity surrounding it if it does not actually benefit the people that are participating in it. Yes, our information document is very clear: "The study will benefit us, as public health practitioners, to better understand food security of women living with HIV and disability in vulnerable contexts. This in turn should benefit the women who will be in a similar situation such as you." But what will it DO for you? Nothing. Sorry. Nada. How do we do research? We do nationwide statistics to come up with a percentage of how many people are food insecure, based on some kind of measure. We write about how many people go hungry, and then debate whether there are 8 million, 9 million or 10 million of them. We talk about policies that need to be designed, or programmes that need to be implemented. And, yes, there are programmes. Why has it been so hard to find these participants? Perhaps it indicates that there are not so many food insecure people as I thought. But what about Anna? What about her life?

I need to share this information. I need to debrief somehow. But I cannot phone my supervisor now, and what does it say in that informed consent form? I will not share with anyone except my supervisors and people in the academic community and policy makers. What rubbish is that? Is this not supposed to be a story that needs to be shared? My husband always tells me that there are two relationships where you cannot force someone to tell you what the other person has said. This is in marriage, and the other one is with your lawyer. They are absolute. My husband is a lawyer, so can I share with him what I experienced today?

I think about going back to see Anna on Thursday. Will her sons have forced her to tell her when we are coming back so that they can steal from us? My digital recorder does not work, so I need my cell phone to do the voice recordings. What if these are stolen again and I have to start again with everything?

I think I will have to go back to the drawing board and see how research processes have been challenged in the past. There must be a new way of intervening. Yes, I know about action-based research and participatory methods. But I cannot change my methodology now. I will explore further by what is included in my wording in the ethics application form: "Since the women living with HIV and disability are from vulnerable contexts, it is necessary to ensure some kind of remuneration for their participation in the study. This will be done through a conversation with them to ask what the researcher could do for them. This will hopefully improve and benefit their situation." I remember having the paragraph in my original consent form: "In terms of remuneration, if you have agreed to participate in the study, please can we have a conversation about how I could in some way return a favour to you for participating in the study. I am hoping that this relationship will be mutually beneficial." Judith had said to me that I should not include this when talking with the participants, since it will create an unrealistic expectation of what can be expected through our involvement. She said this is unwise to do, since it can jeopardise the entire research process and the authenticity of the information learnt.

I know that there will be people out there who have experienced similar situations as myself. As I go about this process, I will read about it and find ways of going around it. In the meantime, the story needs to be told and I need to learn what I can from the people I am interviewing.

Discussion: March 2018

I've got a difficulty in winding down [sic], especially nowadays because my son, who stays in the dumping area, he has been stabbed on [sic] his face. I was asking where he is. He is still at the dumping area. When I tell him to come home, he doesn't want to.

I rest when I'm sleeping. I'm always thinking and my mind only rests when I'm sleeping. I'm trying to think of positive feelings. The only time when I am happy is when I see my kids are here – all of them. Sometimes I will want to clean, then I don't have energy, I just sit. I can say every time, because when I'm doing something, I'm just forcing myself to do it. I sometimes want to do something, then I will say, why am I going, how am I going to do this because I am unable to do it. I would ask myself, "Why am I living this life where other people are living like this? What did I do in this world?" I will just say, "It's, well, it's how God gave me this life". I feel life is not nice for me. I see myself as nothing. I struggle to relax so much, especially because I always speak in my heart, always. I only relax when there is people around, but when I'm alone it happens now and then. I feel sad. It happens always. Especially when I think "What am I going to eat?", and this and that. I love happiness, but where will I get happiness when I'm suffering?

There is no family in Springs now. My mum is alive, living in KwaNdebele^m I don't know my dad. I have two sisters and three brothers that are still alive. It's my brother first. And then it's me. The first two of us, we belong to the same father who we don't know. Then the four, they've got their own father. He's alive but doesn't stay with my mother anymore. He stays with another woman. I don't communicate with him, especially because he's not my father. He was a stepfather. When there is always a quarrel, he will just mention that these two are not mine.

So, the four, it's sister, brother, sister and brother. It's just like boy, girl, boy, girl. Mummy was a lucky one. Some, they are in KwaNdebele. My younger sister is working, she completed school and she's working well. She also built a house for my mother. Other one [her sibling] is in Garsfonteinⁿ. They stay very far. I'm the only one here. When you go to them you have to pay, sleep over and come back the following day. I do have their numbers. They call me and I call them. But physical talking, we don't.

I went home to the party in Moloto^o. My grandmother, she had her ninetieth birthday. I went with my little sister. She's the last daughter in my family She is working at Spar^p. She completed school and she's working well. She also built a house for my mother. And she organised a party for granny because my mother is the only daughter. Granny has only our mother [sic]. So she was just giving thanks to our granny for raising our mother, so that a mother who raised them well [sic]. So, she was giving back to them. My mother is 71. Last time, we went to see the family we were passing because we were attending a funeral of my grandmother's brother, my mum's uncle. It was only me and my little sister. She's the one who paid my transport. I used to help her when I was working, even her schooling and all that. That's why we help each other sometimes.

I tried to find out a bit more about how she cooks and motioned to the stove – asking whether it is gas powered. Anna said that it uses electricity. I asked her, whether she must pay for electricity.

Here [in the area] we've got the normal legal connection. So, what we did is, we disconnected the normal one and then connected with the illegal one.

Reflexive Note: March 2018

It is worrying to hear how sick Anna is. It's terrible to see how she has been caught up in this life, and how it has influenced her for so many years. Anna has had a lot of things happen to her that have been unjust and not of her own doing. I refer to literature and ask questions that would possibly seem an option for Anna, based on her situation – for example asking her whether she or her daughter have been involved

^m This was a Bantustan in South Africa during the Apartheid period, an independent homeland for the Ndebele people. It is close to Gauteng.

ⁿ A suburb in Pretoria East

^o This is a rural village in Mpumalanga

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

in transactional sex to survive. Or whether she has ever been begging to try and get money. Anna says she does not and has not. I am concerned about the normality of things like illegal electricity connections. But where should she obtain money from to pay for the electricity? At least this way she can keep warm, cook her food, and keep food in the fridge to prevent it from going off. It enables her to, at least, have things last a little longer than they would have without electricity.

And I see how debilitating her depression is, limiting her motivation and energy to work. It is frustrating that the CHWs appear to not have been able to assist with taking Anna to the psychiatrist. In the same breath I realise that there are no funds to be able to pay for transport to visit the clinic. What would be options to explore here, to enable her to go?

When we administered the DASS21⁹ to gain additional information for the referral to the psychiatrist, Anna scored 44 for depression (extremely severe), 22 for anxiety (extremely severe) and 24 for stress (moderate). She is very sick. Anna could not have had an easy childhood. It sounds as if her stepfather did treat them differently from his other children. We will have to try and get her to the psychiatrist so that she can get help.

Reflexive Note: April 2018

Today we [Judith and I] took Anna to the psychiatrist. We fetched her from home and had made an appointment with the doctor. I wonder if it is because we come with some authority that they make a plan to see us, or to squeeze us into the line. I feel guilty for all the other people sitting outside. It seems that we are getting special treatment. He [the psychiatrist] looks at my referral and proceeds to do a detailed interview. He is taking his time to try and understand the situation. It sounds like Anna has been contemplating suicide. One really realises how depressed she has been for a long time. He does ask for collateral [information] from us. I do feel useful and hope that things will now change. He spends about an hour with us all. Meanwhile, all the other patients are sitting outside. A very long list of about 30. How is he going to see them all before he leaves at 12:00 or in the early afternoon? How can our healthcare system cope with the demands that it faces?

Anna is diagnosed with major depression, and we proceed to get her medication. Here, however, she has to sit in line. Anna feels elated on the way home. It seems as if she also is experiencing hope. I really do pray that the medication will make a difference. I try and tell her that it might take some time, but she must not give up. And that she must be very committed to taking the medication every day.

⁹ The Depression, Anxiety and Stress Scale – 21 Items (DASS-21) is designed to measure the emotional states of depression, anxiety and stress, through three self-reported scales.

Discussion: May 2018

I'm so happy because that pillies [medicine], yoh. So lovely [sic]. The medication that I'm taking, I am so happy with it. I used to be short-tempered, and I would just be quiet. People will just make me angry, and I'll get bottled up inside. But, since taking the medication, I am feeling very happy. I don't get upset. I don't get anything. It's helping a lot. My heart was always like... always worried. I'll be always worried [sic]. Even when I don't have food, I don't stress so much. Even if I don't have food, I sometimes feel like, ag, its fine. As long as I have you guys. You like, talk to us, I don't have, ja, problems. I'm energetic and I'm able to work now. Before I wouldn't move around myself. I would just clean just in front here, but I wouldn't move around. Because of my energy and this enthuse [enthusiasm], I am able to move around things and do it.



Image above: Anna with the psychiatric medication she has received

I think there is [sic] a lot of people suffering with the stress. If people know there is medication that you can take for the stress...Even myself, I didn't know that I can take medication. I didn't know that there is medication for stress. Right now, I'm very happy, always. Even someone can say something hurting. I'm able to handle it and I'm very calm. It doesn't even bother me, and I just focus. You guys helped a lot and I'm happy.

Okay, with this medication, it also caused me to eat too much. Because I now eat very much. I've got mealie meal^r and then I'll buy cabbage half-cut. If you buy half of it, they charge R5. Potatoes is R5, I combine with carrots and then I eat. Whether there is oil or not, I will just cook and eat. Ja, I wouldn't eat before. I'd eat little bit. I'm going to go when the sun is down and to go there to get mfino, because it's still hot. With this medication - amazing. It's just this foot and my back. But apart from that, I'm energetic. I can do anything.

It's just that now I picked up that my waist [referring to her hip] and my right foot, the one that was in pain, aching, it's getting worse. It's aching. Especially when I'm doing the house chores. My waist, it's painful since then. It happened before, I used to have it before. I started taking medication when I started having stresses.

I have a bit of a stress, because now my daughter has reached an age where her child grant is going to be stopped. She's 17. She is turning 18 on 29 July. I'm worried. There is someone that I know in my family at home that told me that her daughter already, they've stopped the money. So with me, they say because she is still in school, I must go to the Social Development and tell them she's still in school, they could probably extend. There was a lady that once told me that if the child is still in school, they can extend. If you are not married, you don't have a partner who is working or someone who can help financially, [they] can extend it up until the child finishes grade 12.

I spoke to them [my sons] and they [are] understanding. Nowadays I'm very calm. I don't fight so much with them. They also like you guys. They call you our, my doctors. Because they see that you've changed my life. They even told me that I'm not screaming at them. I'm calm and I'm also gaining weight, I'm recovering. They love what they see in me. You guys helped me a lot.

And I told them that I spoke to my doctors; and they also said they want help, they want to leave nyaope. They told me about a place in this area where they have to buy the bottle of that medication [methadone] for R500. They are three. They want to stop smoking, they are willing. But the problem I told them is I don't have R1500 for three of them. My boys were telling me that it's obvious. Even if you can go there and ask them to help us with nyaope, [if] you don't have money, they won't help us. They only help when you have money. It's their policy because that bottle, it's worth that amount at the chemist. The two that stays here went there to enquire and then they were told that. So they just told them the information. They [the sons] told them that their mother is not working and all that. They [the staff at COSUP]^s said they cannot help them, if your mother is not working, there is no way because the bottles has to be paid for. And then they haven't told them in depth that if you don't have money, you can go and one, two,

^r South African colloquial name for maize meal

^s Although this is not the regular policy at the COSUP sites; at the time when the sons went to enquire, there was a shortage of funds in the programme, and new clients were not able to receive funded methadone

three [where to go and what to do instead]. Even if they can give them one bottle. They share. It's better than nothing.

We tried to explore with Anna the possibility of finding employment again as a domestic worker. This could potentially be difficult, since she would need references for this. We ask her about any references she might have.

My concern is that all the people that I worked for, I don't have contact with them. And the ones that I worked [for] at the golf club, they left, there is new management. I'm not sure whether I can get [a reference letter] there.

Since this may be difficult, we tried to explore other ways of earning money.

I can sell stuff. If I had money, I would buy a cow, no not cow feet, chicken feet and intestines. They like them the most here. And then we would stand on the street and sell them. It's just the chicken, not cooked. They prepare them at home. I get them from Watloo^t. There are people that sell them. I can also buy them. Because you buy three chicken feet for two rand. So, when I've got five rand I also go there and buy. Maybe if I can speak with my younger sister, because I don't know anyone who can help me. Maybe she can.... [give a loan to start up the business, to be paid back once she is earning]. You buy in bulk, then you sell them individually. Maybe I can start small, small.

We have seen the outside area, and there are four shacks around the back of the house. We ask her about these.

I used to have people renting at the back. But now I don't have tenants anymore. The boys are sleeping in them. They normally sleep together, but if they've been fighting, they sleep separate. Sometimes when after smoking, they will fight each other, then the other one will move from the one shack and sleep in the other one. They were fixing their own shack. It was leaking on the roof. So, their clothes were damaged. The thing is there are holes. So, they had to start from the beginning to fix it. They need zinc, it needs silicon to cover, to paste that small [hole]. So, they had to fix it. And then one is the storage - that one is not working. That one is leaking. There is no flooring - it's just the ground. So, it needs some concrete and the cupboard [sic].

And then it's a family member [in the fourth shack]. He's related to my granny's side, my granny's sister. He is staying in there. There was a time he was in an accident. He is receiving a disability grant. He is unable to work. It's just sometimes he has friends visiting. When he came here, we were just, because he's [a] family member, we didn't want to make him pay. Because the reason why he came this side is for him to fix the documents for the disability grant and all that. That was the initial plan, he was coming here just to fix the documents and all that, so we never discussed payment. The problem is I'm unable to talk

^t Watloo is an area and a shop. The shop sells general groceries.

to him about paying. I'm afraid to create tension and chaos in the family. When we get that side at home, they will think I am making him [pay me].



Image above: The two shacks at the back in which Anna's sons are living

Reflexive Note: May 2018

Days like today make everything worthwhile. The transformation in Anna is incredible. She is shining, looking happy, engaging, making plans, thinking about the future, having a better relationship with her sons, wanting to make positive changes, gaining weight, eating better, wanting to work, cleaning her house... I don't even know where to stop. We had the most incredible time talking with her and brainstorming about 'where to from now'. What kinds of things could be done to help her earn money so that she can have a better standard of living. Or at least, be able to get food and pay for transport. And her sons are excited about her transformation, so it's motivating them to stop smoking nyaope and turn their lives around! To say that I am thrilled is an understatement.

I am starting to see more and more how complicated everything is now. Immediately when we try and think of solutions, another whole set of barriers arises. It would be great for her to return to working as a domestic worker. But where will she get a reference. And what about her knee that is so sore. She has resources on her property, so she could rent some of the shacks out. But her sons fight because of the nyaope. So she needs two for them. And then the other one is leaking. Find a way to fix that, and then there is no concrete floor or cupboard.

She does have someone who stays in one of the shacks – can't he pay? No, there are cultural and family reasons that would make it very difficult to ask him to contribute. She does not want to influence the relationships with her extended family.

She could sell chicken feet, but where is she going to get the money from to buy the initial stock.

Her sons want to stop smoking; however, they need money to be able to get the medication. She doesn't have enough money for them. The nurses haven't been giving them all the information. She can't go to the COSUP site because it would cost too much for transport. They [her sons] go there [to the COSUP site], and they [the staff] say they can't help.

She needs to see the psychologist. But if she goes, the psychologist will only make an appointment. And then she won't have money to go back again, or she'll have to wait another month when she gets her next medication again to see her. And the social worker she needs to see is in a different area to where the clinic closest to her is. That means she has to go to another place again, and I'm not sure whether she can walk there, or whether it will be a good idea for her to walk there with her inflamed knee.

It's all so very complicated.

But we have a plan forward. We are going to try and work with COSUP to help the sons. And then we will try and get an appointment with the psychologist. Find out about domestic work. And in the meantime, hopefully, Anna will talk to her sister about funding her and go to the Social Development office to sort her daughter's grant out.

I am just a bit worried. Today Anna said, "Even if I don't have food, I sometimes feel like, ag, its fine. As long as I have you guys. You, like, talk to us, I don't have, ja, problems." It seems that they have all started seeing us as miracle workers. We will not be able to continue with her having such high expectations. We are unable to provide handouts. It seems that the household is motivated. And Anna does not seem to be expecting food from us. We did indicate in our informed consent that we would not be providing any payment or food for participating in the research. The sons also have hope in us. She says, "Ja, they also like you guys. They call you our, my doctors. Because they see that you've changed my life."

How many other people are also in Anna's situation? Suffering unnecessarily, because they do not know that there is help available, that mental illness exists, that medication can make a difference... it seems so sad and unfair. The suffering is such an injustice. I say to Anna, "You know, sometimes, it's just about information. You know, you suffered with this so long, and there was always help out there. And now that you can tap into that help, maybe you can tell other people who are suffering like you – look – there is help out there. You must go see the psychiatrist if they can give you pills."

Discussion: May 2018

We are excited to go and visit Anna again. We start off by asking her, how she has been.

I'm alright. Not so good because of my [points to back]. I have got a pain under my breast and also my left arm when I wake up every day and even in the evening.

I used to wake up a lot in the night. But now [after receiving the medication], I'm gone until I wake up. My arm becomes numb and then I've got the back pain and the shoulder pain. Sometimes, at night, I wake up because of the same situation. When the car hit me in the accident, it hit this side and then I fell on this arm. Maybe I'm getting older now, maybe the internal injuries are just coming out.

We advise her, that we have been able to make an appointment for her with the psychologist at the clinic. Perhaps when she goes for this appointment, she can tell the sister at the psychiatrist's office, that she is experiencing these pains in her body – perhaps they can refer her to the doctor. We ask her whether she has made progress regarding the loan from her sister for the chicken feet business.

I haven't spoken to my sister. My sister went home, so I haven't seen her. I am worried because the grant might be cut very soon. We are going to struggle. School uniform and all that. My sons are anxious to know how they can get help. They must leave nyaope. But no, they have not stolen anything else to sell. I haven't seen my [oldest] son. It's better for him to stay there [at the rubbish dump], because when he is here, he is stressing about money for smoking and all that. So, he must rather go that side and sort himself out. There is a lot of issues here in the community. They feel they're alone, suffering. Too many people suffer. Yoh.

Judith tries to motivate Anna. She says Anna has to try and make a plan; that God blesses ideas, and these can become productive. She continues, that "if it's a push, and you want to do it, God is going to bless it, something will come up." I can see how she is trying to assist Anna to look beyond the social grant, towards earning an income for herself. Anna is very religious, and I see how Judith takes on the role of a community worker, a counsellor, a source of support, a friend. What she says is a message for all of us. What are our passions? What are we doing to try and achieve them? Anna nods in agreement and proceeds.

I thought you wouldn't come. I am excited that you are here. Thanks to God that you are here.

Discussion: May 2018

We are on such an emotional rollercoaster. The glory of last week and Anna's newfound joy for life and enthusiasm seems to have dwindled again. She was 'alright', and not 'so happy' today as she had been last week. I don't really understand what is going on. She has all these pains, and it could be so many different things – maybe from sleeping badly at night or doing too much now that her body wasn't used to before. Or recurrent pain from her injury so long ago. Maybe because it's cold? I find it quite frustrating

when I am not able to assess her like a doctor and actually know what is going on. I also don't understand the health care system. Why is it so complicated to get anything done?

I still think, though, that she is doing much better – she looks better and smiles and is motivated. She does have significant issues though and when her childcare grant runs out, I don't know what she is going to do. She already has no money and is living off the bare minimum. I wonder how her sons get food. Or money to buy nyaope. These social networks in the community are complicated. And allegiance to family structures even more so.

We weren't able to stay long, and I explain to her about the striking that is going on and that we need to go back to another participant who had severe problems. Anna is very compassionate towards other people. She is able to put her own troubles out of the way and think about the misfortunate that others experience.

Judith was trying to motivate Anna. I'm not sure whether we allowed to do this [as researchers], but I don't stop her. Anna is very religious, and I think that it is probably what she needs to hear right now. I'll have to find out about this at a later stage. It is part of intervention, and Judith understands the community – here she becomes a community worker, a counsellor, a support, a friend. What she says is also a message to her, and to me. What are our passions? What are we doing to try and achieve them?

Judith is through-and-through a community worker. That is her passion. She is dedicating her entire life to it. I just hope that I can enable her to be paid for what she so deeply loves – really making a difference in the community.

Discussion: May 2018

I'm still doing laundry for my daughter who is in school and my nyaope boys.

I went to the doctor. I saw the doctor who treats my foot. She told me that I've got arthritis and it's still starting, and my knee is already severe... The lady she told me that, yes, it's something that doesn't go away. She said as time goes, if I don't take care of my knee, it will need some extra support inside. So, all I have to do is manage it. She said to me I must come [on] Tuesday again to see another doctor for the back. The arm is still paining [sic]. She gave me medication for arthritis. I keep the medication under the couch, because now I'm always sitting on the couch, so when I drink it, it's always around nearby.

I didn't see the psychologist. I forget it [sic]. I'm thinking too much. I forget. I didn't see the physiotherapist either, and the social worker was not there [at the clinic]. I didn't go to [the] Social Development Department for the grant, nothing. This state [that I am in], I'm still thinking for my children.

I just received a letter from the Social Development saying that I must... they remind me that on the 29th of July it is my daughter's birthday [and] the grant will be stopped, because now she is not age-appropriate [sic] to receive the grant.

My sister is the one who gave me money to go and visit my mum and also bought the mfino for me, the vegetable for me. She is working at Spar. She promised me that by month-end she will see what she can do. We get along well with my younger sister, so she brought the money. I'm going to go and visit my mum.

She said that selling [chicken feet] is a good idea, especially because she's got kids [and] she cannot take care of us and her kids. The thing is, at her work they sometimes want people that pack the shelves, because she's working at Spar. But the problem is with my foot, I cannot stand for long. She will help me; I know she is very kind.

Reflexive Note: May 2018

I like going to see Anna. It makes me happy. But, at the same time, I feel so frustrated. Because change seems to be so slow. There is a list of tasks that she needs to do to move on, and there are things we need to find out. And then, when we come to ask her whether she has done them or gone to the appointments that we made for her, we find that she hasn't.

It seems the priority in Anna's life is her boys who want to get off nyaope. And that is what she is waiting for us to help solve. The other thing would be the social grant since that is running out shortly. And yes, she has been to see the social worker, but unfortunately the social worker wasn't there. She also did talk to her sister about borrowing money, but that won't be happening right away.

But she didn't see the psychologist and she didn't see the physiotherapist. And that seems to be what is clouding my thoughts, because of the appointments we had set up for her. And there is no reason or excuse. She forgot.

You also forget, Helga! It rings in my ears... but the things I forget aren't normally so immediate regarding health and money. Or are they not? She is still getting better; you can't overload her.

In any case, we make a list again, and explain who she needs to go and see and why. The important thing is obviously sorting out the grant. Hopefully, it will be able to be extended. Her daughter is only in grade 10 – she needs money for another two years!

So, we leave again, feeling a little more despondent than we did the last time. But Anna is still hopeful, so I believe that things can change.



Image above: Anna looking out at her neighbours



Image above: The new section of the house that Anna commissioned to be built on



Images above: Various images of the inside of the new section

Reflexive Note: October 2019

I had been in Mamelodi for a research project at one of the schools. When I arrived there, no other staff members were present as there seemed to have been some miscommunication. Instead of driving straight back to campus, I decided to drive by Anna and see how she was doing. As I arrived at the house, I was met with concerned faces. Anna indicated that something was very wrong with Andries and they did not know what it was. They described that he was experiencing acute pain in his stomach and heart, increased heart rate and shortness of breath. And he had difficulties sleeping. They were all very worried. His sister was angry. Following a couple of clarifying questions, I understood that he had experienced oedema in both his feet. This then started progressing up through his limbs and moving onto his torso, arms and head. After about a week, he went to see the doctor at the community health centre, who referred him to Mamelodi Regional Hospital. He was then admitted to the hospital the next day, where he was investigated by a doctor. He stayed overnight and received injections [according to him, for his coughing]. He said that the [heroin] withdrawal cravings were “very bad”, so he insisted on being discharged and signed a Refusal of Hospital Treatment (RHT) form. Upon discharge, he was given a variety of medication. I realised that there was something wrong with his heart because the medication was for heart failure. I initially started writing a referral letter to Mamelodi Regional Hospital, in which I tried to explain that they should admit Andries to hospital again, and that he required methadone because of his substance use disorder. But as I was typing the letter, I realised that this potentially would be a very futile effort, and a more pro-active approach was required.

I had met a professor who was integrally involved at Steve Biko Academic Hospital^u a few months before. So, I called him and explained the situation. He indicated that I should take him to casualty at Steve Biko [Academic Hospital] and ask to speak to one of the registrars, indicating that they should do an urgent assessment. I was concerned about what this would mean for me – taking Andries to the hospital in my car, and what would happen to Andries since I had to go to work to attend a meeting. I wanted Anna to come with, however, she was hesitant, and something appeared to be wrong. After a bit more probing, she explained that she could not accompany me to the hospital, because if she left her home, then her other two sons would be inclined to steal from her whilst she was gone, in order to purchase substances. I understood, and said we had to take his sister, Anna’s daughter. However, she had gone to visit a friend so we had to find her. First things first, Andries wanted to wash himself since he hadn’t bathed in a couple of days. I asked them whether they had any drugs with them, so that he could take the nyaope with him to the hospital until he was able to receive medication [methadone]. They did not, and so I went outside with Anna so that she could purchase some from the people who were selling on the opposite side of the street. They did not want to sell to Anna with me watching, so I had to return inside the house whilst she

^u This hospital is an academic hospital, providing specialised services to the greater City of Tshwane

got the nyaope. Then, Anna and I drove around the immediate community in search of her daughter. We eventually found her and returned home to get Andries.

So, Andries, his sister, and I, proceeded to drive to Steve Biko hospital. Along the way, I asked him several questions about his life, as well as that of his brothers.

Andries had left school when he was in grade 9. He had started smoking dagga^v because of what he termed bad friends. His oldest brother had also left school in 2003 when he was in grade 9, and his middle brother had left in grade 10. They were in a school in Rayton^w at the time. It seems that his mother had placed them there and taken them out of another school as result of the peer pressure through which they had started smoking.

Where they live is in an area that has more permanent housing. The houses have electricity that is received from the government pre-paid boxes, however, most of the connections are illegal. As the informal housing area^x next to these houses also started using illegal electricity connections, the system came under pressure. By four o'clock in the evening, they would start having electricity challenges. So the mothers in the area got together and indicated, "no, we can't afford to not have lights because of other people. The squatter camp took the electricity from the permanent houses." So, they decided to call a man called Baetapele, who was a leader in the area. He owned two taverns that were very successful and enabled him to become very wealthy. Andries noted about the taverns, "The people love them too much". According to Andries, his mother was not involved. But the other mothers were very upset. "Let's call Baetapele and Baetapele should take the wires out. So Baetapele should take the wires out because it was too many people getting the illegal electricity. So, let's get Baetapele to stop some people."

Baetapele got some boys in the area to help him, and they took away the illegal connection from the neighbouring township. There were approximately five vans full of wires. He hired the boys to help him remove the wires and paid them each approximately R500. Amongst the boys receiving this money were Andries' two brothers.

Not knowing what to do with this sudden increase in funds, they went to a shebeen^y and started drinking alcohol. As Andries said, "So the cleverest one said, 'No, this money is too much. Let's take this money to buy'. The other said, 'I want to buy Nyaope'. He goes and buys it. When he bought it, those who were drinking beer, when they watched that guy smoking, smoking, they saw him sleeping, they say, 'This thing is good – let us go and buy it, all of us.' It's where they started the problems. And that is how everyone in the community started, because of the money that they got."

^v cannabis

^w A town in the City of Tshwane Metropolitan Municipality

^x Also called a squatter camp in colloquial South African language

^y In South Africa this is an informal licensed drinking place in a township (also called a tavern)

At that time, Andries was still a small boy [he thinks it was around 2005]. His brothers were in secondary school. His older brother had never struggled with his schooling, he was passing. Even though Andries indicates he was struggling because he did not have shoes, he was passing. But he left school and all the boys who had been going to the same school started smoking [nyaope]. Andries references back to these boys, "The other ones, they are dead. The one who made them smoke, all of them. He did, like, house breaking. [The] community killed him. He broke in and took two, three cell phones, and one camera. And broke some windows."

When Andries observed his brothers smoking at home, he saw that when they smoked, they weren't hungry, and that when they smoked, they slept. So, he asked whether he could try it, and they shared one with him. And, as Andries said, "He gave me one and then I got addicted. When I first smoked it, I had a ... ay, this thing is too much nice [sic]. From now on I will start to smoke. Since that day, 2009. I had [a need for] money too much."

Andries shared more about the electricity connections. He said that the [ward] counselor stays in the squatter camp and gave the people who live there their own lines. Andries says they are supposed to pay for electricity, but they don't. There are pre-paid meter boxes, but no-one pays. He shared how he himself learnt to work with the electricity lines and helped people 'to bridge' [meaning to pass the metered connection and have an illegal connection]. He also hurt himself doing this, "at the house of some Madala". He says, "Yes, I wanted to die that day. It was raining. They wanted some electricity, and I wanted money to smoke. I got a shock too much [sic]. Maybe my God has come and help me [sic], because there, I thought I was dead. And the one, I was fixing those lights for him, he wanted me and he didn't get me. He heard someone say, 'He is there by that pub'. I was at the party. He wanted me to come and help him, so that I can see and fix the lights. When I go to those lights, those lights wanted to kill me. I had been drinking and smoking that day. That day, they [the people at the house] called my mother and my sister. They were crazy [his mother and sister were angry]. That day, they even told the sister [the woman in the house]. They [the people in the house] told my mother who told me to fix that light. My mother said, "When I die, they must make a plan that they die too." They are [were] going to kill the other person. It was 2012. I did go to the hospital. There my body was strong enough; it was not going to die."

Andries says he doesn't have any friends. His mother is his friend. He also looks up to his mother and admires her.

His sister seems irritated with him. She is quiet, mostly. However, when she corrects him because I don't understand what he is saying, one can see that she has limited patience. It sounds like she is very frustrated that he discharged himself from the hospital and placed himself in danger. I don't know if she

² An elder in the community (grandfather)

is frustrated that I insisted that she come with me to the hospital; perhaps she had other plans this afternoon.

Andries shares a bit more about his family. His oldest brother, David, seems to be doing better now. He no longer wanted to live at the rubbish dump because they beat him up there. They are concerned about his [David's] safety. Apparently, he lived at the rubbish dump in Mamelodi for three years. He had also previously been in jail.

Andries says that they beat David up to make an example of him^{aa}, and he went to the hospital, but then he went back to the rubbish dump. He had recently been beaten up again by those living by the rubbish dump. Andries indicates that since David has been living back at home, he does not want to leave the yard at their house. Andries even asked him, "My brother, why don't you want to go and play outside? Why are you worried, what have you done? Just tell us so that we can know". David says, "I do not have any problem [sic], I just want to stay home". So, Andries replied, "Ja, you are lying. It is something you have done, but you won't tell us". According to Andries, last week David stole the rooftop of their mother's house, to "sell to other people". He then bought nyaope only for himself [not for all three of them].

I asked Andries how he gets money and he said that he 'zoolas', which means getting odd jobs or piece jobs. But besides zoola, he doesn't really do anything. In order to get money to buy nyaope, he does some recycling. Sometimes he steals from his mother. For example, the last time he stole an electric plug. He says, this is a 'guarantee', meaning it's an item guaranteed to bring money if sold. He gave it to his brother to sell, and his brother told him he got R60 from it. He then said to his brother, "You are lying. That plug was worth like R300 when we were buying it alone. How can they give you R60?". It was still new, as his mother had only recently brought it when she got it with the washing machine^{bb}. He thought it was okay to sell it, because his mother has another one and they were not using this plug.

He talks about the people that are living in the house opposite them, called "the Street Boys". He says some of them smoke [nyaope], and some of them sell it. There are many people in the area that are purchasing nyaope from them. He is not friends with them, he just buys from them. He then says that he does not have any friends. It is just him; his friend is his mother. And it is just him and his two brothers "the whole day together".

They [Andries and Precious] have both never been to Steve Biko [Academic Hospital]. When we drive past the Tshwane District [Hospital], Andries comments how beautiful it is. When the car guard does not want to allow me to drive in and park, Andries indicates that they should be looking after the vehicles outside to ensure their safety. I am impressed with his concern for me. He realises he is sick. He says that he can hear himself when he is sleeping, he wakes up and has to breathe so fast.

^{aa} It is unclear why they wanted to make an example of him

^{bb} I did not ask how Anna was able to purchase a washing machine with limited available funds

When we got to the hospital, I drove into the parking lot at casualty and indicated that this was, in fact, an emergency. I used my university staff card to get into the hospital and tried to get Andries a file, so that he could be seen by the registrar. Unfortunately, things were not as smooth as I had hoped, and everyone was wondering what I was doing. The intern came from the consulting rooms and said that Andries had to wait his turn, and she could not see him immediately. She also did not want to call the registrar for me.

And so, I left, reluctant, hoping that the right thing would happen, and that he would be looked after. That evening I called Anna. She said that her daughter had returned home, as they had admitted Andries to the hospital. I was very relieved but did not really understand what the cause was. The intern had said that if Andries was really experiencing heart failure, he would be unable to walk. She had seemed sceptical, wanting to return him home. So, something must have happened.

The following day I went to the hospital and tried to find Andries. His sister had told me which ward he had been admitted to, and so I went in search of the ward. When I got there, I was relieved to see Andries smiling in the bed. I asked whether he had received any methadone yet, since my primary concern was that he would experience withdrawal symptoms again and discharge himself. He had not. So, I requested that the nurses please call the doctor or notify him or her, that they provide Andries with methadone, since he was known to have substance use disorder. Then nurse said that she would.

According to the hospital file, upon initial assessment, he was diagnosed with: severe microcytic anaemia, tachycardia of 110, cardiovascular: murmur, respiratory bronchial breathing, and bilateral inspiratory crackles. Transfused 3x RCC [red cell concentrate].

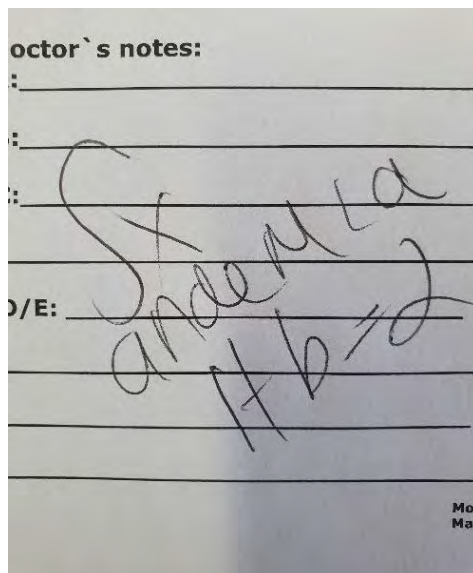


Image above: Photo taken from Andries' file indicating the reason for admission

I did not exactly understand everything – but one thing was clear, had I not been there the day before and taken Andries to the hospital where he was able to receive three blood transfusions, he may not have been alive much longer.

Reflexive Note: October 2019

The next day I went back again to see Andries. When I asked him whether he had received methadone he still hadn't. So, I spoke to the nurse, and she called the doctor. When she arrived, she explained to me that they did not know what the cause of the severe anaemia was. They were doing numerous tests. But she would make sure that he started on a methadone regime. I said to Andries – you're alive! If you hadn't come here, you would have died. He seemed to understand and was very grateful. I called Anna to let her know that Andries was okay, but they did not know what was wrong. She should please come and visit him and bring him some soap, so that he could wash himself.

Reflexive Note: October 2019

I stayed in contact with the doctor over the next few days to try and find out what was going on. At one stage when we met, she said that she thought perhaps Andries had a lung condition, which would basically mean he had at, the most, another five years to live. She said that she was very sorry, but it was a terminal illness, and nothing could be done. I drove home and I cried.

Reflexive Note: October 2019

When I returned to visit Andries a week later, the nurse told me that they had found out what was wrong. He had finally told her that when he had severe stomach pain, he had been to see a traditional healer. Following the prescribed medication from the traditional healer, he had vomited a lot of blood. They had done a gastroscopy and found a grade 3 peptic ulcer.

Key findings included: RVD Negative; HB 3.0 MCV 70.1 Plat: 328; Iron 1.3; Trans 4.3 (2%) Ferritin: 19 Folate: 18.5 Folate: 18.5; WCC: 13.70 CRP 4: PCT: 0.07; PU

Whilst he was in the ward, he was started on methadone and maintained on methadone 10mg PO [per os/orally] 12 hourly. He had responded very well to this regime and did not have the need to use nyaope and could thus finish his hospital treatment successfully.

Andries was discharged a week later with omeprazole 20mg PO daily and FESO4 1 Tablet daily.

Reflexive Note: August 2020

Over the next couple of months, I work with the social worker from COSUP to try and facilitate the process of Anna's three sons to attend COSUP. There is a national shortage of methadone, and funding concerns, so unfortunately, they are unable to start using methadone. At various times, I go past their home to fetch them, whilst the occupational therapy students are engaging in group therapy sessions with COSUP clients. Mostly they are not at home. Once, David comes with me, and attends the session. I feel a softness for them, as we engage in the sessions. The social worker keeps in contact with me and sends me a photo when they come to the site.



Images above: Two of the images that the social worker sent me, showing that the three sons had come to COSUP. The first one was sent in November 2019, and the second one in April 2020.

When the nationwide Covid-19 lockdown is announced at the beginning of 2020, I have great concern for Anna's family. I buy some general groceries and drive to Mamelodi. Unfortunately, Anna is not at home, so I drive to COSUP, where I meet the social worker, and ask him whether he will be willing to take the food to Anna's home when she is there. He does so, and later tells me that they were very grateful for the food.

A short while later he sends me a voice note, indicating that he has also brought food to their household. He tells me, "I just went there to a shop at Pick and Pay, I was just touched, I was extremely inspired by what you did to Anna that day, so I just decided, let me just buy some stuff, and she really appreciate [sic]... I will also assist them... I came there, I met the three sons, all of them they were there, and I gave her the food and then I tell the sons they must come."

It is a number of months before I am able to return to Anna's home. When I arrive, she is not there, however both Andries and Bule are. I arrive all excitedly, saying, "Andries, you're alive, how does it feel to be alive!" He says, yes, it is good, but David is dead. I cannot believe what he says, why, how, what happened. They do not know. One day he went to the toilet, and then they found him there, dead.



Image above: This is the outside pit latrine, which the household uses, and where David was found deceased

My heart sinks. Was there no way to prevent this heartache. How can their destinies change, could this have been prevented? What happened? Why did he die?

Reflexive Note: September 2020

When I eventually see Anna, she is struck with grief. She is looking after a young child, caring for the child whilst the mother is working. This is a good income for her. I am glad that she has been able to make a plan. Her daughter left schooling to try and find a job. There is such a high unemployment rate in Mamelodi, so I am unsure how she is going to find anything. I think about signing her up to the application for domestic work [Due South]cc. However, I do not know how she would work with it, considering she does not have a smart phone, does not have internet, and often does not have electricity.



Image above: Photo of David on the wall

She is also extremely saddened by the death of the social worker at the site. She had seen him as one of her sons, and the loss of both, was, to her, unfathomable.

^{cc} A company that runs an online application through which temporary domestic work can be ordered.

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

Reflexive Note: March 2022

I meet with the COSUP team, and they have continued their engagements with Anna's three sons. They do not want to stop using substances, but they are in the harm reduction programme and are receiving clean needles.

Reflexive Note: June 2022

I am absolutely devastated at what I have seen today. Judith and I went to visit Anna. When we arrived there, I was shaken by the outside area having been turned into a recycling area. There were a lot of people, coming and dropping off mostly empty plastic bottles. I went to the side of the house and asked where Anna or Andries were. They seemed a bit confused but said they will go and find her. Then one person went into the house, and, after a while, Anna came out. She went back inside to get a curtain which she then placed on the concrete edge of the house, so that we could sit on it. We sat down, and I asked how she was doing, very aware of strong smell of alcohol coming from her.

She said she was not doing well. She was mourning the death of her son. Her daughter had been missing since Friday. She was uncertain where her daughter was, since when she borrowed a phone to call her daughter, she had not answered. Her daughter often went away for a few days at a time, but this was the first time it had been for such a long period.

She then told us that her leg was hurting her. A car had driven against her last year (a second hit-and-run accident), and she had hurt herself. She went back inside to get the x-rays. I could not make sense of it and asked her for the appointments that she had. I could see that she should have gone to the orthopaedic department at the hospital but had not done so. She also should have seen both the doctor and the physiotherapist in the last month but had not attended her appointments. We asked her why, and she said that she could not get there because she had too much pain in her leg. She was unable to leave her home because her sons were stealing everything from her. And she would continuously get very angry and frustrated with them.

When we asked her whether she had started drinking, she said that she would wake up at five o'clock in the mornings and often start drinking. When she had had two beers, she would go back to sleep. Most of the day she spent sleeping. She was not eating anything, and she was unable to go to the shops to purchase food. She did not have a cell phone anymore, because her sons had stolen and sold the phone.

She was able to walk around the house, but when she went anywhere else, she had to use her crutches that had been provided to her.

She now had two people from Mozambique staying on the premises outside. They were paying R800 a month for rent. She was also receiving R1000 for the rental of the recycling. I had seen someone receive what appeared to be drugs in exchange for dropping off the recycling. Recycling depots are known to sell drugs.

As we sat outside and she continued telling us what was happening in her life, all the while crying tears of sadness and frustration, I saw men come and go, dropping off recycling, and leaving most probably with drugs. Young men, wearing clothes that were dirty, who themselves had not washed in a long time. Anna also, was wearing a dressing gown and a towel wrapped around her, which were very dirty. She did not want us to come into the house, because she said it was filthy.

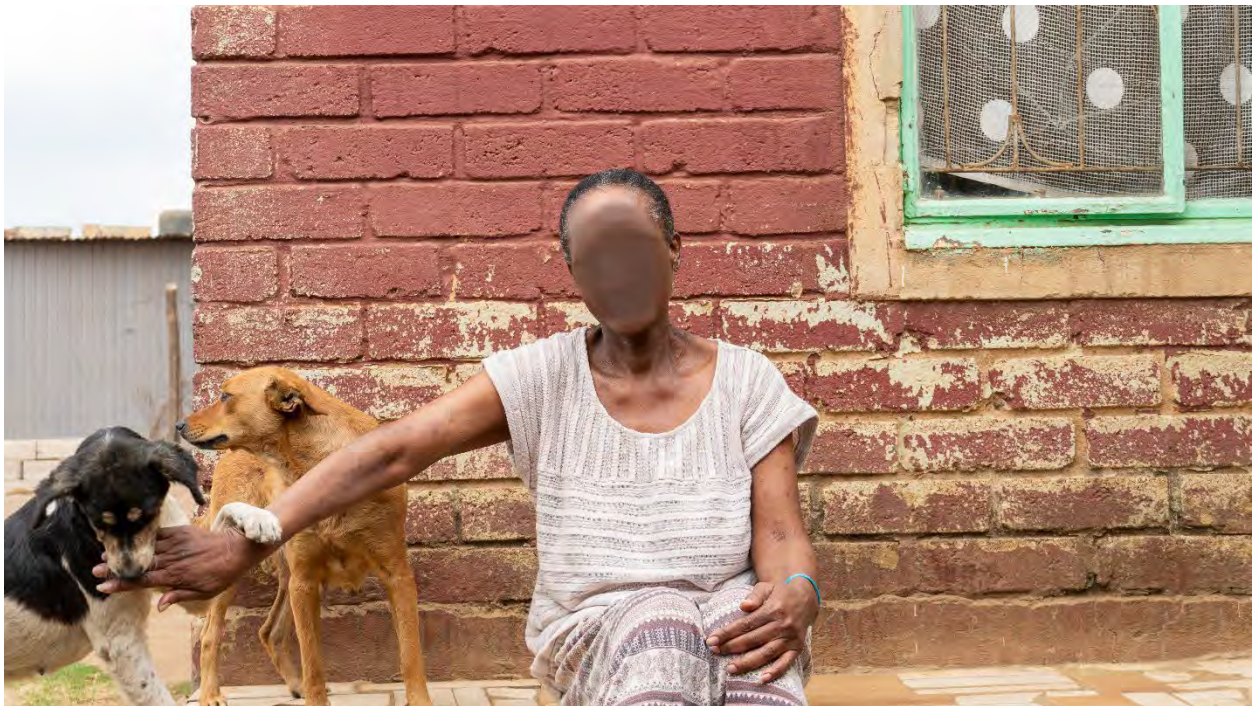


Image above: The steps on which we sat that day since Anna did not want us to go into the house. Her dogs had had puppies. However when I returned, all of them had died.

Anna was reminiscing about the death of her eldest. She said that he had gone to the toilet, and when she went to look for him, he was dead. She did not know what had happened; what had caused his death?

It seemed as if she had just completely given up on life, and the loss she had experienced had blinded her to life around her. I proceeded to tell her about the loss my sister had gone through last year, when her husband died from suicide. I shared the details of my sister's household, with her having four children – the youngest was five months at the time of her father's death. I tried to explain how we cannot give up

on life when we lose someone; we have to continue for those who are around us. Anna looked at me with eyes of empathy as she reached out and offered her condolences.

We worked through with her what she was able to take control of and what she was able to do. We tried to explain why she had to go back to the psychiatrist to review her medication, the counsellor to process her son's death, the physiotherapist to see what rehabilitation was required, and when she would be able to go to Mamelodi Regional Hospital for the operation they said she needed. We tried to set goals with her just for that day... could she sweep the floor? Could she wash herself? Would she be able to go to the shops with someone to purchase something to eat?

It seemed as if she was very wary of going to the shops with the people who were renting from her. She also indicated that she did not have any friends who were able to support her. After a while, Bule arrived. Judith spoke with him to try and find out what was happening and explained COSUP again. He indicated that he was receiving clean needles from them every week (he would receive four per week), similar to Andries. I was distraught to learn that they were both injecting now. Previously they had been smoking only. I pleaded with him to please stay away from Crystal meth^{dd} and that there was no medication to help with it. He said he had been to COSUP, but they had not given him medication.

I had brought some clothes along from home that I had thought to give Anna's daughter and negotiate with her if she wanted to sell them, that she would receive a percentage from all items sold (in this way avoiding a handout, but still aiding earn an income). Since she was not there and because of the change of circumstances, I went to the car to get two items of clothing and said to Anna that this was for her to wear something new so that she could feel clean and stronger. Anna was so thrilled and said that she would go to the community health centre, and she would wear these clothes. She would go and see the psychiatrist, and the physiotherapist, and the doctor.

Anna said that the CHWs had stopped coming to her house. She had not seen them in a long time. They probably felt unsafe to come and were unsure of what to do.

I could not help but feel so helpless. I realise that we must create the opportunity for her to take control of her situation, for her to initiate and make changes, however, I am not sure at all whether she will do it. Judith and I left the home feeling incredibly discouraged and helpless. As we passed by the homes on the street, I realised for the first time how all of them had fences in front of them. This had not been the case previously. The people living in the homes must feel safety concerns to have made these changes, which must have come from the increase of people purchasing and selling drugs at Anna's home. I thought about the lost opportunity of what I had hoped would become a flourishing home, perhaps with a garden – we

^{dd} Crystal methamphetamine (the drug methamphetamine in a powdered crystalline form)

had spoken with Andries previously about starting his own vegetable garden, going to COSUP and learning from there.

Instead, there was devastation.

We drove to COSUP, so that we could speak with the team there. I explained the situation to the social worker information officer and peer educator, who were all there. The peer educator was aware of both Andries and Bule. He said that he goes there once a week on a Wednesday to provide them with clean needles. When we spoke about the recycling, he lowered his head and the social worker asked why. He indicated that he knows there are not good things happening there. We brainstormed about what could be done and the social worker indicated that perhaps we could call the Mamelodi social workers' office to see if they could do a home visit. I asked whether the peer educator could not also assist, perhaps he was able to follow up and intervene. Perhaps the CHWs of COSUP could help.

The social worker indicated, however, that if Anna was not going to take ownership of her situation, if she did not want to change, then it would be fruitless to pursue trying to help her. Also, we were in a situation of being unsafe, but we could not get the police involved because they [the drug dealers] now know that we are working with Anna. I know that I should be scared for my safety. But I did not feel scared; I felt angry, frustrated, and livid, at this injustice.

How is Anna supposed to take ownership, to find motivation, to get going when she is obviously in a deep state of depression. This is why we need to work preventatively with persons who have mental health illnesses, like Anna. She has already been suicidal. I think back to my brother-in-law's death from suicide. What would I do to be able to work more preventatively? One cannot look back and say he had to take control of his life, or he had to change his situation.

As we leave COSUP, I am even more frustrated. I also feel guilty. Guilty for not having been back in such a long time. Guilty for not having done more. I know that as community worker, we can only do so much. I know we are not responsible for other people, that we work within a system, that we need to work with a team. But I can just see the systemic failures again. And the regret at how the situation has taken such a turn for the worse. Last time I was here, I did not think that it was possible for the situation to get this way.

We said we would follow up with the COSUP peer educator after next week Wednesday, when he would have been back again at Anna's home. Anna said she would go to the clinic on Thursday, after she was paid. If Anna could get a disability grant for her depression and for her physical limitation, perhaps she would not need the income from the recycling depot. But how do you negotiate with drug lords that you want to remove the recycling depot from your home and that you no longer agree to it being there?

I do not know what to do. I wish there was an answer or that it would be possible to do something with, what should be, the resources and departments that are available to solve the problem. But there are so

many barriers. But, as I say to Judith, even our visit today is a catalyst. If today can start making a difference, perhaps Anna will go and do something. And that means that if we had not gone to her home, then she would have continued in the situation that she was in. And we cannot say, therefore, that someone with depression, who starts drinking at five in the morning, will start making positive decisions for their life and will suddenly become motivated. Or am I wrong to say this? I start thinking about all the interrelated factors and wonder, how will things change?

Reflexive Note: June 2022

I arranged with the COSUP peer educator that when he visits the household next, he needs to see whether Anna has made an appointment to go and see the doctor and the physiotherapist. I call him at the appointed time, when he is at her house, and speak with Anna. I ask her how she is doing and try and discern whether she reached the small goal that we set with her. She says she is working at it, and she made an appointment to see the doctor, and she is getting the help that she needs.

Reflexive Note: September 2022

A few months pass and I phone the peer educator again to find out how Anna and her children are doing. He says to me that Anna is doing so well. They got rid of the rubbish dump, and she is in a much better place. I cannot believe what he is telling me. I arrange to visit Anna in two days' time.

When I get there, Anna comes and greets me. We engage in an embrace, and I marvel at how she is looking. What happened? What is going on? She looks so well, the house is much cleaner, she looks happy, she is doing well!



Image above: The previous area where the recycling point used to be

I go inside and sit down, and we speak about everything. She says, “That day you came, you told me, if I don’t take my medication, I am going to die. So, I decided to change. I did not want to die.” She went to get her anti-retrovirals [ARVs] from the hospital. She told the people who had brought the recycling depot to her house that they had to leave. She realised how dirty they had made everything, and she wanted it gone. She also told those who had been renting from her house that they had to leave. They cleaned everything up together. Her daughter returned home. Anna stopped drinking alcohol on that day. She says she is much happier.

I know that there are still so many challenges. As we speak in more detail about various things, she shares with me that she is now struggling to remember things. When she puts something down, she doesn’t know where she left it. Fortunately, this does not extend to her medication. She says that the CHWs have not visited her in a very long time; she cannot even remember their names. Also, her knee is still really sore, and she has to go to the hospital to make an appointment for an operation. She will only be able to do this when she goes to the clinic far away in October, where she will be receiving her ARVs. On the way, she passes by Dagga [Mamelodi Regional Hospital].



Image above: Anna in her home

I ask her why she is still receiving her medication from that clinic, which is on the other side of Mamelodi. She says, yes, she has to arrange a transfer to the community health centre, which is much closer. Or otherwise to the other clinic, which is even closer to her. She says she will do so. We talk about how her sons are not going to change at the moment, they do not want to stop using substances. But I explain the harm reduction approach to her, and how, through getting clean needles, they are not getting any other

diseases or illnesses. She explains that they each now get five per week, so they use one needle for two days, then they take the next needle for the next two days, and so it goes on.



Image above: Anna cooking meat on her stove

I try and explain the newly developed Model^{ee} that I have been envisaging with her, to see what she thinks about it. When her daughter is there later in the afternoon, we use the example of her not being able to go and do any shopping for the house, because her knee is so sore. How this then affects her daughter because she has to go to the shops. If Anna was able to have an operation and her knee got better, perhaps she will be able to go to the shops again. We discuss how her sons' substance use affects all the household member bands. How they have changed, because of the sons changing. We discuss the community, and how, through having the recycling unit in her yard, it affected the entire street, and therefore everyone started putting up fences. They agree. We then see, how we can use the model to be able to create change. How can we problem-solve together to see what can be done. For example, if Anna can get her

^{ee} One of the outcomes of the overarching PhD research was the development of a model to assist with COPC implementation

medication from a clinic closer by, how will this impact them as a household. This chapter, currently, ends in hope. I know that it is not the end. I know that there are still going to be many more challenges. But what Anna and her household have demonstrated is that there can be significant change in their household through initiative, taking ownership and making changes. I also realise again and again how small things make big differences. I look forward to the ongoing journey with them.



Image above: Anna and I discussing a picture



Image above: Anna looking out over the mountains of Mamelodi