The Mad Struggle

A Case Study on the Duties and Difficulties of Informal Care for Mentally ill Individuals in a Resource-Poor Township in South African

Andrew Gilmoor

Abstract

In spite of South Africa’s national policy to protect the rights of mentally ill individuals, a lack of adequate resources, feasible planning and commitment, have meant a gap in the mental health care of affected individuals. As a consequence, the burden of care is increasingly felt by the informal caregivers of mentally ill individuals. By means of a case study, the aim of this research is to identify the main actors of informal care and to describe the mechanisms involved in supporting mentally ill individuals in the South African Township of Platfontein. Using qualitative research methods, the lives of two case study subjects locally described as mentally ill, were investigated for a duration of 10 weeks. Insights into the daily activities and relationships present in the lives of the case study subjects were gathered using participatory observation and semi-structured interviews with the subjects and 23 informants consisting of family, friends, community members, and community leaders. Results indicate that the responsibility of informal care weighs most heavily on the family members of mentally ill individuals. While the presence of a clinic does provide access to health care, informal care is most commonly provided in the form of social support, consisting of commodities such as food, money and shelter. A limited record of emotional support was identified. In this research, several factors hindering the efforts and willingness of informal care were also identified. Personal hardships, stigmatism, and unrealistic rules and regulations set by the health care system in place limit the amount of support mentally ill individuals in Platfontein receive. The gap in mental health care in combination with the factors hindering informal care efforts seem to take its toll on the heavily burdened family members taking care of their mentally ill relatives and thus further perpetuate the cycle of poverty that is already very present in the Platfontein community.

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Introduction

“My mother is going this way” Dala states, pointing in the direction of up the street. It’s a heart breaking moment for his cousin, the translator, and us as we soon discover that his mother has passed away years ago. “She gonna buy the food”, he explains. Frequently unable to understand the world around him, Dala has to be continuously reminded that his mother is dead, forcing his family to repeatedly relive those difficult memories of the year 2000. Drool dripping from his mouth, he staggers up the dirt road, going from house to house shouting ‘give me food!’ as he is turned away from households, one after another. He meets his sister and her family on the street. He holds his arm out, gesturing for them to put something in it, and they start to argue. One relative turns to me, and says that Dala is sick in the head, and asks if I will help him. 

Researcher field notes

In recent years the issue of mental health has been increasingly important on the public health agenda. In addition to a growing population of people diagnosed as mentally ill, scientists are beginning to understand that this increasing disease burden is not just a health concern, but impacts areas far beyond the health sector—including educational achievement, work productivity, social development, crime and substance abuse. While these concerns have lead to the initiative for the global scale up of mental health services, mental health disorders remain to be a significant burden of disease worldwide, particularly affecting low and middle-income countries (LMICs) (Eaton et al., 2011). Characterized by its multiple societal-level socioeconomic risk factors, the disease burden of mental illness in South Africa ranks third in the country’s total disease burden following human immunodeficiency virus/acquire immune deficiency syndrome (HIV/AIDS) and an accumulation of other infectious diseases (Bradshaw et al., 2007; Lund et al., 2010; Burns, 2011).

Since the installation of its new government, South Africa has committed itself to improving its national health care system and support systems for people living with disabilities (PLWD). In 2004, South Africa implemented the Mental Health Care Act (MHCA), which sought to protect the rights, and the lives of people living with a mental illness (Burns, 2011). Unfortunately, limited commitment efforts, and human and financial resources have resulted in a gap in mental health care, preventing many of those suffering a mental illness from receiving the care they need (Burns 2011; Eaton et al., 2011). As a means of coping, a growing dependence has been placed on informal care and social support to help alleviate the burden of mental illness.
For the scope of this research, we define informal care as the assistance provided to individuals suffering from a mental illness by the various social networks within their community. Extensive research has shown the importance of informal care on health systems in the developing world setting (Robson, 2000; Root and Whiteside, 2013; Campbell et al., 2013), however less attention has been focused on the impact of such care on both the patients and their caretakers. There is a limited understanding of the influence communities have on the impact, feasibility, and effectiveness of informal care. How mental illness is defined, how it is treated, and how care is given depends largely on the cultural influence of the specific community in which it is implemented (Helman, 2007). Particularly, the role of informal care is strongly shaped by the attitudes, motives, resources, knowledge and understanding of the social networks that influence the lives of mentally ill individuals. By means of a case study, the aim of this research is to identify the main informal caregivers involved in the lives of mentally ill individuals in the south African township of Platfontein, and investigate the different ways in which they provide support. While investigating these questions, important hindering factors of support are also identified.

**Historical Background**

Owing to its troubled history, South Africa, like many lower middle-income countries (LMICs) suffers a high burden of mental illness (Herman and Stein, 2009; Chipps and Ramlall, 2012). In 2003, the Platfontein community in the Northern Cape was established, and the resettlement of two distinct groups into this area began. The two groups, the !Xun and the Khwe (collectively known as the Bushmen¹) have unique histories that have led them to resettle in the Platfontein community. It is this political history, their transition from their traditional to a new way of life and the social implications that are involved, are what makes this particular community so unique.

The !Xun are part of the northern !Kung community, that have originated in southern-Angola. Unlike their southern and western relatives, the !Xun lived as foragers in forest lands, searching and exploiting any available food resources (Robbins, 2006). The Khwe on the other hand are a very diverse group, ranging from traditional hunter-gatherers to highly cultured basarwa², living entirely on what they hunt and the roots, nuts and fruits that their women pick (Robbins, 2006). The !Xun and the Khwe were forced to fight alongside the Portuguese Army and South African Defense Force (SADF) in the Angolan and Namibian independence wars, respectively. With both armies defeated, the Bushmen were forced into exile. Following defeat, approximately 90% of the Bushmen soldiers

1 Bushmen – the self declared term used to collectively refer to the !Xun and the Khwe people  
2Basarwa – the indigenous peoples of southern Africa whose territory spans most areas of South Africa, Botswana, Namibia, Lesotho, Swaziland, Mozambique and Zimbabwe
and their families opted to follow the SADF to South Africa where they hoped for social security. By 1990, the fully dependent Bushmen soldiers and their families were moved into a transitional settlement at Schmidtsdrift, Northern Cape South Africa (Robbins, 2006).

The withdrawal from their home region in Caprivi meant dramatic socioeconomic change for the Bushmen, as they started to suffer loss of employment, loss of wages, and increasing dependency for food aid and security (Battistoni and Taylor, 2009). After arriving at Schmidtsdrift, the previously valued Bushmen suddenly became a government liability. They struggled to adapt to their rapidly changing world, as they grew largely dependent on welfare, became subjected to discrimination, were only able to employ extremely poorly paid jobs and lacked the rights and skills to participate in political processes (Suzman, 2001). Overall, the Bushmen had been integrated into the lowest level of the South African political economy. After having lived for thirteen years in this tented community, they were finally relocated to the permanent settlement of Platfontein (see figure 1).

Though Platfontein was intended as a form of compensation for the Bushmen with concrete housing, water supply, electricity, and various facilities such as a school, health clinic, and general services, the reality is that poor quality infrastructure, and malfunctioning water and electricity supplies have left the community living under challenging conditions. Poor sanitation and improper waste disposal has led to seasonal outbreaks in diarrheal borne diseases, small houses for large families have resulted in serious overcrowding of living space, and several clashes between the !Xun and Khwe groups have been reported (Robbins, 2006; Letsoalo, 2010).

![Figure 1: Map of Southern Africa: The !Xun originated in southern Angola (Black star) where they fought in the Angolan independence war alongside the Portuguese army. Following defeat they joined forces with the South African Defense Force (SADF) and the Khwe in the Caprivi strip of Namibia (Red star) where they fought and lost in the Namibian independence war. Following retreat the !Xun and Khwe soldiers and their families were placed in a temporary tented settlement in Schmidtsdrift Northern Cape (Yellow star). After 13 years, they were finally moved to their permanent settlement in Platfontein, Northern Cape (Blue star).](image)

Partially attributed to their troubled political history, the Bushmen have experienced several challenges adjusting to their new lifestyles in Platfontein. Reports of poor socioeconomic standards of living, health issues, substance abuse, and domestic violence, are significant indicators of mental health issues being present (WHO
Previous fieldwork and exploratory interviews conducted by Thijs den Hertog and student colleagues from previous years, within the PhD research project, have suggested a significant role for social networks in the lives of the mentally ill however less is known about who these social networks are and what role they play in the informal care of mentally ill individuals. This research aims to provide insight on the role specific social networks play in providing informal care to locally defined mentally ill individuals. It aims to answer the question: who are the informal caregivers providing care to mentally ill individuals in the Platfontein community and in what ways is support given?

Theoretical Framework

This research is informed by the Adjusted Informal Care-Support Model, which has been designed for the sole purpose of this research using the iterative process. It incorporates a combination of concepts derived from previously existing models outlining the process of social support for disabled individuals, as well as new concepts specifically identified during this particular fieldwork. It mainly incorporates the organization of social networks presented by the Peer-Support model proposed by Dennis (2003), as well as various possible organizations of functional support laid out by the structural-functional support model proposed by Lin et al (1999). By integrating these two conceptual models, the Adjusted-Informal Care-Support Model aims to demonstrate the role informal caregivers (the support structures) play in providing various support functions. Additionally, the model aims to identify factors that may influence the level of support given (figure 2). The different components of the Adjusted-Informal Care-Support Model are discussed below.

Structural support

Structural support refers to a set of different social structures that may help buffer the impact of having a disability on an individual (Lin et al., 1999). For the scope of this research, we focus our attention on the main social networks that may be identified in a mentally ill individual’s life in the Platfontein community. These various social networks are evaluated on how often they see the mentally ill individual, type of interaction, and impact of interaction between the mentally ill individual and the social contact. These various social structures, also known as the informal caregivers, are the actors involved in providing the various forms of functional support, discussed below.

Functional support

Functional support refers to activities of exchange that serve to reduce the burden of disability. We incorporate two aspects of functional support addressed in the Structural-Functional support model that is believed to best fit the aims of this research: (i) instrumental versus expressive support, and (ii) routine versus crisis support. For the scope of this research,
instrumental support refers to physical or material means by which other members of the community can support someone who is mentally ill, such as providing shelter, or financial assistance (Lin et al., 1999). Expressive support, on the other hand, refers to the emotional or psychological support someone can provide. Expressive support normally comes in the form of expressing sympathy, venting frustrations, and the building up of self-esteem that could encourage the mentally ill individual (Lai 1995; Lin et al., 1999). Both support systems have been found to reduce mental illness burden on individuals in the past (Lin et al., 1986; Lin et al., 1999), however their impact on informal care in Platfontein remains to be established through the means of this research. The second dimension of the functional support category presented in our adjusted model is routine versus crisis support. Routine support refers to assistance on a day-to-day basis, such as regular childcare or homecare, whereas crisis support refers to assistance received when the person is confronted with a crisis, such as seeking medical attention after a violent episode (Lin et al., 1999).

**Effect modifiers**

The final aspects of the Adjusted Informal Care-Support Model are the effect modifiers. We hypothesize that the facilitation of functional support provided by the various support structures is highly dependent on a number of social and cultural factors (Kawachi and Beckman, 2001; WHO, 2005). For the scope of this research, these factors are grouped into two main categories: factors that enable support, and factors that hinder support. Enabling factors can consist of any factors that help facilitate the use of informal care support in the lives of mentally ill individuals. Hindering factors, on the other hand, consist of any factors that prevent or hamper support efforts by informal caregivers. While the small number of case studies used in this research limit the possibility of drawing any direct correlations between these effect modifiers and the extent of social support received, knowing these details about the individual subject participants do suggest reasons behind the different levels of support given.

![Figure 2: The Adjusted Informal Care-Support Model, depicts the process of informal care in which different support structures provide a range of support functions to assist mentally ill individuals. A number of social and cultural factors, collectively known as effect modifiers, are believed to either hinder or enable such efforts.](image-url)
Methods

Methodology

To meet the aims of this research, a case study approach was undertaken. More specifically, a comparative case study was conducted using the hierarchic method in which two case studies were first conducted in parallel with each other and then compared to identify possible explanations for the similarities and the differences in behaviors observed (Verschuren et al., 2010). Each case study follows the life of one person labeled mentally ill by the members of their community. By means of this case study approach, insight is gained on how, and to what extent, do different social networks interact with mentally ill individuals in Platfontein. A triangulation of methods was undertaken in order to comprehend these interactions fully. Distinctions were made between what people ‘feel’ as described in the semi-structured interviews, and what they ‘do’ as illustrated in observation. Additionally, the socioeconomic conditions of the community are studied using observation and literature in order to understand the underlying reasons for the different behaviors observed.

Sampling and recruitment

Two types of subjects were recruited for this research: (i) the case studies, and (ii) their informants. After one week of exploring the Platfontein community, two case studies regarded as mentally ill were recruited for participatory observation—one elderly woman of Khwe origin named Christina, exact age unknown, and one middle aged male of Khwe origin named Dala, exact age also unknown. The case studies were selected on a number of criteria. Firstly, they had to be considered mentally ill by the members of their community. Secondly, ethical guidelines had to be met (see guidelines below). Thirdly, the case studies and their activities were of no threat to the researcher’s wellbeing, and fourthly, the case studies were above the age of 18 from the time fieldwork was initiated. Following case study recruitment, 23 informants were selected for semi-structured interviews. Different informants were selected based on the varying types of relationships exhibited between them and the case studies. Through snowball effect, new informants were recruited as the fieldwork progressed. In total, 11 informants were recruited based on their relationship with Christina, and 10 informants were recruited based on their relationship with Dala. 2 informants were recruited for their general insights and involvement in the community. All subjects were informed about the purpose and implication of the research and provided their informed consent prior to participation.
Data collection

Observation

Observation was used as a means of gathering data on the actions involved in the daily lives of the two case study subjects. With as minimal interference as possible, the case study subjects were followed around for a period of 8 weeks while they underwent their daily activities. Fieldwork notes were taken, identifying important actions and interactions with other people. From these interactions, various informants were selected to participate in semi-structured interviews.

Semi-structured Interviews

Semi-structured interviews were conducted with 23 different informants with varying levels of relationships with the two different case study subjects. Depending on the level of interaction each informant has with the case study subjects, the interviews lasted anywhere between 10 minutes to 1 hour and were conducted in a setting of their choice. The interviews tackled five different areas: (i) a few general questions about the informants background, family, and personal lives, (ii) type of relationship the informant has with the case study subject, and the support they provide (iii) knowledge concerning the suspected cause of mental illness, associated symptoms, and proposed healing strategies (iv) general perceptions on available support and (v) general community impressions on the issue of mental illness and the two case study subjects in particular. Accumulatively, they provide an in-depth, descriptive account of the subjects’ actions, experiences, and feelings.

Literature search

A literature search was conducted using the Internet search engines Google Scholar and PubMed for information on the San history and Platfontein. Search inclusion criteria included any articles with reference to words such as ‘San’, ‘bushman’, ‘Khwe’ and ‘!Xun’ in combination with ‘Platfontein’, ‘South Africa’, ‘Southern Africa’, ‘health’, ‘conditions’, ‘wellbeing’. No filters were used on publication dates. Grey literature was also used for more information on the San in southern Africa, and particularly in Platfontein.

Data analysis

EXCEL was used to generate simple statistical information on the demographics of the study sample. All interviews were transcribed verbatim and together with the field note observations, were analyzed using the computer software ATLAS.Ti ©. The data is presented by means of field notes that illustrate the experiences and observations of the researcher. Published literature was used to verify, compare, and contrast with the findings of this research.
Ethical considerations

This research was approved by the Humanities and Social Science Ethics Committee of the University of Kwazulu-Natal, and therefore subject recruitment and participation adhered to the code of conduct outlined by UKZN Research Ethics Policy. First and foremost the autonomy of each participant and the prevention of harm in the form of anxiety, stress, and stigmatization was top priority. The details and purpose of the study was explained to each candidate prior to recruitment and were only recruited to the study once informed consent was given. Each subject was formally asked to allow audio and visual recording of interviews when necessary, and has only been utilized with consent. Due to ethical guidelines, children under the age of 18 were not allowed to participate in the study.

Results

Subject demographics

Demographic characteristics of the subjects who partook in this study are presented below in table 1. The ages of the selected participants ranged from 21 years old to approximately 80, though several participants did not know their age. The majority of the subjects were female at 64% (n=16) and all subjects were of Khwe ethnicity (n=25). 56% (n=14) of all subjects were married and 80% (n=15) had children. An overwhelming majority of the subjects were unemployed at 76% (n=19).

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Platfontein: Setting the scene

A 20-minute drive from bustling Kimberley’s city center, on the N2 highway heading towards Barkley west, you find Platfontein. The drive takes you past a dumping site on the left-hand side, and a large urban township on the right-hand side. As you continue driving the scenery begins to look like African savannah grasslands. Tall golden grass stretch as far as the horizon, with the famously native African Acacia trees sticking out from in between. If it weren’t for the electricity lines and intersecting road that suddenly appears in front of you, one would not suspect that a township consisting of
some 6500 khwe and !xun people was about to appear to the left. You turn left and drive for another few minutes along a poorly maintained tarred road and then you finally see it: Platfontein. A long gravel road runs parallel to almost the entire township. The first few houses you see to the left are the temporary settlements consisting of zinc scraps and battered refugee tents belonging to the new comers to Platfontein, instant reminders of the troubled war history these people have been through.

The houses in Platfontein vary in level of upkeep. The majority of them are colorful, pinkish/peach colored houses with bright colored doors, painted in yellow, blue, green, brown, etc. Some houses have well kept gardens, with a full lawn of grass, and beautiful plants. Other yards are poorly maintained with mud, random grass patches, and garbage littering the lawns. The broken windows are a sobering reminder of the high levels of domestic abuse experienced in this community. On the Khwe side of the community, dirt roads group and separate houses into neat neighborhood blocks. On the !Xun side of the community the houses are scattered in a more seemingly random fashion, giving the impression that one is deep in the African bush, rather than just a mere couple of kilometers from a major highway and the bustling city of Kimberley.

At first glance, the image of Platfontein leads to many misconceptions. The loud festive music blasting from different houses as early as 9 a.m and the sight of people drinking and dancing, laughing and singing, gives a false image of celebration. In reality the overwhelming level of unemployment and lack of activities have driven many people to drinking as a means to pass the time. The drinking starts early in the morning and does not end until the late night. It takes only one conversation with a person, and the slight whiff of their breath to determine how far along they are in this most common daily ritual. The brightly colorfully painted little brick houses give an impression of a simple, but comfortable lifestyle. The reality is that these colorfully painted 3 roomed houses are packed with families of four to eight or more people—mothers, fathers, uncles, aunts, grandmothers, children, nieces, nephews, cousins. Families who are fortunate enough to have someone who is employed are able to furnish their homes, while those less fortunate sleep on stacks of cardboard and eat on the ground. The winters are cold, and fires are lit inside for temporary relief before going to sleep.

Though poverty is widespread, and the people have little to offer, Platfontein is a textbook definition of community. A single loaf of bread will stretch far and wide from a man, to his children, to their children’s friends, to their children’s friend’s siblings, to their children’s friends’ siblings’ friends’. Here in Platfontein, for the most part, the practice of Ubuntu, which means ‘people taking care of each other’, seems strong.
Meeting the Case Study Subjects

**Dala**

Meeting Dala was an adventure in itself. His unpredictable wandering nature made him impossible to find. After several failed attempts of having his relatives keep him in one place, we finally resorted to radio broadcasting his name, telling people if they saw him to please send him to the radio station. After waiting for nearly two hours our hopes grew weak, but then, finally he appeared at the radio station—his appearance nothing short of a complete mess. Dala was covered in dirt from head to toe, with little twigs sticking onto his clothes, arms and face. One side of his head was covered in red sand, seemingly as though he had been sleeping on the ground outside and he smelt of urine and dry spit. I approached him with caution, not knowing what will come of this interaction. With a big dopey grin, he turned to look at me, and smiled. Researcher field notes

**Christina**

We started our trek around the Khwe side of the community to look for this woman we had heard about, no idea where she would be. We repeatedly walked up one street and down the next. Eventually we found her. My first sight of Christina was of her walking up a dirt path carrying a seemingly heavy bundle of firewood on her shoulder. At some point she drops the firewood on the side of the path and enters someone’s yard and sits on the ground in front of a house. We first approached her with caution, not knowing how she would react to our presence. Christina was an elderly female. The lines that run across her face tell a story of a long history and the hardships that came with it. Most of her teeth were missing, though this was difficult to notice as she did not smile much at first. As we approached her, she met our gaze with pouted lips and an apparent disinterest. This was not going to be easy, I thought to myself. Researcher field notes

From those respective moments onwards, Dala and Christina became the main subjects of a 10-week investigation. Seemingly completely different based on their descriptions, these two individuals share one major life-defining characteristic—that is, to the rest of their Platfontein community, they are considered mad.

**The Concept of Madness**

**Symptoms**

As mentioned earlier the social support provided through informal care varies according to the cultural context in which it is placed. Support heavily depends on the community attitudes, understanding, and knowledge of mental illness. This following section illustrates the local perceptions of what is considered to be “madness”.

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3 Madness is the local terminology ascribed to the term mental illness. From here on forward the term mental illness will be used, while keeping in mind that the local term for mental illness is madness.
They stay in different villages, she was in bagani, and Christina was in omega. She hear that Christina is not home all the time, that things started. That Christina is on the bush walking around, going to the army’s base, wearing clothes that she is not supposed to wear. That’s how Christina’s starting to get mad. Key informant, female, age unknown

In this extract, this key informant explains how she lived in a different region from Christina and did not witness the beginning of her illness for herself. She expresses how she was told of Christina’s actions which have led her and others to conclude that Christina was mentally ill. Walking around aimlessly, being in places that she should not have been, and wearing things that she should not have worn, are seen as characteristics that are linked to madness.

Dala said I thought I was like i died. And then people take me...since that day, after two days, the things he was talking you couldn’t understand him. The mind was changing...The things he used to say that time was non existing things, and he used to say that people wanted to kill him, there are many people who have hit him in the night which is not true. Key informant, female, age 48

In this passage, this key informant mentions characteristics that were not exhibited in the earlier example, however are still considered to be characteristics of madness. She speaks about a particular day in history in which the switch from Dala being mentally ‘healthy’ to becoming ‘mad’ took place. She describes both physical and mental characteristics, to which she ascribes the condition of madness. She reports a loss of physical control and delusions as some of the characteristics of madness.

The last two excerpts are indicative of some of the characteristics people in Platfontein generally ascribe to being mad. The main common characteristics shared by both Dala and Christina include: constantly walking around, wearing attire that is not socially acceptable to be worn, sleeping outdoors in the grass or bush, delusions, and talking things that do not make sense in any normal context.

According to informants, though they are both considered mad, Dala and Christina also exhibit separate characteristics. Two common characteristics that are distinctive of Christina is that she appears to talk to people who are not there, and cursing other people with no apparent reason:

She don’t know what she’s saying, she’s just swearing and she don’t know what she’s doing, so the life change. She wasn’t a person like that but she change. Relative, female, age unknown

Characteristics that are more distinctive of Dala on the other hand are more associated with his physical behavior. Informants
describe epileptic seizures, drooling, walking around naked, and eating things that should not be eaten to be common characteristics of madness exhibited in Dala. Additionally, acts of violence committed by Dala are a characteristic linked to madness that many people associate with Dala.

*ya I first saw Dala by doing funny actions. His tongue used to come out and he used to receive a attack or sometimes fall, his body was cramping then I realized ya something was wrong... Key informant, male, age 75*

These differences in characteristics seem to attribute to how people react to Dala and Christina’s conditions, and ultimately how informal care is provided. The different reactions of people and the causes behind them will be elaborated on in later sections.

The case study subjects in this research were selected based on the community’s labeling of mental illness and not on any clinical presentation of symptoms that are in line with Western diagnostic and labeling systems. In Platfontein, like many other communities, mental illness is seen as anything that goes against the norms of social behavior. In a model proposed by Helman (2007), the different dimensions of social behavior are represented. According to the model, behavior can either be normal or abnormal. Normality is something that is static and varies in different contexts such as time, age and gender. According to the model, abnormality is sometimes socially acceptable on the condition that it adheres to the rules society has set—a controlled situation. A person is considered mad on the other hand, when they are perceived to be behaving in an abnormal way, uncontrolled by societal norms and without particular cause (Helman et al., 2007). The symptoms described by community members in Platfontein are a model example of this. Informants associate behaviors that are not in line with social norms, such as, walking naked, sleeping in the bush, roaming around aimlessly, talking to people who do not exist, talking things that do not make sense and eating things that should not be eaten as symptoms of madness.

The way in which the behaviors described above are interpreted and labeled as madness is culturally specific. However, there is also considerable overlap concerning the classifications of madness across different cultures. In one study conducted in east Africa, the different classifications as to what constitutes madness was investigated. Similar symptoms were described across all four tribes studied in Kenya, Uganda and Tanzania. These symptoms included: wandering around naked, talking nonsense, violent conduct, and sleeping and hiding in the bush—all of which have also been identified in the Platfontein community (Edgerton, 1977).
Causes

Apart from symptoms associated with madness, ideas behind the cause of mental illness are also strongly culturally bound. In many African cultures, mental illness and physical illness originate from different external causes and these causes are a result of human or spiritual agency (Ebigbo 1989; Patel 1995). In Platfontein, when asked what the possible causes of the case study subjects’ madness may have been, an overwhelming majority of informants did not have an idea. When asked to take a guess, the majority of informants suggested witchcraft to be the most likely cause. Few informants regard mental illness to be due to abnormalities of the brain, such as ‘disease of the head’, and epileptic seizures described as ‘shaking of the head’. Platfontein is a model example of many sub-Saharan African beliefs regarding the cause of madness. In a study conducted in Ethiopia, for example, mental illness was attributed mainly to supernatural phenomena including: “(1) possession by evil spirits such as Satan, (2) punishment by god or guardian spirits for sins, broken taboos, or forgotten rituals, or (3) curses, spells or bewitchment by people alleged to have supernatural powers” (Mulatu, 1999).

Though not a common belief, it is still worth mentioning that some community members say that madness is caused by thinking too much as a result of social distress. Additionally, some community members consider madness to be the result of a conscious decision, such as doing things that are considered taboo like, eating or touching something that you are not supposed to, and upsetting the elders. Considering the causes of madness from this perspective may shed light on to what extent community members sympathize with mentally ill individuals, and informal care is given.

A Typical Day

“Christina kuwa gwata!”

It is 7:30 in the morning and the household is already up and busy. The family is up and already performing their daily chores. One daughter is helping the children get ready for school, another daughter is tidying up, and the head of the house is preparing the morning meal. Everyone is doing their part of the morning routine to help each other. Christina exits her small tent from the back of the yard. She walks to the front tent where she prepares her own fire. She sits down next to the fire for warmth, and drinks the coffee she had prepared for herself. By 8:30, with walking stick in hand, she is on the move. For hours she walks along the dirt roads of the Khwe half of the community going from yard to yard visiting people. One family has nothing to offer her, so she leaves and moves on to another household who does not have time for her. As she walks she talks out loud, gesturing as if talking to someone who is not there. Some people smile in amusement as they pass her. Others ignore her completely. Christina enters a new yard and an elderly woman sets out a mat for her to sit on under the shade of a large tree. Christina is given
something to drink as she sits and relaxes. I leave for a moment, and when I return Christina has left. I go back to her house and ask if Christina was home. “Christina kuwa gwata!” she replies gesturing that Christina has left and could be anywhere. I recognize that I have heard this phrase many times when I ask if someone has seen Christina. I begin to realize that Christina never stays in one place for too long, and I admire the energy this elderly lady has for walking all day in this African heat. Eventually I catch up to her as she walks up the dirt road. She enters the yard of a close relative, and briefly talks to her and plays with her child. She rubs the child’s head and they laugh together. Christina asks her a question and seemingly defeated she exits the yard and continues up the road. “Christina is hungry”, the relative says, “but I don’t have any food myself”. She eventually enters a yard where the women are busy doing laundry and washing dishes. Christina is given a cup of something to eat or drink. She wastes no time, and quickly moves on to the next house. The day drags on, as the sun rises higher and the temperature gets hotter. Christina moves from house to house, seemingly empty-handed. As she walks she crosses paths with a young relative and his friends. She asks him something and he seems to respond impatiently, gesturing her to go elsewhere as he passes her. She shouts something at him and begins to chase him, however him and his friends run off laughing. Christina eventually finds a yard where she settles in to relax for the afternoon. At the end of the day everyone is home. Christina sits on the couch inside with her little nieces and nephews, and watches cartoons on the television in amusement. She won’t sit for too long. At any moment she will leave the house and roam the streets once more. Researcher field notes

“The clash of civilizations”

I walk to the bar and find Dala. He is absolutely filthy, wearing clothes that look like they’ve never been washed. The smell of dry spit and garbage gave a sharp sting to my nose. Though his clothes were dirty, he did wear them neatly. He wore a polo shirt tucked into his grey business pants, and a hat. I wondered if this were the uniform he decided he would wear when going to work at the dump. People look at us talk on the street. Some greet Dala in passing. Others are confused by our interaction. I follow him to a relative’s house where he asks for money. She gives him one rand which he uses to buy a cigarette at the zinc-shack across the street. We then walk towards a house where homebrewed beer is for sale and music is playing loud. Crowds have gathered and are enjoying the beer and the company of others in what seems to be an informal local bar establishment. Dala sees another relative and some others. As we approach them he is shoed away. “Go with the guy”, they say, pointing at me. Dala stubbornly ignores them and repeatedly asks for money and cigarettes. Seemingly irritated by this, they gave Dala money and a cigarette so that he would leave. As we walk through the yard of this bar establishment, people stare at the two of us
with curiosity. One man approaches me and asks what am I doing with that guy, “that man is sick in the head”, he warns. Dala and I sit, and as we attempt to have a conversation people walk pass, shaking their heads and giggling. As the day progresses Dala continues to drink and goes from yard to yard, not asking, but almost demanding to be fed. “Give me food, give me food!” he yells, with hands stretched out and clamped together. But no one seems to help. Eventually Dala enters the yard of a close relative. He goes to the back and seems to force himself into the house. No one is home. Moments later, he leaves, with a piece of bread in his hands and mouth. At this stage Dala seems heavily intoxicated. A young gentlemen approaches me, and warns me not to talk to Dala because he is dangerous and cannot be trusted. We walk back towards the bar near his house. As we walk we meet another relative and her soldier husband. Dala holds his hand out towards the husband, asking for something. The husband refuses and the three of them start to speak loudly towards each other— sounding like an argument. Another relative, joins the group and asks if I understand Dala. He says that Dala is physically sick in the head and asks if I will help him. At this stage I realize I have influenced Dala’s day too much, and thought it best if I left for the afternoon.

The following day, Dala passes by me and says he is on his way to work at the dump and then he will go to his uncle in a nearby township. I follow him for a while and he turns into the yard of a house near the beginning of Platfontein. Dala enters the yard where a relative and another friend are sitting and rolling a joint. I notice how this relative talks to Dala, like a normal person— different from what I’ve observed with other people he has interacted with. Unlike most others, this relative makes no mention of Dala’s apparent mental health problems. He allows Dala to take a glass bottle from his garbage which he then puts in his little shopping bag and begins walking towards the dump. I follow Dala from far behind, so he doesn’t notice me following him. As Dala walks down the main road out of Platfontein, he is almost on the middle of the road. The sun is scorching hot, but he keeps up a fast pace and I can barely keep up. An ambulance passes by and Dala goes off the road to avoid being hit. At the beginning of the main street Dala takes a right turn and walks towards the dump along the side of the highway. I cringe with fear for his life as I see giant trucks passing just a meter or two from him as oncoming traffic. Many thoughts ran through my head as I saw this tiny person, wearing clothes that were too big for him, shirt tucked into pants, and bag over shoulder, heading to work with purpose. The contrast between this petit man from Platfontein and the major trucks and company cars of Kimberley that narrowly miss him was an interesting juxtaposition to witness. Here is where the two worlds collide, I thought, a clash of civilizations. As I am now on the same highway following him from behind, I worry about my own safety. I repeatedly ask myself how far would I go for research, and
turning back I realize this is far enough. Researcher field notes

These two extracts paint a dramatic picture of events surrounding a typical day for Christina and Dala. In both extracts, several different types of interactions with different social networks are identified. These interactions shed light on the types of relationships Dala and Christina have with the community members and furthermore highlight some of the various forms of informal care they receive by means of social support. The following sections will elaborate on the actors involved and the roles they play in providing informal care to Dala and Christina.

The informal caregivers

Based on the interactions observed between different community members and Dala and Christina, two main types of informal caregivers can be roughly identified: (i) family and (ii) community member acquaintances.

The actors of informal care

Family

It was observed that, when wandering around the community going from house to house, Dala and Christina almost exclusively visit family members, including siblings, cousins, distant cousins, nieces, nephews, aunts and uncles, where they receive various forms of support. For both case studies, the amount of time spent with their families, and the amount of support received by their families is unparalleled to any other social network in the community.

Based on the amount of time Christina was observed to spend with her sister Matumba, and the amount of support she seemed to receive, it was deduced that Matumba is one of the main informal caregivers in Christina’s life. It is apparent that Matumba is the person that Christina sees the most on a daily basis. Matumba used to visit Christina regularly when she lived in a different house with her son John—also considered to be mentally ill. When it was evident that John was physically abusing Christina, Matumba took her into her own home to protect her. Matumba provides shelter, food, and comfort for her older sister Christina. She expresses that sometimes she can hold a decent conversation with Christina, but that at a certain point, she no longer makes sense, and all Matumba can do is sit and listen:

\[\text{those days they used to sit and when she have maybe something to eat for Christina she cook and then they eat, at a point she used to talk about things that really exist, but then she start talking something (crazy).}\]

Interpreter’s translation, Key informant, female, age unknown

While Christina lives with Matumba, she plays a small role in the household, and does not partake in household chores. In Matumba’s household, Christina’s sister and nieces help each other with the daily chores.
chores such as cooking, cleaning and gathering firewood. Christina seems to mostly cook for herself, eat by herself, washes her own clothes, and collects her own firewood:

*she’s mentioned like Christina is like lazy she don’t want to do anything, just do like this and this and this.*
Interpreter’s translation, Key informant, female, age unknown

This isolation from the household seems self-induced according to Matumba and Christina’s nieces, and has limited the extent to which Christina and her sister personally connect. The fact that Matumba is unemployed and has three unemployed daughters living in her household means that she has limited resources to additionally take care of Christina.

Because Dala currently lives on his own in his father’s house, the main family informal caregivers were less obviously identified, compared to identifying those in the case of Christina. Upon speaking with several informants, and observing Dala’s frequent visits to one particular household, Dala’s uncle Peter appears to be one of his main informal caregivers. Peter has been a main provider for most of the family. Though he has fallen ill in recent years and no longer has the means of supporting his relatives, Dala remains a main receiver of the support he can offer. He is frequently seen visiting Peter for food and something to drink. Peter expresses that as a family member, he supports Dala whenever he can:

*He used to come to me...the family...when I was not sick I used to help him...I used to buy him clothes and new shoes and whatever.* Key Informant, Male, Age 75

**Community member acquaintances**

There is evidence supporting the involvement of other community members apart from close family and friends that adopt the role of informal caregiver. Informants unrelated to Dala or Christina have mentioned times where they have given them food or money. Based on interviews with these informants, this provision of support does not occur too often, but only sometimes when they ask and if they can provide it:

*We give as he (Dala) ask from us, sugar, we give him...he does not ask us every day, but some days he does, and he gets from us, but not every day.* Community member, female, age 30.

Though giving food and money can be seen as providing informal care to Dala and Christina, people in Platfontein often help each other out in this way, indiscriminately of their health situation. One community member acquaintance explains that though Dala asks him for money, he does not give Dala money any more frequently than he gives other community members (community member, male, age 23).

In a community as small as Platfontein, Dala and Christina are at the least recognized by
everyone on the khwe side of the community. Therefore those who are not considered family are most likely to be considered community member acquaintances. This is however not to state that there are no other forms of relationships. For instance, the extent of their relationships on the !xun side of the community, has not been investigated in this research.

**Motivations for support**

In the previous section, the two main informal caregivers family, and community member acquaintances are identified. Based on observations and interviews with different informants, a number of motives for providing support have been suggested. In this section we highlight some of the main reasons suggested for why informal caregivers provide Dala and Christina with support.

**Financial capabilities**

It was logical to assume that individuals with a higher financial status are more capable, and therefore more willing to provide support for mentally ill individuals like Dala and Christina. In the case of Dala, in particular, financial capabilities appear to have a significant influence in who the main informal caregivers in his life are. Observation and interviews with various informants have indicated Dala’s uncles Jason and Peter to be one of his main informal caregivers. As a present employee of the army, Jason has more means of providing for Dala compared to the rest of his family. Jason lives in Rodepan with his family, a nearby, yet more developed township. Dala regularly visits his uncle Jason, where he receives food and money. His other relatives in Platfontein regularly send Dala to his uncle’s house on the 15th of every month, knowing that he was just paid and can afford to support him.

*Every 15th he comes here. I am often at work but he will come here. If he gets the ma (his wife) then she will give what she can...she gives the food and when he is finished then he asks, give me please a 5 rand or 2 rand. Ma gives him and he thanks her and...then he leaves.* Key informant, male, age unknown

As a war veteran, Dala’s uncle and main informal caregiver, Peter, is also known to be a main provider for the family because of his financial capabilities. His health issues in recent years, however, have limited the extent to which he is able to contribute.

Though financial capability seems to play an important role in who takes on the role of informal caregiver in Dala’s life, the situation in Christina’s life seems to contradict these findings. As mentioned earlier, Matumba, Christina’s sister is one of the main informal caregivers in her life. However, unemployment, and several other family members to take care of, does not make her the most financially capable candidate. Observation has suggested that Christina’s brother Matthew lives at a higher standard than most people in
Platfontein. Relative to the standard, Christina’s brother Matthew lives in a large, well-kept house, with household appliances and owns two cars—a luxury that most community members do not enjoy. It is by these observations that Matthew seems to be in a far better financially capable state to take care of Christina than most of her informal caregivers. Interestingly however, observation suggests that the opposite seems to take place. Their infrequent visitations and seemingly ‘estranged’ relationship support this hypothesis. In the 10 weeks of observing Christina’s daily activities, she only visited her brother on one occasion. Talking from over the fence, the interaction was brief, and she left without entering the yard. Interestingly, while Christina has no problem visiting other family members to ask for food and money, she is ashamed of asking her brother for assistance:

I don’t come to this house. If that one (referring to her son John) if he’s hungry that’s why, if he’s hungry and he sends me to come, that’s why I ask him (her brother Matthew) for food. It’s a shame to come each and every day to your brother’s house. Case study subject, female, age unknown

Feelings of responsibility

Because of high rates of poverty, it is clear that not many people have the financial capabilities to take on the role of informal caregiver in the lives of Dala or Christina. However, despite the socioeconomic burden, several family members and community member acquaintances take on this role. Additional motives for adopting this role of informal caregiver point towards feelings of responsibility, felt by various relatives and community members. When investigating what the reasons were for having these feelings of responsibility, most information gathered about the informants suggest these feelings to be a result of past family ties, or a social obligation.

Past family ties

When asked about their past relationships with Dala and Christina, many informants recall ‘happier’ times when they were younger, before the onset of their mental illnesses. They also spoke about their duty to support them because of their shared history and family ties. Christina was older than most of the informants interviewed, and in the olden days she played the role of caretaker for many of them. Informants speak of a time when she would look after them, play with them, and teach them new things about life.

She used to come to me every day, and I used to take her as a human being (speaking in present tense). That time when I was growing up I know this is my aunty so she look after me so I take her as my aunty as a normal person, not even she’s normal but I can take her as a human being. Relative, female, age unknown
Dala on the other hand, was only an adolescent boy when his mental illness began. Most informants remember him as a young very helpful hardworking boy, with a promising future ahead—a hopeful future in which he would be able to help take care of his family.

At that time when he wasn’t sick he was the one who used to help me...He used to help me with wood fire anything, helping with wood fire collect, fetching water, look after my sheep and goat...I always remember what he did for me. He was very helpful as a young child and like if he isn’t sick then he was helping me with most things like going to work and bringing stuffs at home, because when he was young he was helping a lot and I can imagine like if he’s growing up now then he was doing a lot for me. Key informant, male, age 75

Though shared history and close family ties seem to be a good motivation for taking on the role of informal caregiver, the behaviors and activities of some ‘close’ family members contradict this interpretation. In the case of Christina, for instance, her brother and sister, with whom she shares a common history, do not provide the same level of informal care. After observing the relationships between these siblings, it was clear that the role of informal care was more heavily weighed on the sister Matumba, then the brother Matthew. As one key informant mentions, traditionally it is not expected for the brother to take care of the sister. In their tradition, the women in the family handle ‘women’ problems—problems that the male members of that family have no business or obligation to involve themselves with.

Christina’s estranged relationships do not end with her brother, but also with her eldest son Simon. Simon is one of Christina’s three sons. His resistance to participate in this research suggests that he is uncomfortable talking about his mother’s illness and has difficulties coping with it—an observation made based on his dismissive body language and obvious frustration when we spoke to his mother and cousins in his yard.

Social obligation

In either case, no matter what the relationship was like prior to the onset of their mental illness, in Platfontein, it is generally thought that it is the family’s responsibility to take the role of informal caregiver. Discussions with informants have indicated this to be partly due to a social obligation that is believed to be the cultural norm in the community. Several informants speak of this social obligation with unquestionable doubt. In Platfontein it appears as though community members take care of each other irrespective of their capabilities to do so, and this is even more the case with individual families.

It’s like I help mine and they should help theirs. But I don’t have a
I am Dala his uncle, Dala’s mother was my sister, she died. I speak with an open heart because it is my responsibility. I am the oldest uncle of Dala that is left. Dala’s father is not looking after him, many things have happened. Key informant, male, age unknown

It is this limited capability of taking care of their mentally ill relatives that defines this responsibility as a social obligation. This concept of ‘families taking care of their own’ is not a new concept. Across different cultures worldwide—both western and non-western—families take care of each other. What makes us view this particular case as a social obligation is the family’s dedication to taking care of their mentally ill relatives, despite the increasing socioeconomic burden it inflicts, and possibly estranged relationships that are also at times evident.

Some evidence of this is supported in past research conducted in SSA. In rural South Africa for instance, there is an increasing financial, physical, and emotional burden on elderly women taking care of their adult children or orphaned grandchildren due to the increasing burden of HIV/AIDS affecting these populations (Schatz, 2007). Additionally, due to infectious diseases such as HIV/AIDS, an increase in non-communicable chronic diseases is also burdening an innumerable number of families and communities in SSA with financial, physical and emotional strain (de-Graft Aikins et al., 2010). Also in SSA, an increase in family burden consequently resulting in a decrease in family productivity has led to a rise in epilepsy-associated stigma in different regions. Though the families will not abandon their relatives, the social worth of the epileptic individual has been devalued and leads to growing tensions and resentment (Baskind and Birbeck, 2005). In an environment often plagued with poverty, disease, unemployment and war—a history the Khwe and !Xun of Platfontein are all too familiar with—social capital is a vital resource in every household. Because of this, we believe that strong family ties are essential for survival in such conditions, and every individual must do their part. Manual labor is divided amongst every family member, whether it is firewood collecting, picking vegetables, working in town, etc. Once a person cannot fulfill their unwritten duty, it negatively impacts the rest of the family unit, as seems to be the case for Dala and Christina.

Though these feelings of responsibility are most heavily weighed on the family members of the mentally ill individuals, some community member acquaintances also feel that the community itself should share this responsibility:

> It is sad how people just leave him (Dala), we are a community, we are
supposed to be together, not just throw someone out. Community member, male, age unknown

Sometimes we, our peoples they used to watch him (Dala) where he went, where he is, because sometimes he don’t get any help from no one. Community member, female, age 30

Feelings of Reciprocity

Reciprocity is a characteristic that is not found in many of the relationships Christina and Dala have with their informal caregivers. However, despite it being uncommon, evidence suggests it to be an influence in providing informal care. For some informants, the shared company of having someone around like Dala or Christina, helps them in times when they feel lonely. For them, Christina or Dala provide company, and in return they provide food, money and shelter. Christina’s niece Rebecca, for instance, is considered a main informal caregiver, with whom her relationship does seem to be mutually beneficial.

Christina frequently visits Rebecca and receives food or something to drink. As most people describe a strictly ‘giving’ type of relationship with no reward, Rebecca is one of a select few of relatives who describe their relationship with Christina as mutually beneficial due to emotional reciprocity. Rebecca expresses that at times life can be lonely in Platfontein, and people do not seem to visit each other. Christina visits her and gets food in return while she keeps her company.

It’s like I will say we are close, because, she used to come to me and I said we used to spend some time together. And uh as we are spending time together and maybe I have a problem or there’s something disturbing me and um I used to say with her...I don’t have some friend who come to me and she’s the one who come to me and I like to talk with her she’s my friend...and she discuss with me my problems. Key informant, female, age 30

Other, more distant relatives, share the same sentiments in which they express that they are happy when Christina comes over because she keeps them company when they are lonely:

I don’t mind because nobody is visiting me, she is the one who is visiting me and talking with me and then I am laughing. Community member acquaintance, female, Age 21

This feeling of reciprocity, however, is not shared by most of the informal caregivers in Christina and Dala’s life and seems to be one of the root causes of disappointment when taking care of them. Christina’s brother Matthew, for instance, seems to also have a sense of disappointment towards Christina’s illness because of her
lack of contribution towards the family. When asked if Christina helps with anything in his household he responds:

*no there is nothing she can help me with. I used to feel that she should help.* Relative, male, age 49

In the case of Dala, these feelings of disappointment towards his lack of contribution are more widely identified. Dala’s uncle Peter, like several of his other relatives express their frustration with Dala’s condition and of the burden it places on his family. With nothing to talk about because of his mental illness, and his inability to support himself, Dala’s relationship with his family is solely based on receiving their support with little evidence of reciprocity:

*There is no relationship, like, we don’t understand each other, ya that time we understood but now we don’t understand each other...When he’s here he just cries of hungriness. I’m hungry, coffee, something. He need food.* Key informant, male, age 75

Additionally to this lack of reciprocity, Dala’s inability to fulfill his assigned role as a family and community member seems to create further upset. As a young male adult, Dala should be contributing to his family’s livelihood. It is he who should be taking care of the women and elderly in his family. Several family members share this sentiment:

*I asked Dala, when will you do the right thing...That you help me, I am old, my sister died, now you are the oldest that needs to help me. Who is going to help me?* Key informant, male, age unknown

*She was wondering maybe that time Dala will finish school and then one day he will support her. Cus then one day when she find out he was mad, and then her hopes was that he will not make it. But she still love him and she still there for him.* Interpreter’s translation, Key informant, female, age 52

**Support Strategies**

Now that the main informal caregivers in Christina and Dala’s life have been established, this following section investigates the various means in which these different actors provide informal care.

**Instrumental support**

For Dala and Christina, their daily mission is to find a means to satisfy their hunger as well as their cravings. From dawn until dusk they roam the streets visiting the various family and friends they know in search of opportunities to do so. In Platfontein, the main means of support given to people like Christina and Dala is instrumental support. A number of different forms of instrumental support have been identified while conducting this research.
Commodities

In Platfontein, it was observed that the most common forms of instrumental support for Dala and Christina include: Food, beverages, money, shelter, and clothing. It is noted that this practice is not exclusive for the mentally ill, as it is common practice for community members to search for means of getting food on a daily basis. It is worth arguing, however, that the disabilities set against Dala and Christina, make it more difficult for them and so they are more dependent on the charitable donations of others compared to the average community member.

*It’s like it’s difficult to help him in another way. But when he come close to me I used to help him with food.* Key informant, male, age 75

*If she come to me and ask anything like food and something to smoke I used to give if I have.* Relative, female, age unknown

Government Grants

While the financial capabilities of the informal caregivers are seldom enough to provide the support necessary for Dala and for Christina, there are government grants available to provide assistance for such support. One grant in particular is given to people who have a disability and are physically or mentally unable to support themselves. Christina receives this monthly disability grant, while her son John, who is also considered mentally ill does not. Christina’s relatives claim that because John does not get the governmental grant, they share the grant given to Christina between her and her son. Despite several attempts to obtain a government grant, Dala still does not have one and thus receives no financial support from the government. Informants claim that Dala has destroyed his ID card and without it he cannot apply for the government grant. Repeated attempts by family members to renew his ID card have failed. This struggle to obtain a government grant is further elaborated on in a subsequent chapter.

The Clinic

Within Platfontein, the health clinic is another form of instrumental support that is available to mentally ill individuals such as Dala and Christina. The clinic is the only health service provided in the Platfontein community. It caters to several of the major health problems experienced in the community such as HIV and TB, as well as mental illness. According to the head nurse, the clinic presently has 22 mentally ill patients on record, all of which have been diagnosed with alcohol or drug related psychosis with one exception of depression.

Dala is one of the 22 patients on record at the clinic, however, there is no record of Christina as a mentally ill patient. A select few of Dala’s relatives have claimed to take him to the clinic on different occasions, however there are only two confirmed occasions on which he has been taken to the clinic in Platfontein. His first visit to the
clinic was in January of 2009 after he was referred from the hospital in the city, and officially diagnosed with epilepsy. Since that day, there has been no record of Dala returning for treatment at the clinic, despite the claims from his relatives. Dala did return to the clinic however, in February of 2013 for injuries he sustained to his jaw during a conflict in a nearby township.

Though the clinic is a formal health care setting, there seems to be a heavy emphasis on the cooperation of informal care. This idea is suggested by planning and implementation of several treatment protocols set out by the clinic that involve the help of informal caregivers of mentally ill individuals. The head nurse explains that in first instance usually the family of the patient comes to see the nurse and she then goes to evaluate their condition. If the person says they are fine, and that they do not need treatment, the clinic cannot take them, as it is the patient’s right to refuse treatment. The nurse evaluates the person’s behavior, by seeing if they are talking ‘strange things’ or talking to themselves. If the patient is violent, police assistance is requested and they are taken to the hospital in Kimberley to get diagnosed. Once the patient is diagnosed, they must then return to the clinic for a treatment plan. In these scenarios, the informal caregivers are heavily involved in home-care. They must ensure that the patient takes their medication every day as prescribed, and ensure that it is taken with food. After the diagnosis, the patient must be brought to the clinic every day for the first two weeks in order to get used to taking their medication on a regular schedule. Though it depends on the specific prescription, treatment usually entails a daily consumption of tablets with food, and they must return to the clinic for a monthly injection. The clinic only provides tablets for one month, after which the patients have to come back for a new package. After 6 months, the patient will see a psychiatrist for reassessment of their condition and to determine if the medication needs to be changed. Throughout the course of treatment, home-based health workers from the clinic are meant to make weekly checkups on the patients and their informal caregivers to see if they are complying with their treatment regimens. During these check-ups the patient needs to demonstrate how and when they take their medication. If the patient does not return for renewal of their medical prescription, an investigation by a member of the clinic staff will take place.

**Expressive support**

In all interviews, most informants spoke about the various types of instrumental support that Dala and Christina may benefit from. Very few informants neither mentioned providing any form of expressive support nor acknowledged the necessity of expressive support. Expressive support was operationalized as emotional support and feelings of comfort for the understanding of the informants, however the concept proved to still be difficult to understand during interviews. Through careful
observation however, noticeable instances of expressive support were noted on rare occasion with Christina. During the fieldwork it was unclear whether many community members were laughing at or with Christina. Christina would walk into a group of people and say something, and everyone’s reaction would be to laugh. Interestingly enough this did not seem to bother Christina, but instead it made her smile and interact even more. This observation was in sharp contrast to an incident experienced with Dala during an early interview, where people’s laughter made him upset and want to leave. When further investigating the laughter Christina experiences, informants stated that they laugh to make her feel comfortable and included. While what she says does not make sense most of the time, laughter reassures her that she is not being ignored and that people want to include her.

Christina comes there (to her niece’s house) every day or at least almost every day. She sits and talks and then she goes somewhere else. She feels better when she sits with people and talks. The people in the yard give her food or tobacco. They talk amongst each other. When she comes sometimes she is able to talk normal but then in the conversation she also goes ‘off track’. They all laugh together. Her niece said it makes Christina feel better when they sit, talk and laugh together. Christina jokingly turns to us and says that we are her children. We ask her if we can hang out with her for a day. Everyone laughs. ‘I am not looking for a husband’, she says wittingly.

Researcher’s field notes

This observation is interpreted as a type of expressive support in which informal caregivers help build self-esteem and to encourage mentally ill individuals such as Christina.

Routine versus Crisis Support

While studying the daily activities and interactions of Dala and Christina, a clear picture could be made for what can be described as routine support, and what defines cases of crisis support. Christina and Dala for instance, visit several specific family members on a daily basis, drawing the conclusion that the support they receive from these informal givers is quite routine. Whether or not these relatives are able to provide them with support such as food or money depends on their daily circumstance however. While relatives usually say that if they have any means of supporting them on a given day, they would do so, the insecurity of daily life in Platfontein means that food or money is never guaranteed on any given day. Therefore while it seems logical to conclude that the support of food, money and shelter by informal caregivers is routine, the conditions in Platfontein mean that Dala and Christina, like many community members, often go without such support.
Additionally, while the clinic requires the cooperation of informal caregivers of mentally ill patients to receive treatment on a daily basis, this also does not take place for either Dala or Christina. Based on interviews with informants it was deduced that they only make use of the health facilities offered in Platfontein in rare crisis situations. When investigating what ‘a rare crisis situation’ entails, in the case of Dala it appears that his family only takes him to the clinic when he starts acting violent towards himself or towards others:

And he was also trying to kill his mother, so all the time we have to protect him. Protect his mother from him. He was a danger in our family. So then is when we realized now we have to take him to...the hospital.

Key informant, male, age 30

There is no record whether Christina has been to the clinic in Platfontein. For hypothetical purposes, the family was asked on what occasion *would* they take Christina to the clinic. It appears that Christina would be taken to the clinic only if she experiences a physical discomfort, such as a headache or excessive coughing. Medical attention for her mental illness was not suggested:

At a point when Christina is having a headache or coughing too much, then is when she want to take Christina to the clinic but she don’t want. Key informant, female, age unknown

### Factors hindering support

**A place of worship and ridicule**

Christina walks into the churchyard where there is a group of people, mostly middle-aged to elder women. Christina starts to speak openly. One woman touches Christina’s hat, appearing as if to admire it. The woman then touched her own skirt, appearing to show it off. Almost immediately, Christina begins to shout and point in an accusing manner. The women in the churchyard began to encircle her, curious and entertained at what Christina was saying. They mostly laughed, and one elder woman, mimicked Christina from behind her, imitating her expressions. Clearly angry, she leaves the churchyard, still shouting and pointing. The women continue to laugh and joke. For Christina at least, prayer and worship will have to wait another day. Researcher’s field notes

**A deceptive friend**

I follow Dala to his house with the things I had purchased for him as a goodbye present. Two elder women stop him and attempt to have a conversation. One woman starts to pull things out of the bag, seeming to me that she was claiming some of the things I was trying to give to Dala. Dala was now sitting on the ground in front of us, with the bag completely ripped open. The woman had grabbed the bag of oranges, an empty beer bottle, and the sweet biscuits. I explain to them that I bought these groceries for Dala. After telling him something in kweledam they give him
back the groceries and get another bag for him to put the things in. I walk with Dala to his house. At his house, his friend John is there to greet us. He asks me what was in the bag and I told him Dala’s things. I walk inside Dala’s house with him. It is completely empty of furniture but covered in garbage. Dala goes into the backroom where he proceeds to take a piss. I say goodbye to Dala and leave. For a brief moment I turn around to find John fighting Dala for the bag of biscuits I had given him. Eventually John takes the bag of biscuits. I was disappointed to see this deceptive behavior. In front of me, John appears to be the supportive friend, however behind my back he seems to take advantage of Dala. I see them leave together, Dala holding the oranges and John holding the biscuits. John gestures that they are going to sell the oranges to make money. Later on I see them still walking together. This time, John is holding the oranges. I got the feeling that Dala had little control over this situation, and that he was not going to get much benefit from this situation. Researcher’s field notes

In talking to different informants and observing the daily lives of Dala and Christina, the difficulties and burden in providing support were unmistakable. The extracts above, describe situations in which a number of challenges have hindered informal care efforts and led to Dala and Christina’s suffering. This following section will address important issues that have been found to hinder informal care efforts for mentally ill individuals. In doing this research, 4 major themes have been identified as factors hindering support efforts (i) substance abuse, (ii) Clinical regulations, (iii) personal hardships, and (iv) stigma.

Substance abuse

The informal care that Christina and Dala receive is not always beneficial to their wellbeing. Christina is often seen receiving tobacco while Dala often receives alcohol and cigarettes. Alcohol, drugs, and tobacco are commonly used in Platfontein and as a result allow mentally individuals like Dala and Christina to be easily exposed to them. These items are not only further detrimental for their health but some family members worry that it also subjects them to danger:

So let him stop those things they ask him to stop. I think then the treatment could help him. He is still doing the things people are trying to stop him (from doing). Even me you know he asks me sometimes to smoke…I don’t give him all those things. I would rather give him money but not cigarette or a beer, but somehow he gets those things.

Key informant, male, age 30

Clinic Regulations

Though the clinic appears to have a very comprehensive procedure for dealing with mentally ill patients, a large portion of the responsibility is placed on the informal
caregivers. The local situation in Platfontein makes these rules and regulations difficult to comply with for both caregivers and their patients. With the help of discussions with clinic workers and interviews with the informal caregivers some of these issues were brought to light.

Unrealistic demands on the family

The first, and major limitations to providing informal care are the unrealistic demands on the family to do so. As can be interpreted from the clinic procedures mentioned earlier, a large portion of the responsibility for taking care of the mentally ill patients is placed on the family. For the first two weeks, the family must ensure that the patient goes to the clinic to take their medication. If the patient resists treatment, the family must ensure that they are escorted to the clinic on a daily basis. Additionally the family must bring the patient to the clinic on a monthly basis for their injections and prescription renewals. There are several accounts of Dala’s health condition improving with treatment, however he soon relapses into a poor state because treatment was never continued. One explanation given by a relative is that there is no one to take Dala to the clinic. The fact that all medication must be taken with food poses another major burden on the family. In households faced with extreme poverty and daily struggles for food, taking medication with food on a regular basis during the day is an unrealistic luxury for many. The extra demands of the clinic on the family’s required constant presence further exacerbate the dire conditions they are often already faced with.

Resistance to treatment

Though many informants have attempted to take Christina or Dala to the clinic, they were always unsuccessful due to their strong resistance. Several speculations for this resistance have been made. For one, Dala and Christina have continuously denied ever having a mental condition and therefore refuse to go to the clinic. Another interesting possibility is the fear of stigmatization. In a community such as Platfontein, where HIV and TB are highly endemic, if you are seen going to the clinic, you risk being associated with one of these tabooed illnesses (Tomaselli, 2013). Based on this observation it can be stated that privacy and anonymity is an important factor for many patients. In this respect, certain clinical practices have compromised this patient confidentiality that community members seem to desire. Medical files providing patients’ names and medical histories, for instance, are freely provided to those who request it. A second procedure that raises concern about privacy issues is the calling of patients’ names over the radio, instructing them to come to the clinic for their psychiatric consults. These public announcements make it very easy to determine who the mentally ill patients are within the community.
Admittance protocol

There is no record of Christina ever visiting the clinic in Platfontein. When investigating the reason behind this, several family informants have stated that they have attempted to take her but she did not want to go. A similar story holds for Dala in which he also refuses to go to the clinic despite the attempts of his relatives. Their behavior prove to make treatment almost impossible as, according to the clinic, treatment can only be given if the patient agrees to it. An only exception to the rule stated by one health care worker is that if the patient is inflicting violence onto others, they can be admitted against their will.

Insufficient resources

The Platfontein clinic has rules in place that are meant to facilitate the use of home-based care, ensuring that patients follow their treatment plans and that there are no losses to follow up. These rules however are not always put into practice. In the case of Dala for instance, there has been no follow up on his mental illness since his first diagnosis in January 2009. He has not returned to the clinic for treatment, nor has any clinic worker investigated why he has not returned. One clinic worker blames the lack of follow up on the psychiatric specialist. He states that this incident should have been brought to the attention of the psychiatric specialist, but they missed it. He says that in addition to not being so experienced, they also have the added burden of keeping track of the Anti Retroviral Treatment (ART) regimens of the community’s HIV patients. This example, and the clinic worker’s explanation for the lack of follow-up on Dala’s condition bring to light the issue of insufficient resources available for catering to the clinic’s and informal caregiver’s needs. With overworked staff members managing major disease burdens such as HIV and TB, and not enough resources to pay each patient the attention they require, even more responsibility is placed on the informal caregiver to ensure that treatment regimens are fully complied with.

Government Grants

A common complaint of family informal caregivers is the difficulty in obtaining government grants for their mentally ill relatives. Dala’s family has tried on numerous occasions to apply for his government grant however was not successful because they did not have an ID for him. Dala’s uncle claims that he was not allowed to get him an ID because he was not considered immediate family. Dala’s father on the other hand, was continuously unavailable to apply for his ID. The lack of success in obtaining Dala’s ID card and government grant are a reflection of the rigid requirements set in order to obtain them—requirements that are unrealistic for Dala and his family to meet.
**Personal Hardships**

The ability to provide informal care through means of social support is strongly influenced by the personal situations of the informal caregivers. Unfortunately the general living conditions in Platfontein are poor and can therefore hinder support efforts. The majority of the population in Platfontein is poor, and struggle for food and other resources on a daily basis. In a population with a 96% unemployment rate, many people are struggling to survive as it is and the extra burden of taking care of Dala and Christina is something that many people cannot afford. Some informants state that even though they are willing, they do not have the resources to support Dala or Christina. “To help Dala is like I said I don’t have a job. If I have a job it is better for me I can take care with my own I can give him money” (key informant, female, age 48). While some informants are employed, they feel that they have a responsibility towards supporting their more immediate family before they can support people like Dala or Christina. “I cannot on my salary take care of him. I also have children and a house that I have to pay for” (Key informant, male, age unknown). Additionally the time it takes to provide informal care, such as supervising Dala or Christina when taking their medicine, or bringing them to the clinic on a daily basis, is time taken away from work productivity. Despite the general feel of communal sharing and helping each other, poverty and illness has severely limited the extent to which people can help one another, and for these reasons, those who cannot help themselves such as Dala and Christina, sometimes suffer the most.

**Stigmatization**

So far in this section we have looked at practical factors that hinder the ability to provide informal care, however there are additional social factors that may also hinder the willingness to provide informal care. For research purposes, these social factors are generally collectively classified as stigmatization. Based on the observations made in this research, two main factors, fear and unawareness, have been identified that may contribute to this stigmatization.

**Fear**

Fear is a powerful tool in influencing social norms. As described earlier, family and friends are the main informal caregivers for people like Dala and Christina. They understand their behaviors and have grown to accept them. People who do not know Dala or Christina on the other hand, do not know what to expect when they see them, and therefore are less likely to provide assistance. When asked how do you react when you see someone who is mentally ill, one informant responded, “I don’t do anything...I don’t always talk to them, I just pass them. I just see them and go pass them. I don’t even talk to them” (Community member, male, age 23). Particularly in the case of Dala, his sickly appearance and at times aggressive
behavior invokes fear in several community members and thus hinder their willingness to help them:

I’m just a little bit...uh how can I say it, afraid of him, because I don’t come closer to him, because I don’t know what he gonna do to me...I think he can beat or he can do anything to me...I don’t interact with him. Community member, male, age 23

Unawareness

For the scope of this research we define unawareness as a lack of knowledge that consequently hinders people from making informed judgments and decisions concerning mentally ill individuals. As described earlier, many community members have little knowledge over the causes of mental illness and the type of help mentally ill people need. Not knowing how to deal with mentally ill people has led some community members to make decisions that may not necessarily be best suited for the patient. Some people, for instance, believe that removing them from the community and putting them in isolation with others just like them would be the best solution:

“They need to be introduced into a society, to institutions, where they are taking care of people, (with) those kinds of positions” (Community member, male, age 36).

Other people dismiss their concerns all together, stating that they cannot be helped at all:

That’s not to heal. Somebody can’t heal her. Its like somebody sacrifice her, for something...When I see her and I know that ya this is dead. Somebody sacrifice her. Key informant, male, age unknown

There have been multiple reports from informants stating that Dala has also been wrongfully imprisoned, and accused of rape. The facts of this matter cannot be verified, however family members insist that Dala has never committed such acts and that he was imprisoned because people feared what he might do if left free. One informant brings up an important topic concerning the improper punishment and mistreatment of mentally ill people accused of crimes they may or may not have committed:

He was spending 1 to 2 years in jail for a crime he didn’t commit. Because a person like him can’t even remember what he was doing on the very same time. Or you can ask him one question and ask him the very same question after two seconds he will give you the same question two different answers. I believe the law can’t put him in jail, he don’t even understand. You can’t just put him in jail. You can punish him but he won’t realize he is being punished. Key informant, male, age 30
Fear and unawareness collectively have caused people to prejudge the lives of mentally ill individuals such as Dala and Christina, and have as a result also limited people’s willingness to care for them, both instrumentally as well as emotionally.

*(Dala is) somebody I know...not a close friend...The difference is, Dala’s mind is not like, just like me...We are also human beings but he is not a really person...He’s different because I don’t want to be close with him. But I know him.* Community member, female, age 30

**Discussion**

This study has shed light on important issues surrounding informal care in a resource-poor setting. In 2001, the WHO published a list of ten recommendations for public mental health priorities in the World Health Report. One of these recommendations was the involvement of communities, families and consumers (WHO, 2001). The dependency on informal caregivers has been thoroughly demonstrated in low, middle and high-income countries (Tausig et al., 1992; Mulatu, 1999; Patel and Prince, 2001). Like in Platfontein, this dependency is most heavily weighed on the family members of mentally ill individuals.

In a study conducted in Cincinnati USA, 150 different caregiving settings were identified involving 409 caregivers of mentally ill individuals. Family members dominated the caregiving system with 72% of the caregivers reported to be kin of the mentally ill individual (Tausig et al., 1992). In a study comparing the perceptions of mental and physical illness in Northwestern Ethiopia, 450 adults were interviewed to explore their beliefs and perceived importance of various treatments for different physical and mental illnesses. Results indicated that home and family care were the primary source of care and more strongly suggested for mental than physical illness (Mulatu, 1999). In Goa, India, focus groups were used to discuss the concept of mental health conditions in elderly people. A majority of key community informants expressed that dependency needs of the mentally ill were almost entirely the responsibility of the families of the mentally ill individuals, with little or no use of formal services (Patel and Prince, 2001).

The traditional arrangement of families taking care of their disabled relatives is common practice worldwide, however evidence suggests an increasing burden on families particularly living in resource-poor settings (Seeley et al., 1993; Patel and Prince, 2001; Baskind and Birbeck, 2005; Schatz, 2007; de-Graft Aikins et al., 2010). This research was initiated with the aims of identifying support systems for mentally ill individuals in Platfontein. Interestingly, one of the main findings that came up in doing this investigation were the negative conceptualizations of the experiences of informal caregivers with taking care of mentally individuals such as Dala and Christina. The main negative
conceptualizations we identified include struggles in providing support, casting these individuals off as incurable, frustrations in baring the responsibility to support, regret for not having a functional relationship, and disappointment for a lack of reciprocity.

We hypothesize that there can be several explanations for these negative conceptualizations, including cultural explanations that are intrinsically embedded in the community, as well as practical matters that are more household specific. A common cultural explanation of madness is the belief in supernatural causes. The belief that witchcraft is the cause of people’s madness may prevent people from viewing madness as a medical condition and prevent them from seeking out medical attention for treatment or a cure. However, these causal beliefs do not necessarily always match health-seeking behavior, as some informants who believe witchcraft to be the cause do still say that they would bring the mentally ill person to the clinic. Speculations of witchcraft being the cause of mental illness can also lead to community members spreading rumors about whose fault it may be, resulting in family members feeling guilty, or upset (Gona et al., 2010). This seems to have been the case for Christina’s brother Matthew. Because he seemed to be more financially well off than the average community member, people accused Matthew of sacrificing his sister by performing witchcraft in order to achieve a higher status. Matthew expresses how these rumors upset him as he tries his best to take care of her and it goes unappreciated.

Additionally, viewing madness as a consequence for performing an act that is considered taboo, such as upsetting the elders, may make people believe that these individuals are responsible for their own condition (Mavundla et al., 2009). These beliefs could have an impact on the extent to which other people sympathize with the mentally ill individual—as was witnessed on few occasions in Platfontein.

Practical matters that could explain the negative conceptualizations by informal caregivers are specific to the conditions within the households of informal caregivers. One particularly interesting hypothesis for differences in how families cope with mentally ill relatives is the perception of the individual’s role in the family. In a resource poor setting such as Platfontein, strong family ties are what are necessary for survival. Each individual member plays his or her role in supporting the family and their social worth is largely based on their ability to fulfill this unwritten duty (Baskind and Birbeck, 2005). These unwritten duties may be a key factor in explaining the differences in care between Dala and Christina in this study. Before the onset of his illness, and as a young male, there were high expectations for Dala to grow up and be a main provider for his family. The role changes in his family as a result of his illness seem to translate into the frustrations witnessed when studying Dala’s family network of informal
caregivers. As described earlier, relatives such as uncles and sisters wish for a time when Dala would be healed, and could finally support them.

She was wondering maybe that time Dala will finish school and then one day he will support her... When she find out he was mad, then her hopes was that he will not make it. Interpreter's translation, Key informant, female, age 52

Christina on the other hand was an elder female who had already brought up children before the onset of her illness. It seems that the expectations for her to provide for the family are less than is the case for Dala, and therefore her illness seems to be met with less resentment. These unwritten duties seem to be one way of dictating the level of urgency for seeking treatment for the mentally ill individual. Evidence suggests there to be a greater sense of urgency of informal caregivers to seek treatment for Dala compared to Christina. We speculate this to be the case because some respondents hoped that Dala could one day still be cured and provide for his family. These hopes seem less present in Christina’s family, though the lack of urgency to seek treatment for Christina may also be explained by other factors that have not been explored.

In a study conducted in 2006 in Limpopo South Africa, findings similar to this research were also concluded. The study explored the experiences of informal family caregivers in taking care of mentally ill relatives and discusses four major themes: experiences in providing physiological/physical needs, emotional needs, security needs, and experiences associated with a medical healthcare program (Mavundla et al., 2009). In discussing these themes, the author identifies support mechanisms and challenges that were also identified while conducting this study. Both studies report that the main forms of support provided by informal caregivers to include the provision of food, shelter, clothing, and emotional support. They also both report the financial burden of providing these different forms of support and the struggle for seeking care. We believe that the similar findings reported in the 2009 study, validate the findings of this present study in demonstrating the process of informal care in providing support for mentally ill individuals in resource-poor settings in South Africa.

The study conducted by Mavundla et al (2009) seems to be the best reference up to date in describing this process of informal care, however, the selection criteria used to recruit patients, and methods chosen for data collection unfortunately provide a limited view of informal care. The study selects for household family caretakers and patients who regularly visit the clinic, however, excludes informal caregivers and patients who are unable to visit the clinic, as well as relatives and non-relatives who do not live with the mentally ill individual, yet still provide some form of informal care.
By including these other social networks in this present study, we believe this research provides an even more accurate description of informal care in a resource-poor community in South Africa. In Platfontein, we identify a number of community member acquaintances that share the responsibility of providing support for Dala and Christina with their relatives. With our wider inclusion criteria for selecting case study subjects and more extensive data collection strategies such as participatory observation, we demonstrate that mentally ill individuals such as Dala and Christina, are not as isolated as Mavundla et al. (2009) previously suggests. We indicate that the burden of informal care is not confined to the household family members of the individual, but is a collective effort by distant relatives as well as community member acquaintances, and that mentally ill individuals have the ability to seek out these sources of support.

Research Design

There were a number of limitations that were unavoidable and must be factored in when considering the conclusions of this article:

Time restraints

Due to time constraints, a limited period of 10 weeks was allocated for data collection. Though substantial insight was gained, conclusions are based solely on this 10-week period. It is worth noting that the behaviors and situation could change for the subjects and their informants over a period of months, or years. For instance, Dala’s father whom according to several sources is his main source of social support was away working on a farm during the duration of this research. It can be suggested that in the absence of his father, Dala’s life may look somewhat different then normally. Though Platfontein is relatively safe, reports of violence are not uncommon. For the research team’s safety, they did not stay in the township as a result. Consequently, daily observation time was restricted to between 8.00 and 18.00. As a result, there is no record of what occurs in Dala or Christina’s life outside of these hours.

Language barriers

As the main languages spoken in Platfontein were Khwe, !xung, and Afrikaans, only 25% of the community population spoke English (Letsoalo, 2010). As a result, language barriers between the researchers and community members limited the depth to which communication was established. During observation, the researchers could not understand the spoken words exchanged and had to rely heavily on facial expressions, body posture, and tones of voice to make interpretations. Additionally, there were times when the English phrases used during interviewing were not understood by informants and resulted in misinformation being given. Using one translator throughout this research made the interview process much easier as well as consistent for collecting data. However, at times it was evident that the translator
rephrased informants’ answers according to how he interpreted it rather than verbatim. In their 2004 article, Temple and Young claim that there are several dilemmas presented with language translation in qualitative research, and that it is necessary to acknowledge the issue, as it most certainly impacts the way your data is interpreted (Temple and Young, 2004). Given the time and resource limitations of this project, the use of a translator during the interviews resulted in what is described as the ‘early domestication of the research into written English’ (Temple and Young, 2004, p.174). As language is seen to be very culturally bound, this strategy limits the cultural context to which the data is tied. This could have forced us to make generalizations of what was being said, missing important details of personal accounts given by the informants. The triangulation of methods strategy adopted by this research helps to reduce such limitations by validating what was reported in the interviews.

Ethnographic bias

One major advantage of the method of observation is that it offers excellent insight into the interactions of the people being studied and verifies whether what was stated in the interviews was true or not. In the case of Dala, for example, one informant contradicted himself when stating in an interview that he did not give Dala any money, while in reality he was observed to do so. Despite these advantages, one major limitation of observation is the influence of the researcher’s presence, referred to as ethnographic bias. Though it would be ideal to remain objective and not influence the lives of the population being studied, a researcher’s presence will always influence a situation to a certain extent. Sometimes informants say what they think you want them to say. They may also behave the way they think you want them to behave. Informants may have also paid more attention to Dala and Christina’s presence, behavior, or needs in the presence of the researchers. Dewalt et al (2011) studied the influence researchers conducting participatory observation in fieldwork had on their data. They conclude that bias is an unavoidable systematic occurrence and cannot be separated from the accounts that the researcher writes. For instance, the willingness of people to talk, and the level of truth spoken, reflects a level of confidence and comfort with the researcher (Dewalt et al., 2011). The type and quality of the data reflects the characteristics of the researcher, including age, gender, ethnicity, sexual orientation, experience, etc. While these biases are unavoidable, it is imperative that the researcher’s reporting make these biases as explicit as possible, to allow the reader to use them in judging and interpreting their work. Though these biases are unavoidable, the use of additional methods such as semi-structured interviews does increase the quality of reporting data (Verschuren et al., 2010).
Important lessons and Recommendations

While the role of informal caregivers in both resource poor and resource rich countries is well documented, this research, using its qualitative methodology, obtains a more humanized account of the reality of informal care in a resource-poor setting. Firstly, it gives a more accurate description of the informal caregiving system in Platfontein, identifying the main actors and what roles they play. Secondly, it highlights some of the important challenges, social pressures and personal struggles of taking care of mentally ill individuals in a resource-poor setting. Lastly, by understanding the specific challenges faced by informal caregivers, this study identifies areas for improvement where informal and formal care services can work together more effectively.

One important lesson learnt is the need to re-evaluate the assumption that family can and should provide adequate support to their mentally ill relatives. The loss of income, and social capital due to having to deal with the burden of having a mentally ill relative seems to further perpetuate the vicious cycle of poverty for themselves and the entire community (Gona et al., 2010). It is imperative for appropriate support and relief programs to be put in place to relieve some of the burden on family and community members who provide informal care.

Unfortunately there is limited documentation demonstrating the improvement of informal care for mentally ill individuals in a resource limited setting, however lessons can be learned from mental health services scale-up initiatives in general. Based on some of the different studies conducted, we propose three approaches to improving the conditions of informal care for mentally ill individuals in a resource-poor setting:

Accountability

While there are legislations in place in South Africa that are meant to protect the rights of disabled people such as mentally ill individuals, there is a general lack of political commitment to do so. Eaton et al (2011) demonstrate that being persistent, showing evidence of effective interventions in other places, and placing responsibility are effective ways of increasing the priority of improving mental health care on political agendas.

Education

An important finding in this study was the lack of awareness of the cause and treatment options of mental illness by the majority of informants. As described earlier, we hypothesize that this may result in stigmatizing beliefs that hinder people’s willingness to help. Community members should be educated on how mental illness can be dealt with. However, rather than an imposition of western models, this education should be a negotiation to the cultural beliefs of the community. In an article published in 2002, Leininger et al discusses the culture-care theory. It
explains that traditional explanatory models of care should not be dismissed in place of biomedical explanations (Mavundla et al., 2009). Though this theory is meant specifically for the integration of traditional and modern health care procedures, we believe it also applies to the general knowledge of mental illness. Additionally, engaging community leaders, elders and healers, have been shown to improve mental health awareness and encourage sharing responsibility or the burden carried by family members. (Rangawsamy et al., 2008; Patel et al., 2010; On’okoko et al., 2010; Eaton et al., 2011).

Improving access to care

An important issue that must be addressed to improve the quality of informal care is the improvement of access to mental health services. As demonstrated earlier, access to medical care is made difficult by the rules and regulations of the clinic. Clinic practices should be re-evaluated and specifically adapted to the conditions of the community in order for patients and their families to be able to comply with treatment regimens. Extra effort should be made to improve the attitudes and expand the depth and quality of training clinical staff, community volunteers, and family members. In addition to providing quality care to mentally ill individuals in an informal setting, the skills they learn can be beneficial in any future situation, including employment opportunities (Patel et al., 2010; On’okoko et al., 2010).

Conclusion

This research has brought to light some of the main actors and support mechanisms involved in the informal care of mentally ill individuals in Platfontein and have highlighted some important factors that hinder support. In doing so it is our hope to have facilitated a gateway into establishing intervention strategies for improving the role of informal care and the wellbeing of Platfontein’s mentally ill as well as their caregivers. While the results of this research are specific for mental illness in the South African township of Platfontein, it can be used as a guideline for outlining some of the main issues surrounding the support of mentally ill individuals in different communities experiencing difficult challenges such as poverty, disease, and violence.

Author’s disclaimer

The views presented in this article are strictly based on the observations made and interviews conducted by the author (ARG) and fellow researchers in Platfontein. These views do not necessarily correspond to any official policy that may be established in the community. ARG is a master’s student of biomedical sciences at the Vrije University Amsterdam. This research was conducted in order to fulfill his master requirements for the specialization of international public health. As principle investigator, ARG’s role was to write the research proposal which was to be approved by his supervisor, data
collection by means of semi-structured interviews and observation, transcribe and analyze interviews and field notes, and present the results by means of this article.

Acknowledgements

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APPENDICES
## Appendix 1 Subject Interview List

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<tr>
<th>Subject number</th>
<th>Name</th>
<th>Relation to case study</th>
<th>Gender</th>
<th>Age</th>
<th>Employment</th>
<th>children</th>
<th>Marital status</th>
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<tr>
<td>7</td>
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<td>30</td>
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<td>8</td>
<td>Skambo’s mom</td>
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<td>9</td>
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<td>Female</td>
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<td>about</td>
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<td>17</td>
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### Subject Demographics

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</table>
Appendix 2:

Case study Interview Guide

Introduction of interviewer

Hello, my name is…………………………………………. I am a masters student from the Netherlands and I am here as part of a research project that would like to know more about if and how people like yourself receive social support here in Platfontein. I would like you to know that you can trust me and that no one will know that the information you give me comes from you. I would also like you to know how much we value the information that you provide and how important it will be for future potential intervention programs.

During the interview, I would like to discuss the following topics:

(i) Your background  
(ii) Your perceptions of the social support available to you in Platfontein  
(iii) Your perceptions of any type of discrimination you may feel here in Platfontein

Now with your permission I would like to record this conversation. You will be completely anonymous. Shall we get started?

General information

<table>
<thead>
<tr>
<th>Main questions</th>
<th>Additional questions</th>
<th>Clarifying questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>• What is your name</td>
<td></td>
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</tr>
<tr>
<td>• How old are you</td>
<td>• When is your birthday?</td>
<td></td>
</tr>
<tr>
<td>• Are you married?</td>
<td>• What is your husband’s/wife’s name?</td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Follow-up</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Do you work?</td>
<td>What is your occupation?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Can you expand on this?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Can you give an example?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Is there anything else you would like to add to this part of the discussion?</td>
<td></td>
</tr>
<tr>
<td>Do you have any children?</td>
<td>Can you describe what everyone in your household does for a living?</td>
<td></td>
</tr>
<tr>
<td>Who lives at home with you?</td>
<td>Can you expand on this?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Can you give an example?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Is there anything else you would like to add to this part of the discussion?</td>
<td></td>
</tr>
<tr>
<td>Can you describe what you do on a daily basis?</td>
<td>Can you expand on this?</td>
<td></td>
</tr>
<tr>
<td>What are some of the activities you take care of in your household?</td>
<td>Can you give an example?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Is there anything else you would like to add to this part of the discussion?</td>
<td></td>
</tr>
<tr>
<td>What is your level of education?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tell me something about your life here in Platfontein</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Can you expand on this?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Can you give an example?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Is there anything else you would like to add to this part of the discussion?</td>
<td></td>
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</tbody>
</table>

Structural support
<table>
<thead>
<tr>
<th>Main questions</th>
<th>Additional questions</th>
<th>Clarifying questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>• What kind of activities do you take part in here in Platfontein?</td>
<td>How do these activities make you feel?</td>
<td>• Can you expand on this?</td>
</tr>
<tr>
<td></td>
<td>How often do you take part in these activities?</td>
<td>• Can you give an example?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Is there anything else you would like to add to this part of the discussion?</td>
</tr>
<tr>
<td>• Who do you consider to be your friends here?</td>
<td>• What kind of things do you guys do together?</td>
<td>• Can you expand on this?</td>
</tr>
<tr>
<td></td>
<td>• How often do you see them?</td>
<td>• Can you give an example?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Is there anything else you would like to add to this part of the discussion?</td>
</tr>
<tr>
<td>• Who are your closest friends and family members?</td>
<td>• Why do you consider them to be closest to you?</td>
<td>• Can you expand on this?</td>
</tr>
<tr>
<td></td>
<td>• What kind of activities do you do together?</td>
<td>• Can you give an example?</td>
</tr>
<tr>
<td></td>
<td>• How do they help you?</td>
<td>Is there anything else you would like to add to this part of the discussion?</td>
</tr>
<tr>
<td></td>
<td>• How do you help them?</td>
<td></td>
</tr>
</tbody>
</table>

*Functional support*

<table>
<thead>
<tr>
<th>Main questions</th>
<th>Additional questions</th>
<th>Clarifying questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Do you experience any difficulties in your life here?</td>
<td>• What kind of difficulties do you experience?</td>
<td>• Can you expand on this?</td>
</tr>
<tr>
<td></td>
<td>• Why do you</td>
<td>• Can you give an example?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Is there anything else you would like to add to this part of the discussion?</td>
</tr>
<tr>
<td>think you experience these difficulties?</td>
<td>you would like to add to this part of the discussion?</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>• What kinds of facilities are there in Platfontein that can help you?</td>
<td>• How do they help you</td>
<td></td>
</tr>
<tr>
<td>• How often do you make use of them?</td>
<td>• Can you expand on this?</td>
<td></td>
</tr>
<tr>
<td>• Can you give an example?</td>
<td>• Is there anything else you would like to add to this part of the discussion?</td>
<td></td>
</tr>
</tbody>
</table>

|Do you receive support? In what way?| • Who provides this help?|
|• How often do you get this type of help?| • Can you give an example?|
|• How does it help you?| • Is there anything else you would like to add to this part of the discussion?|
|• How does it make you feel?| • Can you expand on this?|
|• Can you give an example?| • Is there anything else you would like to add to this part of the discussion?|

Social stigmatism

<table>
<thead>
<tr>
<th>Main questions</th>
<th>Additional questions</th>
<th>Clarifying questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Do you feel like part of the community?</td>
<td>• can you explain why?</td>
<td>• Can you expand on this?</td>
</tr>
<tr>
<td>• How often do you feel like this?</td>
<td>• Can you give an example?</td>
<td>• Is there anything else you would like to add to this part of the discussion?</td>
</tr>
</tbody>
</table>

• How would you describe, in general, the way people treat you? | • Why do you think that is the case? | • Can you expand on this? |
| • How does it make you feel? | • Can you give an example? | • Is there anything else
Case study informants Interview Guide

Introduction of interviewer

Hello, my name is…………………………………….. I am a masters student from the Netherlands and I am here as part of a research project that would like to know more about how mentally ill people receive social support here in Platfontein. I would like you to know that you can trust me and that no one will know that the information you give me comes from you. I would also like you to know how much we value the information that you provide and how important it will be for future potential intervention programs.
During the interview, I would like to discuss the following topics:

(iv) Your background
(v) Your relationship to ..........................(case study participant)
(vi) Your perceptions of the social support available to mentally ill people in Platfontein
(vii) Your perceptions of stigma against mentally ill people of Platfontein

Now with your permission I would like to record this conversation. You will be completely anonymous. Shall we get started?

General information

<table>
<thead>
<tr>
<th>Main questions</th>
<th>Additional questions</th>
<th>Clarifying questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>- What is your name</td>
<td></td>
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<tr>
<td>- How old are you</td>
<td>- When is your birthday?</td>
<td></td>
</tr>
<tr>
<td>- Are you married?</td>
<td>- What is your husband’s/wife’s name?</td>
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</tr>
<tr>
<td>- Do you work?</td>
<td>- What is your occupation?</td>
<td>- Can you expand on this?</td>
</tr>
<tr>
<td>- Do you have any children</td>
<td>- Can you describe what everyone in your household does for a living?</td>
<td>- Can you give an example?</td>
</tr>
<tr>
<td>- Who lives at home with you?</td>
<td></td>
<td>- Is there anything else you would like to add to this part of the discussion?</td>
</tr>
<tr>
<td>- Can you describe</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Can you expand on</td>
</tr>
</tbody>
</table>

52 | Page
what you do on a daily basis?
• What are some of the activities you take care of in your household?
this?
• Can you give an example?
Is there anything else you would like to add to this part of the discussion?

**Relationship to Mentally ill individual**

<table>
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<tr>
<th>Main questions</th>
<th>Additional questions</th>
<th>Clarifying questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>• How do you know this person?</td>
<td>• Where did you meet?</td>
<td>• Can you expand on this?</td>
</tr>
<tr>
<td>OR</td>
<td>• When did you meet?</td>
<td>• Can you give an example?</td>
</tr>
<tr>
<td>• How would you describe your relationship with this person?</td>
<td>• How did the relationship develop in this way</td>
<td>• Is there anything else you would like to add to this part of the discussion?</td>
</tr>
<tr>
<td>• How do you feel about your relationship?</td>
<td>• Why?</td>
<td>• Can you expand on this?</td>
</tr>
<tr>
<td>OR</td>
<td>• Why not?</td>
<td>• Can you give an example?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Is there anything else you would like to add to this part of the discussion?</td>
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</table>
Perceptions of social support available to mentally ill people in your community

<table>
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<tr>
<th>Main questions</th>
<th>Additional questions</th>
<th>Clarifying questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Do you think this person has a problem and needs support?</td>
<td>• Why do you think so? OR • Why not</td>
<td>• Can you expand on this? • Can you give an example? • Is there anything else you would like to add to this part of the discussion?</td>
</tr>
<tr>
<td>• To your knowledge, is there social support available to the person?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• What kind of support is available?</td>
<td>• In your opinion how important are they? • How do you know this?</td>
<td>• Can you expand on this? • Can you give an example? • Is there anything else you would like to add to this part of the discussion?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• What role do you play in providing support to this person? OR • If you could, would you want to provide more support to this person?</td>
<td>• How would you provide this support?</td>
<td>• Can you expand on this? • Can you give an example? • Is there anything else you would like to add to this part of the discussion?</td>
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# Perceptions of stigma against mentally ill people in your community

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<tr>
<th>Main questions</th>
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<th>Clarifying questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>• What do you think of mentally ill people in the community?</td>
<td>• Why do you think so?</td>
<td>• Can you expand on this?</td>
</tr>
<tr>
<td>• In your opinion is there discrimination against mentally ill people in your community?</td>
<td>• Why Or • Why not?</td>
<td>• Can you give an example?</td>
</tr>
<tr>
<td>• Are there a lot of people with the same opinion?</td>
<td></td>
<td>• Is there anything else you would like to add to this part of the discussion?</td>
</tr>
<tr>
<td>• Are there a lot of people with a different opinion?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Can you name some examples in which you think mentally ill people are discriminated against?</td>
<td></td>
<td>• Can you expand on this?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Can you give an example?</td>
</tr>
<tr>
<td></td>
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<td>• Is there anything else you would like to add to this part of the discussion?</td>
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## Conceptual Model Coding Sheet

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<thead>
<tr>
<th>Theme/category</th>
<th>Description</th>
<th>Codes/labels</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Community Participation</strong></td>
<td>Involvement in community organizations (eg. Sports clubs, prayer groups)</td>
<td>Sports team, choir group, prayer groups</td>
</tr>
<tr>
<td><strong>Network Relations</strong></td>
<td>Personal interaction with individuals (eg. Friends and colleagues)</td>
<td>Friendship, colleagues, boss, teacher</td>
</tr>
<tr>
<td><strong>Intimate ties</strong></td>
<td>Intimate relationships in which secrets are shared and reciprocity is evident (eg. Life partners)</td>
<td>Husband, wife, son, daughter, mother</td>
</tr>
<tr>
<td><strong>Perceived support</strong></td>
<td>Respondents perception of what type of support is available, and how acceptable is its quality</td>
<td>I feel, I think, in my opinion,</td>
</tr>
<tr>
<td><strong>Received support</strong></td>
<td>Type of support available in reality</td>
<td>??</td>
</tr>
<tr>
<td><strong>Instrumental support</strong></td>
<td>Physical or material means by which support is received (eg. Caregiving or money)</td>
<td>Caregiving, childcare, money, food, items</td>
</tr>
<tr>
<td><strong>Expressive support</strong></td>
<td>Psychological or emotional support (eg. sympathy)</td>
<td>Emotion, feelings, sympathy</td>
</tr>
<tr>
<td><strong>Routine support</strong></td>
<td>Support received with high frequency on a regular basis (eg. Babysitting)</td>
<td>Daily, hourly, regular basis, every day, every week</td>
</tr>
<tr>
<td><strong>Crisis support</strong></td>
<td>Support received when respondent is confronted with a crisis</td>
<td>Once in a while, only when, major accident, death, loss, sick</td>
</tr>
<tr>
<td><strong>Labeling</strong></td>
<td>Characteristics that label someone as different (eg. Mentally ill)</td>
<td>Classified, different</td>
</tr>
<tr>
<td><strong>Stereotyping</strong></td>
<td>Labeled person is linked to undesirable characteristics (eg mentally ill → socially disruptive)</td>
<td>Looks bad, disruptive, slow, loud, irritating</td>
</tr>
<tr>
<td><strong>Separation</strong></td>
<td>Labeled person is placed into distinct groups</td>
<td>Them, they, those people</td>
</tr>
<tr>
<td><strong>Status loss</strong></td>
<td>Evidence of inequality (eg. Unemployment, low paying jobs)</td>
<td>They do not, they should not, they don’t have</td>
</tr>
<tr>
<td><strong>Discrimination</strong></td>
<td>Systematic exclusion and marginalization</td>
<td>???</td>
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## Appendix 3:

### Interview Coding Sheet

<table>
<thead>
<tr>
<th>Theme/category</th>
<th>Description</th>
<th>Codes/labels</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feelings of compassion</td>
<td>Descriptions of a relationship in which the informant expresses love, and care for the subject</td>
<td>Love, care, very close,</td>
</tr>
<tr>
<td>Feelings of responsibility</td>
<td>Descriptions of a relationship in which the informant expresses one's duty to care for the subject</td>
<td>I have to, because they are family, I must, responsibility</td>
</tr>
<tr>
<td>Feelings of remorse</td>
<td>Description of a relationship in which the informant expresses feelings of remorse</td>
<td>Feel sorry, feel bad, feel sad</td>
</tr>
<tr>
<td>Causes</td>
<td>Description of the causes of madness as expressed by the informants</td>
<td>Witchcraft, thinking too much, sacrifice, disease, eat something, touch something, drugs, alcohol, I don’t know</td>
</tr>
<tr>
<td>Instrumental support</td>
<td>Physical or material means by which support is received (eg. Caregiving or money)</td>
<td>Caregiving, childcare, money, food, items, hospital care, clinic, government grants</td>
</tr>
<tr>
<td>Expressive support</td>
<td>Psychological or emotional support (eg. sympathy)</td>
<td>Emotion, feelings, sympathy</td>
</tr>
<tr>
<td>Routine support</td>
<td>Support received with high frequency on a regular basis (eg. Babysitting)</td>
<td>Daily, hourly, regular basis, every day, every week</td>
</tr>
<tr>
<td>Crisis support</td>
<td>Support received when respondent is confronted with a crisis</td>
<td>Once in a while, only when, major accident, death, loss, sick, emergency</td>
</tr>
<tr>
<td>Labeling</td>
<td>Characteristics that label someone as different (eg. Mentally ill)</td>
<td>Classified, different</td>
</tr>
<tr>
<td>Stereotyping</td>
<td>Labeled person is linked to undesirable characteristics (eg mentally ill → socially disruptive)</td>
<td>Looks bad, disruptive, slow, loud, irritating</td>
</tr>
<tr>
<td>Separation</td>
<td>Labeled person is placed into distinct groups</td>
<td>Them, they, those people</td>
</tr>
<tr>
<td>Status loss</td>
<td>Evidence of inequality (eg. Unemployment, low paying jobs)</td>
<td>They do not, they should not, they don’t have</td>
</tr>
<tr>
<td><strong>Discrimination</strong></td>
<td>Systematic exclusion and marginalization</td>
<td>???</td>
</tr>
<tr>
<td>-------------------</td>
<td>----------------------------------------</td>
<td>-----</td>
</tr>
<tr>
<td><strong>Relationships</strong></td>
<td>Description of the interactions taking place between the informant and the subject</td>
<td>Reciprocity, mutual benefit, commensalism, being used, taking,</td>
</tr>
<tr>
<td><strong>The beginning</strong></td>
<td>Description of what took place when the subject was first suspected to be mad</td>
<td>Omega, Namibia, first time, Schmidsdrift,</td>
</tr>
<tr>
<td><strong>Reactions</strong></td>
<td>Description of how informants react when they see the subjects</td>
<td>Laughter, avoidance, scare, normal, happy, sad, angry, irritation</td>
</tr>
<tr>
<td><strong>Feelings of community</strong></td>
<td>Description of how informants feel about Platfontein as a community</td>
<td>Community, togetherness, helping one another, for themselves, own business, to bring down</td>
</tr>
<tr>
<td><strong>Personal hardships</strong></td>
<td>A description of the personal difficulties in one's life</td>
<td>Its hard, no work, no money, no food, difficult, need, don't have,</td>
</tr>
<tr>
<td><strong>The clinic</strong></td>
<td>Description of the clinic's role, rules and regulations</td>
<td>Rules, regulations,</td>
</tr>
</tbody>
</table>
Appendix 4: FieldWork Notes Platfontein

23/03/2013

The Kalahari Festival

A beautiful event to watch. The !Xun and the Khwe really take pride in their traditional culture, though acts of westernization are clearly becoming evident. Differences between Khwe and !Xun dress code were quite interesting.

09/04/2013

Meeting Kya

The day started at around 11 in the morning when Thijs and I arrived in Platfontein to meet with Skambo and find Kya. We started our trek around the Khwe side of the community to look for this woman, no idea where she would be. We walked up one street and down the next, asking people 'have you seen kya' most people responded with a no, without excitement, or curiosity as to why we were looking for her. It seemed to me that it comes as no surprise to hear the question 'where is kya'. As if her house would not be an obvious place to find her. One household did laugh with enthusiasm, as if wondering why were we looking for 'that woman'. Eventually, and it didn't take very long, we found her. My first sight of kya was of her walking way up the dirt path carrying a bundle of sticks (later to be recognized as firewood) on her shoulder. At some point she drops the firewood on the side of the path and enters a yard and sits on the ground in front of a house.

We first approached her with caution, not knowing how she would react to our presence. Skambo introduced us as foreigners working on health problems in the community. She was very skeptical at first, and questioned our intentions of being there. While many things she said were unclear, or seemed random, that at least, was very clear. I carefully explained to her our purpose of being in Platfontein and our intentions, and how we were doing research that we hoped would provide information on how some of the community’s members were living and hope that it would eventually contribute to improvements on their wellbeing.

Eventually we were able to trust each other a bit more and we all sat down on the grass where we proceeded to have a conversation. The conversation was extremely interesting. I asked her questions, some of which she answered directly. Other times she would go on to tell a story about Namibia, and the church in Windhoek, and about different peoples and the divisions between them. Some of her responses sent the people around us into hysterics as what she was saying didn't seem to make any sense. She also asked me questions about myself, my family, how I receive support, etc. This interaction really made the conversation interesting and stimulating. One interesting thing that stood out was when I asked her if she knew a lot of people and had many friends. I asked this question because she seemed to know a lot about the people around her. Everyone that passes by she was able to tell us something about them. She told me that she knew many people but did not have many friends. She then proceeded to say that she didn't know why she didn't have many friends, and didn’t know whether it was them or if it were her to be the blame. In her eyes she was normal. Though interestingly enough, she did admit to having a disability which made doing chores like gathering firewood a challenging task.

We tried on several occasions to ask her if she received support, to which she answered no, and who her guardian was. Eventually we were given the name !wha, who was the mother of the light skinned girl with curly hair we met at the first place we found Kya. Eventually we were able to go and try to find this !wha lady, her supposed guardian. As we walked I helped her with her firewood, for which she seemed really appreciative. This was pretty much my first act of participatory observation, and I really enjoyed it! When we
arrived at the guardian’s house however, she was not home. We then decided it was time to get going and asked her if it were okay to see her again and spend time with her. It was great to hear that she was fine with it and I look forward to spending much more time with her.

Other information I gathered was that:

- she has three sons, two of which are considered mentally ill
- one son passed away, and the other mentally ill son is considered too violent to talk to. His name is Sagi
- the third son, is mentally fine, and lives in Pretoria. He seems to be in town at the moment though.
- Kya is a traditional name and means ‘searching’
- Kya also goes by the name of Kasivi

Meeting Poti’s Uncle: Johnny Ernesto

Right after meeting with Kya and Skambo, Thijs and I picked up Sonia and drove to the town/township/neighborhood of Rodepan, where Poti’s uncle lived. The neighborhood itself seemed quite rough, and poor, however the house itself, where Johnny lived was already quite a contrast to most of the conditions we’ve seen in Platfontein itself. Instantly, it was clear that Johnny was somewhat more wealthy than the average person in Platfontein, and we could already understand why Poti sought out support from him. The lawn was well kept, and the house looked quite nice. Modest in size, but well maintained. We were greeted by his two daughters and wife, whom were all very pleasant and also interested in our discussions about Poti.

Johnno was very enthusiastic to meet us but unfortunately he was under the impression that we would be able to provide direct help/assistance for Poti. After explaining to him that our purpose for being here was to gather information that we hoped would eventually lead to improvements into people’s lives who are like Poti, he still agreed to participate in our research.

He explained to us that he feels responsible for poti as it is his deceased sister’s only child, and feels like a father figure to him. But he also says that Poti is quite troubled and has many challenges. Interestingly enough he says that poti was a normal child and it was only in 1999 when he went to work on a farm with his father did his mental issues begin. Interestingly enough this may be the same farm that Poti keeps referring to where he says he still works as he has mentioned in my first interview with him. Johnny went on to explain that when Poti returned from the farm he thought his mother was a ‘monster’ or ‘demon’ of some sorts and he had to kill her before she hurt him. At some point he set the tent in which they lived on fire. But I do not yet know the details of this story. In any case, Poti became a threat to his mother’s life, and she was afraid of him. So they kept them apart from each other, even until her death in 2000 (something).

Johnny says that he gives poti money whenever he visits and food as well. But if johnny is not at home, poti has to wait outside until he returns. This gives me the impression that the family is also afraid of Poti in some ways and he is not treated like any other family member or friend. It was difficult to gather information about poti and Johnny’s emotional relationship, but it was clear that johnny felt sorrow at his nephew’s condition and responsible in some way for taking care of him.

Johnny expressed his anger at Poti’s father’s side of the family for neglecting poti and always sending him to johnny for support instead. Johnny spoke about things he has given poti like clothing and shoes that the family has taken away from him. Though this is all very informative it would be very interesting to get the other side of the story from the father’s side of the family but Poti’s father is currently working on a farm somewhere for six months.
Johnny says that in 2004 when Poti’s violence, and substance abuse got worse, he was taken to the hospital. Poti was provided with medication but has not been taking it and his family in platfotnein do not check to see if he is. Johnny knows that Poti needs help but he honestly admitted that he did not know what type of help would be available to him. At the end of the interview he told us that he thinks poti understands the purpose and implications of the research and that he also understood and really appreciated what we were doing.

He also said that if poti was not a part of his family he would still feel sympathy for the person going through such a problem as well as for the family.

10/04/2013

**Observation outside Skambo’s house**

Today I started my morning by sitting outside of skambo’s mom’s house waiting for thijs and eva to finish their interview and for me to work with skambo. It was very interesting sitting outside and watching people as they walked by. Apart from looking at me and probably wondering who this person was sitting on the stoop of this house, people were just going about their daily lives. In groups people walked from one house to the next, down the street, here and there. I don’t know where they all go, or if they even have a purpose to go there. Loud music was playing throughout the street, to which no one seemed to mind.

**Meeting Ana, Kya’s sister**

Once skambo arrived we went for a walk to search for Kya’s sister Ana. Ana lives in a small house with her three daughters, and kya. She came outside and greeted us with great kindess. We explained to her who we were and what our research was about. She was very willing to participate in our research and ws happy to meet us. I explained to her that the research was not intended to directly benefit kya but was a means to gather more information about people like kya and hopefully in the future provide information on where support is needed in the community for people like kya. She understood and was fine with it. She also confirmed that she didn't think the research would harm kya in any way and so we took that as the informed consent.

15/04/2013

**Interviewing Ana, Kya’s sister**

Skambo was finished with esther and had to go to work soon so we were in a hurry to get the interview done. It started off fine. We got to ana’s house and she was ready for us with two chairs. It looked like she was in the middle of doing laundry. Her daughter was home as well but inside most of the time. ...

16/04/2013

**Observations from Skambo’s house**

People were again walking around, seemingly without a purpose. Some elders were catering to their gardens. This time, people seemed to be more used to me being there, as they walked by and said bamba. Esther told me that skambo said that people are offended if you walk by and do not say hello as it reminds them that people feel like they are less important than others. Good music was playing again at skambo’s and esther was dancing a little bit. A woman told skambo’s brother in khwedam, to stop looking at the girl dance. I’m not sure if that was a compliment or an insult towards esther.
Meeting Poti

I saw a man walking from the distance through someone’s yard towards the street. He was wearing gumboots and a thick wool sweater which judging from the temperature looked way too warm to be wearing. As he came closer, stumbling along slightly I finally recognized his face, poti! With those dumbo ears I could recognize from anywhere! I gave him a hug, and he seemed to recognize me. First thing he asked was for a cigarette. I told him no. I then asked where he was heading and he said to the shop. I told him I would try to catch up with him later but never found the time in the end.

Meeting Kya

Skambo and I proceeded to find Andre, Kya’s son at the place he was staying. When we got there we saw Oberto, kya’s nephew from her husband’s side (husband’s sister’s son), and rebecca, kya’s niece (sister’s daughter). Andre was out in town but would be back soon. Skambo and I waited for him. He came back and we were able to speak to him briefly but he did not have too much time so we postponed the interview until the next day. Andre didn’t seem too comfortable talking to me, and was a bit reserved but I hope that will change. Kya came into the yard at some point and sat down next to us. Interestingly, Andre completely ignored kya’s presence. They did not interact whatsoever. Skambo says they hate each other. After explaining my research to Andre he agreed to meet with me tomorrow. After he left skambo and I had a conversation with Kya, some of it I was able to record after asking for her permission. Kya instantly asked me what I was talking about with her sister yesterday. At first kya seemed to talk about all kinds of things, mostly about people and what they were doing. As well as Namibia and the church in Windhoek. She kept mentioning me, and that I was part of a group or someone was going to talk to me, it wasn’t very clear. There were times though where I could ask her something directly and she would answer. She says she has many sons, but how is she supposed to remember how many. I asked where they were and she said she didn’t know but also pointed in the direction of the graveyard where I could find one of them. I asked her about andre and her response was that that boy is not married. She spoke a great deal about her concern for sagi and her other sons. She wanted me to help them. I asked her what was wrong with Sagi and she said that he was mad. And that he needed a traditional healer (for which she gave a name) to put something on his head and heal him. I asked her if she had any health problems (which I think skambo directly translated into mental health problems – need to talk to him about that) and her response was: I don’t know why my sister told you that I was mad, I am not mad. Interesting how she seems to be in denial about her own madness but is very aware of her son’s issues. She then spoke about her brother, and how it was shameful for her to ask her brother for food. I need to relisten to the recording for more information. Kya said many things that didn’t make sense. She also spoke in different languages that didn't seem to make sense. Oberto and his friends were sitting in the background evesdropping, seemingly for entertainment. And often laughed at the things she said. Kya didn’t seem to notice. I wondered if it bothered them the things that she said, but it didn’t seem to, it seemed to just entertain them. I don’t think andre laughs at the things his mother says. It doesn’t seem to be funny to him.

Discussion with Skambo

After meeting with Kya, skambo and I started to walk towards the library. Skambo asked me what I thought was the cause of her madness, as he was now confused the more he spent time with me and her. I asked him what he thought it was and he said that he thinks witchcraft causes a person to go mad, but he didn’t understand how related and he thought no. he suggested that maybe someone bewitched kya and her family in order to become rich or something. And he even suggested maybe someone like her brother. Its quite interesting to see the strong connection made between mental health/madness and witchcraft.
Emmanuel and Reikert

I met these two jokers before at the bar behind the shop and now I saw them in front of the shop. Emmanuel, a seemingly happy drunk, wanted to speak Afrikaans with me and I did the best I could with my limited Dutch and even worse Afrikaans. Either way, we were all amused. I went to the back of the shop to the liquor corner where I found them again and had discussions with them about me, what I do, where I’m from and what I was doing there. Emmanuel repeatedly asked if I could take him back with me to Europe. I felt really sorry and I explained to him that I couldn’t. and that I was here to try and make their lives better, no matter how indirect. Emmanuel works at the shop and Reikert works at the radio station. They’re both from !xung. The fact that this is the second time I’m seeing them at the liquor corner is a little worrying but they are great guys. I asked them if they knew Poti. They responded with surprise: Poti! Oh that crazy guy? Haha. I asked them what they thought of him and they said it was sad how people and the community neglect him. Emmanuel said: it is sad how people just leave him, we are a community, we are supposed to be together, not just throw someone out.

Skambo and arranged dating

Later before going home Skambo opened up to me and Eva saying how he was stressed about life and money problems. He is dating a girl (the first in his life and he is 24) that his mother set him up with. But he does not like her as he feels like she is changing him. He is afraid to leave her because he thinks he will be disowned by his mother and family. Skambo complained about his problems and joked about having a drink to help him forget. It seems that drinking to forget one’s problems is very common here.

18/04/2013

Kya at her sister’s place

When walking towards Andre’s house, we saw Kya in her tent and heard her talking. We decided to pay her a visit. To our surprise, she was actually alone in the tent and talking to herself. Skambo found this hilarious of course. Her nieces and nephews were in the main house and seemed used to this type of behavior. Kya was inside the tent making a fire and talking about all kinds of different things with herself. Skambo did not translate much but at one point said that Kya said I took her money. When I told her that I did not take her money, she said then it was my uncle. On that note we told her we would see her later and we carried on our way towards Andre.

Andre – Kya’s son from Pretoria

Today I tried to call Andre but he did not pick up his phone. We then went by the house at 11 in the morning and we were told he was still sleeping. We came back more than an hour later after interviewing Poti’s aunt and we were told that he was busy. It was clear to us that Andre was now just avoiding us and he did not actually want to have an interview with us. It’s a pity because as the only living, and sane son of Kya, he would have been a key subject. But the fact that he is resistant to speak to us is a very valuable observation. I suspect talking about his mother’s health condition is a very sensitive topic. When we saw both him and his mother he made no acknowledgement of her presence. While people laughed in the background at the things she was talking about, he did not respond, nor did he seem amused in any way. It seems that he was embarrassed for her or even ashamed of her. Whatever the reasons, it is clear that Andre does not want to speak to us.
**Interviewing Poti’s Aunt**

Poti’s aunt was a very lovely woman to talk to. As we entered the house I could already tell that they were a bit more privileged than the standard person who lives in Platfontein. Clean house. Nice furniture. Much of this I imagine is thanks to Sonia, who has been supporting her mother and family. The aunt gave some very interesting insights into the life of poti and her perceptions of his condition. When she spoke about poti at times she got very emotional and spoke with real passion. I mainly gathered that the main support she gives him is food. She doesn’t believe the community can do anything for him and the only thing that can help him is the church. Poti’s aunt is a strong devoted Christian and many things she says has to do with that. Many of her stories did fortunately coincide with what his uncle said earlier. They both also see Poti as a son. Interestingly poti used to take medication daily at the clinic which would make him better, but no one has kept track of it.

**Walking around the !Xung side**

After my interviews I went for a walk on !xung side of the community. My impressions were that everyone was much more friendly and willing to talk than normal. People said hi to me and I said hi back. I had a few short conversations with people. I came across two domestic fights, in two separate yards, giving me the impression that the !xung side was slightly more aggressive than the khwe. Than I realized, everyone was also drinking a lot more heavily. Only later did I realize that it was not just the !xung side but also the khwe side drinking heavily on this particular day. It could be because payday was yesterday. Interestingly, one guy greeted me with a soldier’s salute when I greeted them.

**Talking to Riekert**

I bumped into Riekert very coincidentally as I was talking about him with Thijs on the phone. He was standing outside with some friends and then we started to talk. For almost an hour we had a wonderful conversation about life and goals. He explained to me how he felt that Platfontein could be seen as a permanent place for many people because they were given real houses, electricity, etc. but for him it was different because he wants a challenge—a challenge of living in a new country with a new culture. Riekert explained to me his dreams of moving to Berlin, studying journalism and supporting his family from there. I felt like Riekert really opened up to me today, even though he was a little intoxicated. He also said he would help me as a translator on the !xung side if I do find a subject.

19/04/2013

**Talking to Jason**

- mother left when he was little
- lives with dad and step mom
- told me poti used to kill dogs and eat them (second person to tell me this)

**Looking for Jonna**

- went to his house, lots of siblings
Talking to Kya and Ana

- saga passed by
- kya’s behavior seemed to change
- ana laughed when kya talked nonsense
- kya was almost making fun of me, asking me if Jason was my son. When I replied no she laughed. It seems like our relationship is getting better.
- kya spoke to Rebecca (ana’s daughter) and she responded to her normally

Meeting up with William and his family

It was chaotic. Because it was the Friday of pay day, many people were very intoxicated all over the community. When we found esther and eva they were apparently with william’s siblings. They were all very intoxicated. I need to do more investigation to find out who is who. It seems like William would be a great subject for my study. He speaks great English, and has a lot of interaction with other people that would be good for observation.

20/04/2013

School talent show

An early start for a Saturday but for a good cause! Today we went to support the Platfontein school talent show. It was a really nice day to be in Platfontein as for me it was really just about having fun and not thinking about the research. We first played dodgeball with the kids, which was really a lot of fun! Those kids are so energetic and happy it seems. The talent show started later than planned (of course) but was really nice to watch. The girl mc (need to find out what her name is) said that the talent show was created in an effort to bring awareness to some of the social problems affecting the community, such as drinking and domestic abuse. All acts were dances, many of which were really good. It was very interesting to see how the youth of Platfontein really look towards modernity in music and dance, though there are hints of their old traditions subtly put in place. Some dances completely adopted different cultures, such as the indian dance. It makes you wonder where they came up with that idea and how they view different cultures. It seemed that the really young kids stuck close to the traditional dances and customs they knew.

The audience consisted mostly of participants and few parents. It makes me wonder how much do parents support their kids in what they do. The winners of the talent show was skambo’s modern dance group. They were great!

21/04/2013

Bango Interview

- very Christian guy
- says people don’t trust him
- seems to be starting a movement himself
- there were several people in his yard just sitting there
Kya observation

Kya was first in skambo’s mom’s yard and then I found her across from the little zinc shop. She was sitting in the yard of someone just talking. From what I could see the woman outside doing the laundry was not paying too much attention to her, but the young boy seemed to be interacting quite a bit with her. From where I was standing it looked like a conversation but he was also laughing at the things she said. Maybe he was just entertained by the things she was saying.

Clinic visit – Head Nurse Sister Alexander

There is no Psychiatrist in the Platfontein Clinic. There is a psychiatrist coming from West-end Hospital (doesn’t seem to always be the same person), that person will give a date at which he/she will be at the clinic. Then the clinic will tell the radio station to send out the names of people and they will come to the clinic to see the Psychiatrist.

Currently there are 22 mental health patients. All except for one are diagnosed with a Psychosis (related to alcohol and drugs abuse according to nurse Alexandra). The one is diagnosed with depression. Nurse Alexander explained how a parent came in with the girl and she is never looking at people. Even when she is by the house she sits and looks down, she does talk to people but not look at them. The girl asked the nurse to send her to the big hospital, she asked why because she gets her medication but she persisted because she felt she had to go there. Nurse alexander said “fine”.

The initial contact of people with a mental disorder with the health care institute differs. Sometimes family comes to the clinic to ask for advice. Then the Nurse Alexander goes to visit them and tells the person that they want to take them to the hospital. If the person responds that he/she is fine and doesn’t want to go then the nurse can’t do anything "it is the patients right". She mentioned how a family member came and she went there and the person was saying he is fine, and he was making hearts and crosses out of metal (sounds like normal activity). She asked the mother now what must I do? He says he doesn’t need to go, then the mother said "no it’s fine I’ll come back when he is violent". If the person has symptoms such as talking to him/herself, talking strange then she is able to use some more force to take him. If the patient is violent then Nurse Alexandra will write a letter and call the police, they take the person to the hospital in order to get a diagnosis. Family is always involved in the beginning, also with helping the person to take medication, she always asks someone to go with them when she explains about the use of medication.

After diagnosis, the first two weeks they will ask the patient to come to the clinic each day. This is done in order for the patient to get used to taking the medication. The medication consists of tablets and one time a month a shot, precise medication depends on what the doctor prescribes. Medication usually needs to be taken with food, adding to the difficult of having medication be properly administered in platfontein. The clinic gives tablets for one month and then they have to come back for a new package. After 6 months they will see the psychiatrist again to see if medication needs to be changed, remain the same or if the patient can be discharged.

Nurse Alexandra believes most patients keep to their medication. There is a home base health worker from the clinic that is each day (or 1 to 2 times a week, this needs to be verified) checking up on patients (all patients in the clinic) to see if they take their medication. When patients come back they also ask the patients to show how they take their medication and when they take it. When the patients go to a farm to work and the nurse doesn’t follow up on it they will probably not get their medication when they run out. That is why nurse Alexander asks when they go to a farm to give the name and number of the farmer, then she faxes the medical file/treatment and asks the farmer to go to a clinic nearby and pick up the medication. If patients do not come back for their medication they then visit the patients at their homes and investigate why.
When asking about when patients get better she said that the patients they have now have been there for a long time. They take their medication but continue to drink and do drugs, that is why they struggle to get better.

Story of patients not keeping to their medication from the clinic (one with carcinogenic wound, taking dressing of and putting leaves and “toothpaste or whatever the people tell them to put on”) and story of person with HIV AIDS that refused treatment and went to Namibia to pay 15000R to a traditional healer, after two years coming back being very sick, nurse Alexander is asked to come she says “why did you go there and spend 15000, and now you want help, if I want I can turn my back because you refused treatment earlier I have the papers (patient file)”. “I made a picture of him and printed it to show what happens”. Nurse Alexander has many frustrations in her work, her stories of people not keeping to their medication and or diet, refusing treatment to find help with traditional healers, using traditional medicine alongside other treatment are all filled with frustration. Discussing the research of cooperation with traditional healers is received with a defensive attitude. She mentions how she doesn’t know how to cooperate because she never met them “they don’t come here, how can I refer patients if I don’t know who they are?”. When I mentioned “but even if you did know them”, she told the story of the person with HIV AIDS going to Namibia to a traditional healer. This stresses the believe that traditional medicine doesn’t help. I believe this goes further than HIV AIDS and incorporates all diseases for which a biomedical treatment is available. Nurse Alexander stressed that she doesn’t believe in traditional medicine because she is a devoted Muslim. She mentioned how people say they are Christian or Muslim but they are not truly devoted if they believe in Sangomas tour doctors and others. When she is sick she mentioned how she does the Muslim ritual of washing and praying. This, it seems, may for a non-believer be just as strange as using traditional medicine, Nurse Alexander, however doesn’t seem to make that connection. She goes on to explain that she also said to the government that she can’t work together with “those people”.

The privacy issue at the clinic mentioned in the report of Stephy became visible once more when Nurse Alexander started the conversation by mentioning how she just went to visit the traditional leader Nepa (pointing to where he was living) and that he was diagnosed with hypertension and ... back in 2010 and that he doesn’t keep to his diet and medication. In addition when we carefully asked what the possibilities where to hear if the study subjects of Andrew were patients at the clinic and whether they were diagnosed, she replied that we could leave the names and she would check the files. The procedure of calling out names over the radio station when the psychiatrist is at the clinic is also a privacy issue, even when the names are not mentioned in relation to the psychiatrist it is very likely that people will match the names and know it is related to mental disorders.

23/04/2013

Meeting Sonia – Poti’s sister

When walking towards sonia’s house I realized that this part of Platfontein was a lot more ‘run down’ than the rest. If Platfontein had a ‘ghetto’, this would have been it. It was 10:15 in the morning, and we first found sonia’s children playing on the street. I already wondered why weren’t they in school. They showed us where Sonia was. We found Sonia drinking at the local bar with some friends and her youngest child. We then went to have the interview at poti’s father’s house, which was right next to the local bar. Poti stays at this house by himself for the moment, while his father and undes work on a farm in another province. The house was in poor condition, with shattered windows and the door completely bent outwards.
Sonia spoke about how hard life was for her with very little support from her family. The main support she receives is from her husband who is a soldier. She says that she loves poti like a brother and that she tries to support him as much as she can.

I got a sense that she was telling me what I wanted to hear at some point, in terms of taking care of poti. When I asked Sonia what she thought, she said that she thought poti’s sister was also lying sometimes. As the other side of poti’s family complains that poti is neglected by them. Sonia also said that that side of the family is quite poor for Platfontein standards. None of poti’s sister’s children are in school, nor did any of them complete school. The youngest most recently dropped out because she had a problem with her shoes apparently.

**Meeting Esta – poti’s niece**

Esta, is sonia’s second eldest daughter. I had a short interview with her about poti, but she didn’t say much that was different from her mother. The interesting thing about her was that she has little memory of poti before he went mad. Esta has a young baby boy and lives with her mother and siblings in the house next to poti’s. it is interesting that all of them are crammed in one house while poti is alone in the other. (hints of isolation)

**Meeting Ernesto – poti’s cousin (traditional brother)**

We met Ernesto near the beginning of platfontein where he was drinking with a few other guys. I soon realized that I met him the Friday before with thijs, but he was a lot more drunk then. Ernesto spoke English very well and was a well spoken guy. He told me great detailed stories of his relationship with poti. How they used to play together as kids, and how poti was his soccer coach. He spoke of how potis behavior changed when he started doing drugs and alcohol, but also of how he started getting seizures and was acting crazy. Interestingly Ernesto thinks poti’s problem is ‘traditional’ (same as spiritual as according to bango whom we spoke to yesterday). Ernesto also describes a type of support he believes poti needs, that exactly matches a mental institute’s description. Ernesto also knows sagi, they were good friends in the past. While Ernesto thinks that sagi and poti are two different cases, he does agree that they need the same kind of help.

**Schmidsdrift drama**

On the !xung side we witnessed history in the making! Apparently the remaining families that were left in schmidsdrift were being forced out of schmidsdrift and into Platfontein today. There houses were broken down and furniture all taken by truck and dumped next to the church on the !xung side of the community. For a couple of hours we sat there and watched as community members went through their stuff as the people from schmidsdrift had not arrived as yet. At first we thought that some people were stealing stuff but apparently they were just holding them for some of their family members who were coming from schmidsdrift. We were around long enough to witness the first bus load of people come by. It looked like one family but im not sure. It was very strange to see these people taken to Platfontein by force and how they had to go through their stuff in front of everyone. Some people seemed to recognize them and their were some warm reunions, but in other instances there was laughter, and im not sure how accepting and welcoming the rest of the community will be towards them. Afterall, these people did not want to come to Platfontein...
24/04/2013

Poti’s House

I went to Poti’s house in the morning to see if he was around but as I expected he was not. I’ve been told that he leaves his house very early in the morning to go wandering around. I went into his yard, next to the bar where music is blasting all day long. Poti’s house was in terrible shape on the outside, and still too my surprise, in even worse shape on the inside. There was no furniture whatsoever. The place smelled horrible, and it was completely covered in filth. As I entered and called poti’s name I heard a dog growl, and then I ran off.

Interview with Skambo’s mom

I interviewed skambo’s mom about kya. When I told her that I wanted to talk about kya, she laughed quite hard. But we were able to speak. She was not able to tell me much however.

Interview with Joyce

I interviewed joyce about poti. It was interesting because at first she told me she just knew him as a neighbor and that she was sometimes afraid of him. Later on when I asked her to label her relationship with him as either: friend, close friend, acquaintance or stranger, she said he was like a brother to her. This makes me question what value people give to the term family, and makes it difficult to evaluate the strength of relationships in the community. When I asked her why would she describe her relationship as such, she says she treats everyone like a brother or sister.

25/04/2013

Observations Kya

Today Kya was quite active. When we first arrived at the radio station she was standing there talking to people. From what I observed most people were just standing there and watching her. She eventually started to walk back towards her home. Talking to herself and sometimes others. Sometimes people reacted, and other times they didn’t. At some point I saw her at a house near poti’s (pink/cream color house with something written above) and she was eating with some people there. I need to go and speak to them at some point, and discuss their relationship.

Interviewing Mojo

the interview with mojo at first felt very rushed. I got the feeling that he was a bit annoyed by my questions and that he was impatient. But the longer we spoke the more calm it was and the more comfortable we all were. The main thing that stood out for me was that mojo spoke about people in the community in mainly a negative way. This was unusual to me as most other people spoke quite kindly about each other. Another interesting thing was that he was aware that people were spreading rumors about him causing his sister’s illness. Claiming that he used witch craft on her in order to become more successful. Yet at the same time he blamed a dead relative for doing exactly that. Interesting. Later when I spoke to skambo I asked him what he thought and he said he thought mojo spoke honestly. This is interesting because I got a different vibe. One limitation of this research and doing the interview in a different language is that I cannot pick up on social cues so accurately. I was under the impression that I was annoying mojo and he did not want to talk, but it seems that skambo didn’t feel that way. So far mojo has one of the nicest properties I’ve seen in Platfontein. Two houses, two cars, two laundry machines, a satellite dish, a clean yard. I asked if he works and he says no.
At the moment he says his daughter Magdalene supports the family. She is a news journalist at the radio station. And she is also someone I should definitely try to interview.

**Interviewing kamoti**

First real honest answers from anyone. He says poti and him don’t have a real relationship because they cannot talk about anything. He is sorry that he cannot help poti as much as before. All he has now is his pension, which him and his other family members have to also live off of. Kamoti looked really sick and his living conditions were quite poor as well.

**Interviewing tresa**

Young girl, husband works for sasi. She seems to tolerate kya by letting her come to her yard, talk to her and feed her. It seems this relationship is mutually beneficial as tresa also seems lonely, as she says ‘noone comes to visit me, so I don’t have a problem when kya comes to visit’. So they seem to keep each other company. Her relationship with kya does not seem as close as other family members with kya yet apparently they are related (distant aunt or something..). One thing I asked, which gave me the impression that many people are unable to answer is how do they treat different people differently. They seem to class everyone as the same, and love them all equally. Sounds very utopic, but not likely.

**Scouting more interviews**

- Pieter
- Johannes
- Khwe leader
- ???

28/04/2013

**Kya Observations**

I first found Kya sitting in the yard of a person (almost opposite sonia’s place, corner house which usually plays good music). She just sat quietly on a blanket that seemed to have been set out for her. This gave me the impression that she was welcomed rather than simply tolerated at this house. She seemed to be there for quite some time (atleast over an hour from 1 pm). By 3 pm I saw kya again, walking on the same road of the house that I saw her at earlier. This time she was walking up the road, and seemed more agitated and angry compared to when I saw her at the first house, where she seemed quiet and calm. She walked up the road shouting things at people and sometimes not to anyone in particular. Her behaviour did spark some attention from passer-byers. She stoped at one house on a corner near the street of the bar (purple house, iron bars in front of the door) and tried to talk to the woman sitting in the yard breast feeding her child. The woman did not seem to react to kya and she eventually started to continue walking, that is, until she saw me. Kya then stopped (still in front of the yard) and started speaking to me, but I couldn’t understand what she was saying. The lady in the yard that kya was initially trying to talk to then found this quite amusing and started to laugh as I struggled to communicate with kya. I turned to her and asked her what she said and then she called a friend from inside the house to come and see ‘the entertainment’ in front of her yard. The two ladies continued to laugh and I asked the second lady what kya was saying. She simply said ‘that lady, she is crazy…’. I followed kya up the road to the front of the bar, and then she turned around and headed back down the road and into a yard where 4 people were sitting down.
Kya sat down comfortably on the ground and the woman casserra gave her some tobacco which she proceeded to sniff. I sat down with them and tried to get to know everyone and their relationship to kya. Eventually this arrived and we managed to have some dialogue.

Kaa comes there often, every day or at least almost every day. She sits and talks and then she goes somewhere else. She doesn’t like to stay too long on one place, one day she may be acting crazy (angry) with a person she is staying with long. She feels better when she sits with people and talks. The people we spoke to give her food or ‘sniff’ the tobacco you put up your nose. They also talk together, when she comes she sometimes is able to talk well but then in the conversation she also goes ‘off track’. They also laugh together, casserra said it makes Kaa feel better when they sit, talk and laugh together. It seems Kaa also intentionally makes jokes such as saying that we are her kids and that she is not looking for a husband when we asked about hanging out with her for a day.

Kaa first asked us what is in our hearts that we keep looking her up and talking with her, asking why we were so interested in her. We explained the research and that we want to know how she lives, she seemed satisfied with the answer, nodding affirmatively. According to the translator (not sure about this) she asked us what she must do to come to the straight path because she knew something was wrong with her. Although this may not be exactly what she said the recognition that ‘something is wrong’ was later confirmed by her suggestion that the translator bewitched her and that Andrew bewitched Sacchi. When we asked again about if we could join her for a day she said that she doesn’t like the idea of sitting with just the three of us (she wants to stay with different people). This answer was probably because I asked if we could join her for a day or the morning or afternoon, thinking that she is not allowed to go her own way.

When the translator explained the purpose of research he mentioned that we want to know what the world of people such as her looks like. Then apparently she asked how other people look at people like her or Sacchi. She asked if people want to kill them. She asked if people are scared when they see Sacchi, or she implied that people are scared (not sure about this).

Casserra mentioned that she worked for the red cross, during that time they used to take the ‘mal’ people to the clinic for medication and clean the houses of the people. because of lack of funding the red cross left Platfontein, she is not sure what happened precisely. Now she work(s)ed for another NGO and they wanted to continue to take the ‘mal’ people to the clinic for medication but the NGO said that they only pay them to do TB and HIV related work.

Casserra mentioned that people like Sacchi are not taken care of by someone and therefore not get their medication regularly that is why the condition becomes worse. When asking about causes for people becoming like that the translator first of all said how do we know? He mentioned how it may happen because of an accident but he doesn’t know. Casserra mentioned how Sacchi used to be a good learner at school and then he started talking too much one day, they took him to the clinic they said he was ‘mal’ but as mentioned before nobody was there to help him take the medication everyday.

The church had a collection for Sacchi and someone else (didn’t get the name) to be able to clean the house and buy some food. It was in 2008 that they did it and then on Saturdays they would go past the house. But that people don’t have so much money to keep supporting them (she was also speaking for herself). It would be interesting to find out what triggered this initiative to begin with. Interestingly, no one I’ve interviewed so far has mentioned the church’s role in providing material support to the mentally ill. So far its only been spiritual if anything.
When we asked about how Kaa is different or the same from Poti, the person working in the church of Dennis (see interview of Eva) mentioned that Poti understands things better while Kaa it is more difficult to make her understand things. (he also gave an example of some sort of instructions Poti would be able to understand, don't know what it was about actually. Him and the others agreed that poti was ‘better’ than kya in the sense he better understood the world around him and could hold a normal conversation for longer.

While sitting in a circle talking to kya people who walked by took quite some interest in us. People (particularly young teenagers) stopped to listen to what we were talking about, as if entertained that we would try to have a conversation with kya.

Poti and Kya Observations

29/04/2013

**Kya Observations**

11:30 – I find Kya sitting in the yard of her niece Recuna. She was playing with her niece’s baby. I walked up to the fence to say hi to kya. She spoke back to me but I couldn’t understand what she was saying. Recuna translated a little bit. I asked recuna if I could speak to her later, she said yes but she doesn’t speak English. I will have to come back with skambo. Recuna lives in the yellow doored house on the main road. There is a parked car on the inside of the yard. Recuna is kya’s sister’s daughter. I need to find out which one.

11:50 – I walk back to recuna’s house but kya has left. Recuna says that she gave kya money and she went! I then followed her trail. I find her at the zinc store on skambo’s street where it appears that she’s bought tobacco. She then sits down next to the zinc store, at a pink house with black bars infront of the door. The house is directly opposite of sonia’s. At first no one is home but then two young women, one carrying a child comes in. they take the chairs inside and seem to tell kya in passing that she cannot stay because they were just leaving, so kya gets up and leaves. I speak to the girls and they turn out to be related to kya as well. Their father, simon mojo, is kya’s nephew. One of the daughter’s, Christina, told me she was late for work. But I could come back tomorrow as she will be home all day, and was willing to speak to me. Her English was quite well and she works for thirst and hunger.

12:00 – Kya goes to Sonia’s house and sits inside with them. People talk and laugh with her.

12:15 - Kya leave’s Sonia’s house and continues walking up the road. She appears to be talking to herself as she walks up the street, or talking to someone that no one can see. As she walks, people that pass by, respond to her, and laugh at or with her (I couldn’t tell which one).

12:20 – She walks towards her own house and as she does so Sagi is just leaving. They interact for brief moment and she hands him what looks like some small money and he leaves. As he leaves she continues to look in his direction until he passes the corner. She does not notice me walking past her. Then kya goes inside.

12:22 – Kya goes to the bathroom

12:25 – she goes back inside the house and I join her and her niece Rebecca who is already sitting inside. She sits down on the couch and seems to relax. She folds a scarf that was lying on the tv. She’s speaking to me but I don’t understand her. I ask Rebecca what kya is saying but she doesn’t understand her either. Kya is talking in another language (which other people say doesn’t exist). I talk to Rebecca a little bit, and discover that she’s 20 years old and speaks Afrikaans. I realize my Afrikaans is too poor to attempt a conversation so I
explain in really bad dutch that I will be back and if it were okay I would like to speak to her about kya later. She says its fine.

12:34 – I leave. And sit across the house, but out of view.

12:36 – Kya leaves the house, and directly afterwards Rebecca leaves and locks the door behind her. They walk in opposite directions of each other. It appears to me that kya had to leave because Rebecca wanted to leave. My impression is that kya is not left at home alone in the main concrete house. Though I have seen her by herself in the tent.

12:42 – Kya has walked up the road and sits down in the yard of the pink house with iron bars, playing music. The house is on the same street as the bar. There are other people sitting in the yard as well. My impression is that kya goes to yards where there are already people. I still need to confirm if she only goes to yards or houses of family and friends or other people as well.

12:47 – she leaves the house, and bumps into the niece casserra and her child. She plays with the child a moment, rubbing his head and laughing. And continues walking. I ask Casserra what is kya up to and she says that kya is hungry, and she’s looking for food. She could not offer kya any food because she did not have any at home herself. I then asked if she thought kya was disturbed by my following her and she said no. kya seems to walk in the direction of her brother mojo’s house.

12:52 – Kya goes into a yard directly opposite her brother mojo’s. in fact mojo is sitting in his yard with another person, but she doesn’t even react to him. She enters the yard of the peach house, brown door. Kya sits down in the yard, while the women around her are busy doing the laundry and dishes it seems. She is given something to drink or eat in a cup.

13:01 – she leaves the yard and continues to walk down the street in the direction she came. She sees mojo, her brother in his yard and walks towards him. They discuss something for a couple of minutes.

13:05 - the discussion ends and she continues walking

13:08 – she enters a new yard, with a green bush hedge as a type of fence. She sits down on the ground with other people around her. I also see casserra in the yard. She sits here for a very long time, but I cannot see what is going on behind the hedge. I suspect she is getting food here because she sits for a very long time. From this moment I leave and take my lunch break.

14:10 – Kya stands amidst a discussion taking place at the tented house directly at the end of skambo’s street. She is not actually taking part in the discussion but she is standing there. There are people shouting, a parked truck in front of the tent. People making dramatic movements either in response to the events surrounding the discussion or due to drinking as it is the end of the month and pay day as I imagine.

14:13 – She goes into yard opposite skambo’s house, next to what I call my ‘observation tree’. Again, the yard already has people sitting there. She gets nothing there and then she goes to skambo’s house.

14:15 – She leaves skambo’s house.

14:20 – She runs into the 20 year old nephew that stays with Andre. She asks him something and he seems to respond impatiently in passing and points sharply into one direction. She shouts something and chases him for a split second. The nephew and his friends run off laughing.
14:23 – Kya sits at a house far behind the observation tree with people in the yard (with tent). The people eventually leave but Kya remains sitting there, even after I leave 20 minutes later.

01/05/2013

**Bouncy castle-food sharing experience**

Today I witnessed something quite beautiful when I was at skambo’s house with the bouncy castle event. I gave skambo and Jason my meat patties, and they ripped off pieces for their family, who then ripped off more pieces for their friends, etc etc. Eventually there was hardly anything left for each person, but as I watched this distribution of food, no one refused to share their piece. Everyone, without a single incident of resist gave up half of their share. For me this was an amazing example of communal living and definition of community. It makes it hard to believe some of the interviewees I have when they say that everyone is looking out for themselves and not caring about each other. But of course maybe its different for people with mental problems..

02/05/2013

**Poti Observations**

9:11 – I went to Kya’s house to see if she was home. Rebecca said that kya was already gone, and check by the mbamba shop. I search around for her. Its early morning but on this Thursday morning, two days after pay day, people have already started to party. I went to a bar on the far side of the khew side, near the border, and music was playing loud with people in the yard. At some point celine dion was playing on the stereo, and that changed quickly to African music. People danced, drank and laughed like it was a typical holiday-day.

9:30 – I walk to the bar and find Poti. He is absolutely filthy, wearing clothes that look like they’ve never been washed. He smelt of dry spit and garbage. Sharply burning my nose in stench. Though his clothes were dirty, he did wear them neatly. His polo shirt tucked into his grey business pants, and a hat. I wondered if this were the uniform he decided he would wear when going to work at the dump. His polo shirt read ‘straats sport’. Reminded me of what venturo said of poti being his soccor coach in the past. Could there be a link there somewhere? People look at us talk on the street, and a guy greets poti

9:52 – we walk to sonia’s house because he wants 1 rand for a smoke. Him and Sonia and matumba talk. He says he has to protect me from people. Matumba gives him money.

10:04 – We walk to the Mbamba shop for smokes, but they don’t have any

10:07 – we walk to another store where Poti buy’s 1 smoke for 50 rand cent

10: 19 – Poti and I walk back towards the bar where he finds one of his other sister’s(Kayana or Shinee). As we approach them he is shoed away by them. “go with the guy” they say, pointing at me. Poti asks them for something and after some resistance, they gave him money and a cigarette. It almost looked as if they just gave him money to get rid of him. With hand gestures and spoken language, they shoed him away again.

10:22 – we get to the bar and another guy comes up to me and asks what I am doing and says ‘that man is sick in the head”. I told him I know Poti and he said okay and let us carry on. Poti and I sit. We talk for a bit. When we talked together people looked at us as if it were funny that I was trying to communicate with him. They laughed and shook their head. Kids called his name in a seemingly mocking way. Compared to kya however, people approached poti more, and called out to him, and had half-normal conversations. He says he didn’t go to the dump today, today he stayed in playfontein. He says he makes 10 rand at the dump. He asks me for
money/cigarettes/something to drink. I give him my orange juice, which someone tries to take away from him (seemingly only in a teasing way though because he was smiling while he did it, but poti instantly took it back, but wasn't really smiling back).

10:30 - He drinks the orange juice that I give him and he tells me he is going to sleep.


10:40 – I go to Joyce's house next door to the bar, where I see Poti still at the bar, walking around alone.

10:45 – he sits and smokes on the logs outside the bar. He coughs a lot as he smokes. He sits next to a group, not really part of it, but close enough to have some input in their conversation. At some point his neighbor, Matumbo sits near us, listening to our conversation and smiles. I ask her if she knows Poti and she says yes he is her neighbor (one door over- green door, to the right). She agreed to meet with me next week for an interview.

11:15 – Poti goes to his uncle kamoti's house opposite the bar. He helps bring beer crates inside when a truck pulls over in front.

11:22 – I see him drinking at kamotis. I don't think this is a reward for his help, as it was only a coincidence that the truck pulled up as he was going to his uncle's house.

11:25 – Poti walks on the street, a woman calls him from the bar and says something. I cannot tell if she is saying something about me hanging out with him, or about him personally. But poti pays little attention and continues walking.

11:26 – he walks into his yard and goes inside his house

11:35 – I see him leaving his sister's yard a few houses down. He sees Venturo Ernesto, his cousin, on the street. at first venture pays no attention to poti but is only talking to me. Then poti asks him for money. Venturo gives him a few rand cents. Poti then goes into pink house with music and crates of beer stacked ontop of each other (looks like another bar-like establishment). He sees kya, says hi, and she ignores him. He is given a bottle of local beer and he sits down to drink it. As I talk to kya, poti seems to be laughing at us.

11:39 – Poti leaves the bar and continues to walk up the street. He is laughing as he walks.

11:45 – We pass Ana, Kya's sister's house. She is racking leaves outside her yard. She asks poti how he is doing. He asks her for money for food but she doesn't give it to him. He tries to tell her that its for me, but she laughs in disbelief. We continue walking.

11:48 – He goes to Skambo's house and gives two empty bottles of beer in exchange for 2 rands.

11:51 – we walk back towards the bar near his house. A guy named Kava warns me not to talk to Poti because he is crazy and cannot be trusted. I explain that I know poti, and we continue walking. He says he will go to Kamoti's for food. As we walk we meet his sister and her husband, in soldier uniform on the street. Poti holds his hand out towards the husband, asking for something. The husband refuses and the three of them start to speak loudly towards each other—sounding like an argument. Simon, a relative, joins the group and asks if I understand poti. He says that Poti is physically sick in the head and asks if I will help him. I explain to him what I'm here to do. I then give poti, his sister, her husband and their two kids some food.
12:00 – At this point I feel like Poti is quite drunk, and I am influencing the situation too much, so I decide to leave.

08/05/2013

Poti Observation

Approximately 10 A.M: I found Poti sleeping under a tree in the shade outside in front of the main road. He had drool coming from his lips and he wasn’t very clear mentally today. He couldn’t really understand what I was saying.

Makaunda

She asked me what is the use of my research, and she complained that lots of people do research but SASI just sits on top of that information and never does anything with it.

09/05/2013

11:00 – Kya is sitting by skambo’s mom’s place.

11:10 – Kya at her own place

11:12 – I see poti drinking at his uncle Kamoti’s place. The streets are busy with people drinking and walking around.

11:14 – Poti passes by me and says he is on his way to work at the dump and then he will go to his uncle Johnny Ernesto in Rodepan. I follow him for a while and he turns in at the house opposite of Manuel.

11:20 – I see he leaves his bag at that house opposite manuel and he goes back to his house for a moment

11:24 – He walks back to house opposite manuel, where his cousin Johnny is hanging out with another guy. I join them for a while. Poti sits quietly while I talk to his cousin Johnny, who is half portugese and half Angolan. They are passing a joint around. I notice how Johnny talks to Poti, like a normal person. He doesn’t ever mention to me that poti has mental health problems, like many other people do when they see me and poti talking.

12:00 - Johnny allows Poti to take a glass bottle from his garbage which he then puts in his little shopping bag and begins walking towards the dump. I follow Poti from far behind, so he doesn’t notice me following him. As Poti walks down the main road into Platfontein, he is almost on the middle of the road. The sun is scorching hot, but he keeps up a fast pace and I can barely keep up. An ambulance passes by and Poti goes off the road to avoid being hit. At the beginning of the main street Poti takes a right and walks towards the dump along the side of the highway. I cringe with fear for his life as I see giant trucks passing just a meter or two from him as on coming traffic. Many thoughts ran through my head as I saw this tiny person, wearing clothes that were too big for him, shirt tucked into pants, and bag over shoulder, heading to work with purpose. the contrast between little poti from Platfontein and the major trucks and company cars of Kimberley that narrowly miss him was quite special to witness. So here is where the two worlds collide (hopefully not literally). As I am now on the same highway following him from behind, worrying about my own safety I ask myself how far would I go for research, how far would I go for research, and realize this is far enough and I turn back.
13:00 – I go to the shop where I meet Tsholofelo (which means Hope). He is a young traditional healer from a nearby township and his roots are from Botswana. Tsholofelo is one of the most interesting people I’ve met in a long time. He wore normal western clothes, but with a wrap around his waist and a beautiful beaded necklace and matching bracelet. He told me he likes to come to Platfontein to drink every now and then because it is much more relaxed and quiet than other locations/townships to do so. I told him that I was studying people with mental illnesses and this sparked a very interesting discussion. He said to ‘us’ these people are mentally ill, but to him they are just spiritually intune or spiritually on a different level. This isn’t the first time I’ve heard this, so I was intrigued. He claimed that westernization and religion like Christianity is ruining many African cultures. People only believe what they can see and touch, and less of the unknown. He says that money and power is the driving force of belief. As a poor man, why would anyone follow his beliefs? But if you’re a Christian, rich, and powerful like the president, of course people follow your lead. I agreed with him on this, and also think it is a huge shame of how African cultures are becoming diluted to such western views.

14:15 – I see kya leaving christina’s house near the zinc-built shop. Speaking in general, she tells us that if she asks people for something, or if she talks to people, and they ignore her, they will not see her again for a very very long time. This observation reinforces some other observations I’ve made and conversations I’ve had with people that say that kya gets very angry when you ignore her, so they often laugh with her as a mechanism to make her feel included. But not everyone does so. Kya then proceeds to ask skambo for money, and threatens to hit him if he doesn’t (in a joking matter). Skambo gives her some change. I tell kya that she looks pretty today (she was wearing a purple dress that I haven’t seen her wear as yet, and a matching purple head scarf, and necklace made of white shells). As skambo translated what I said into me (her husband) thinks she is beautiful, kya started to talk about her real husband. Skambo gave kya a beautiful necklace as a present. A young woman laughs as she walks past us and sees us trying to communicate with Kya.

14:18 – Kya goes home

14:30 – she sits outside between the cement house and the tent and rests in the shade. There are people at home and in the yard, but they do not interact with her.

14:35 – Kya leaves her house. I notice that she is waving at people that are not visibly there.

14:42 – Kya goes from one yard to another, as if either changing her mind or being sent out from these different yards. She goes back up the street and heads to skambo’s house.

15:00 – Kya sits and hangs out in the yard of Casserra. Casserra is having her hair braided.

15:30 – Kya goes back to skambo’s house, but no one seems to be paying attention to her, and she leaves right away. I decide to go to christina’s house and kya actually follows me and walks straight inside. They laugh for a moment together (kya and christina’s mother) and kya leaves again right away.

15:36 – Kya enters the yard of the relative with the yellow door on main road. Her mood seems to change dramatically. She is screaming at someone in the yard that is not apparently visible, at least to me. She leaves the yard and walks down along the main road, stopping at intervals to shout and point at someone or some people that are not there

16:15 – the streets are busy with people walking around. New meeting/drinking points are popping up in yards where I have never seen them before. I speak to Hennly George. She begs me to try to help her find a job by talking to SASI. She says sasi doesn’t hire people like her and from her side of the community. She says she
drinks all day because there is nothing else to do. She has no money and gets no support except for her two young children. But she can do nothing for herself.

16:50 – I find Kya walking home. She enters her yard as sagi leaves the yard. They interact, she gives him money. He goes to the shop and buys what looks like a cigarette and he goes back home. Kya gives him fire wood, which she herself collected, and he leaves again.

17:15 – Kya goes to her shack in the back of her yard and she appears to rest. I walk around for a bit and notice many children playing on the streets. The bars are completely empty. At this time it seems like most people are going in doors to keep warm. Several people are starting camp fires in their yard.

17:30 – I say bye to Kya at her home. She is sitting in front of the fire in the main tent.

10/05/2013

Kya observations

10:40 – Kya leaves lolita’s house holding a bag of sugar in her hands. She goes to Skambo’s house.

10:52 – she leaves Skambo’s house and goes across the street to the shop. She buys a cigarette. She points and talks to some imaginary person in front of the store.

10:57 – Kya goes home, and goes into her small zinc shack room in the back of the yard.

11:11 – Kya walks about, in and out of her room, with a bucket in her hand. She sits down on the stoop on the side of the main house, alone, drinking something.

11:30 – at this time she is still there sitting alone outside. Her niece is home with her baby but does not interact with her. It’s a quiet morning, and not much is going on outside.

12:00 – Kya is at the radio station. People stand outside in front, not really paying attention to her. She walks down the main road talking to herself.

12:06 – she walks to yellow doored house on the main street. She asks for something, and the man hands her something and she continues to walk. She seems agitated. Yelling out loud to imaginary people on the street. Some people in their yards look at her as she passes.

12:13 – she goes to christina’s house but there is no one home.

15:00 – I find Kya at home.

Poti observations

15:54 – as we leave Platfontein I see Poti coming back. He is walking with a large bag of maize on his shoulder.

14/05/2013

11:08 – the streets are quiet, as I walk with Eva down Poti’s street. Poti comes out of his house in his boxer shorts and a sweater. He washes his legs and feet in the front yard. Then he sits down on the stoop in front of his house. Seemingly just observing the morning’s activities. He sees me, and he makes a gesture asking for a cigarette. I refuse. I go and sit with him and he starts to talk about the difficulties of life in Platfontein. No
food, he says. The people suffer. Then poti starts to talk about his wife (he does not really have one). He says his wife went to buy food for their baby (also not true). I asked him what was the name of the baby and he said john, and then he said poti like himself.

11:30 – Venturo walks by and sees me and poti sitting in the yard. He walks into the yard and comes to say hi. He tells me he has to go to Bloemfontein as a witness to a crime and he was on his way to his uncle kamoti to ask for some money to help him get there. Venturo doesn't greet or even look at poti while he is talking to me right next to him. He says bye to me and leaves. During this conversation poti sits, occasionally uttering 'ya' when venture says something to show that he understands what is being said. Although I don't think he actually understands what is being said. Steven walks by and smiles at us. He says something (seemingly friendly) to poti, and keeps walking. John and his friends next door see me sitting with poti. They look and sometimes laugh in our direction. John walks into the yard and he starts talking to me. He does not pay too much attention to poti. Poti asks him for a cigarette, John says no. John and poti are apparently related. But John then also said that we are all related, brothers and sisters. Poti goes to the boys sitting in the yard next door and gets a cigarette bud from them to smoke.

11:57 – I leave.

15/05/2013

10:01 – I see poti walking on road to the dump in his ‘work clothes’

x time – I ask Ana where’s kya and she replies ‘kya kuwa gwata!’ with her hands making a gone gesture. Did no find kya for the whole day. John tells me that poti told him I should look for him by his house. He says poti likes me too.

Observation note:

I realize that people who are considered mentally ill live in somewhat isolation from everyone else. Poti lives alone in a house while his father works out on a farm. Sagi lives by himself in a house away from kya or the rest of his family. And kya sleeps in a shack at the back of her sister’s yard. Kya also does many domestic things alone. She fetches her own fire wood. Washes her own clothes, and cooks her own food.

16/05/2013

12:40 – I see poti walking along the main road and then towards a house near the khew/xung boarder. He goes to his cousin Anton’s house. He enters the yard where people are standing and he asks for food. The cousin says she doesn't have food for him today. Poti then goes to sit on a chair away from the group (of five people, including William). Poti is just watching them but not interacting with the group. The group also does not really interact with poti, except when they give him a cup of beer. No one is really interacting with William either though William is walking around and does interact a bit more with the others. William then take poti’s cup of beer. Five minutes later poti leaves the yard and as he walks away he gestures with his hands that he wants food (points hands to mouth) he does this repeatedly for a few seconds and then continues walking on.

12:50 – Poti walks into his sister sonia’s yard and enters her house, though her door is closed. I don’t think anyone is home by the looks of it since everything was closed. He comes out a minute later munching on bread in his hand.
12:52 – Poti goes home and into his own room. I hang out for a minute in the yard next to his house. The bar is full with people. Music is playing. I see one woman vomiting outside at the back of the bar.

13:00 (approximately) – Kya is sitting on the stoop at casserra’s, with cassera, her two sons, recunda, and her son. Kya talks, to which casserra and recunda occasionally respond, but not always. Kya ask’s me what is in my heart. I tell her love. I ask her what is in her heart, and she starts talking about something else..windhoek church. She then asks me to which church do I belong and I respond Windhoek. She says something to which recunda laughs. I ask recunda what she said and she said that kya is getting angry because you never give her food. I give her my orange and she eats it while drinking coffee casserra has given her. Casserra is inside preparing food for them. When casserra comes out, kya jokes that she is walking ‘soko soko’. They laugh together. When I ask casserra what soko soko means, she says that kya says she wabbles like a fat person when she walks. Casserra doesn’t seem offended at all.

13:45 – I go to the clinic to search for Kya’s and Poti’s files. Clive helps me finds poti’s files however there is no record of kya. Clive explains to me that Poti was referred to from hospital on January 15th 2009. Initial diagnosis was epilepsy. Though in addition to a prescription of epilem 500 mg, poti was also prescribed haloperidol 2.5 mg, which is a drug prescribed exclusively to psychiatric patients. Treatment should have continued for up to 6 months. Judging from the file however, clive stated that there was never any followup to this condition. Because sister alexander said that usually if patients do not come back for their treatment, the clinic follows up personally, I asked clive why this was not done. He admits that yes they should have followed up and does not know why they didn’t. he says it should have been brought to the attention of the psychiatric specialist, but she missed it. He says she is not so good and also has to keep track of patients with ART treatment for HIV. So she has a lot on her plate. This was a very interesting observation for me because it made me realize that neglect of mental health patients in Platfontein is not just due to problems with family, or communication with the clinic, or other groups, but it is due to a collective failure due to many reasons. A small seemingly non-linked matter of the clinic being understaffed, and some employees being overworked, has also contributed to this neglect in mental patients. Poti himself has returned to the clinic when his jaw was broken in February of 2013. At the moment poti’s file says he is epileptic but not a psychiatric patient. Based on my and clive’s observations, clive thought this was also not the correct diagnosis. I asked clive how can poti get treatment and he says poti simply has to come back to the clinic for a re-diagnosis. And if poti resists, the family has to bring him in. And if they cannot get him to the clinic, it will be difficult. Because, as clive states, poti is not violent, and not a danger to others, so there is no pressing priority to get him treatment. Clive mentions that if they are violent, then together with the police they go and collect the patient. As a matter of fact, clive stated, even today they had such a case on the !xung side of the community. Poti, though dirty and disoriented, is not a danger to others, he is not priority, though he is a danger to himself. This conversation has sparked curiosity in clive and he said he will checkup on this case tomorrow. When I mention kya, clive has no record of her. I explain to him a little about kya and gave him her full name so he can also check up on her. When I mention the last name juharra, clive is very surprised to know that the juharra family are an educated, well off family of journalists and should know better..

15:00 – I walk towards kya’s house. The weather is getting dark, and the streets are quiet, and its about to rain. I enter the house to find kya sitting on the couch by her self watching spongebob square pants. She points to the couch, gesturing me to sit down. I join her and we quietly watch spongebob. We both laugh at the same part when spongebob gets caught on a hook. Ana is cooking food, which smelt great. She comes and sits down across from me and also watches the television. Then one by one, three children ranging from teenagers to toddlers come and sit down to watch as well. At first kya doesn’t really speak to anyone, then one
of the young teenage girls asks Kya for something. Kya replies and the girl looks at me and laughs lightly. I say bye and Kya says 'eh' to which Ana laughs.

15:20 – I walk towards Poti's house and the street is ridiculously loud and rowdy with drunks. I see a fight at the bar next to Poti. Rather than trying to break up the fight, people circle the two young men, as if to cheer them on. Rebecca, Poti's niece is walking with a girl whose face is completely bruised up and bloody. Apparently her husband had beaten her up for asking for 10 rand.

16:23 – I find Kya walking towards the somalian store. Two youth boys walk next to her. They shout things and point to her aggressively. It seems to me that they are tormenting her, because they are loud and speaking in a mocking tone. They follow her to the store where she buys a cigarette. Kya repeatedly mimics what the boys are saying to her, as if to defend herself. The boys leave. Another boy, younger, possibly 12, talks to Kya directly for a brief moment and leaves.

16:33 – Kya walks towards her house. Though she has a general direction she occasionally pauses to talk and say things to people that are not apparently there. She then sees Sagi and directly walks towards him and gives him money.

16:35 – She sits inside house on the couch again. A brief moment later she leaves home again and she talks to me on the road. An older man sees the two of us talking. He calls out 'mama Kya' in passing and laughs at us trying to communicate.

16:44 – Kya approaches a woman in a truck in front of the store at the end of Skambo's street. The woman replies to Kya in a teasing way and drives off.

16:48 – Kya walks into church, and directly walks out again. I speak to the pastor and he says church starts at 17.00. Kya walks around talking to herself.

16:55 – Kya walks back to the church yard. There are a group of people, mostly middle-aged to elder women. Kya starts to speak and one woman touches Kya's hat (it appeared as if she were admiring the hat). Then the woman touched her own skirt to show it off it seems. Then Kya started to shout things and point. The women began to encircle her, curious and entertained at what Kya was saying. They mostly laughed, and one elder woman, mimicked Kya from behind her, imitating her expressions.

17:03 – Kya leaves the church yard, still shouting and pointing. She is clearly angry. And the women continue to laugh and joke.

17/05/2013

The goodbyes

We get to Platfontein at 10 am and I immediately start looking for Poti to give him the groceries I bought for him. On our way to his house I see Kya at her house. She is just leaving, and is in a very bad mood. I tell Rebecca I want to give Kya some food but another girl says that Kya is upset so I should maybe come back later. We walk all over the place for Poti, some young men say he is on the other side, but we don't find him there either. I see Kya go to Skambo's mom's place. Skambo's mom and another lady are talking over the fence. As Kya approaches. Kya joins them and they start talking amongst each other. They laugh together. I continue walking to find Poti but I don't find him so I then say my goodbyes to Kya. She is sitting at Skambo's mom's having a cup of coffee and eating bread. I give her my old shoes and she says something, to which Skambo's mom laughs hysterically. This goes on for a bit and then I give Kya a bag of groceries. She clings on
to the bag instantly showing possession over it. She smiles at me and says danki. I can see that she really appreciated it. She says in khwedam that she does not want me to go. I hug her and we leave.

I eventually find poti; he is walking in the direction away from his house. When I see him he looks quite disoriented and cannot communicate with me. He is holding his pants up with one hand, drool coming from his mouth, and smells and looks particularly filthy today. He is certainly in worse shape than I’ve seen him before. We walk to the car. On our way to the car a woman calls out to him, he barely responds. Another couple people do the same. As we walk a dog runs up to poti very aggressively barking and trying to bite his ankle. Poti does not even flinch, barely aware of the dog’s presence. And the dog does not try to attack me either. It immediately makes me think about the stories I’ve heard of poti eating dog. Did he try to attack this dog? Did this dog somehow know of what poti does? As we walk we walk in silence. As I ask poti something he only smiles goofily. And he continues to walk with the goofy smile, still not respondent to anything around him. We get to the car where I give him the groceries. He barely says thank you. The first thing he tries to grab out of the bag is the empty bottle of beer. The woman security guard at the radio station tries to speak to him, but he doesn’t really respond to her. I follow poti to his house with the stuff. Two elder woman stop him and attempt to have a conversation with him. One woman starts to pull things out of the bag, seeming to me that she was claiming some of the things I was trying to give to poti. Poti was now sitting on the ground in front of us, with the bag completely ripped open. The woman had grabbed the bag of oranges, an empty beer bottle, and the sweet biscuits. I ask the second woman if they are family and she says that they are the sister of his mother. I explain to them that I bought these groceries for poti. After telling him something in khwedam they give him back the groceries and get another bag for him to put the things in. I walk with poti to his house. At his house john is there to greet us. He asks me what was in the bag and I told him poti’s things. When he sees that I have bought groceries for poti he asks me for something. I told him that I already gave him a bag of peanuts the other day, and he said he shared them with poti (I didn’t really believe this). I tell him to ask poti for something. I walk inside poti’s house with him. It is completely empty of furniture but covered in garbage. Poti goes into the backroom where he proceeds to take a piss. I say goodbye to poti and leave. For a brief moment I turn around to find john grabbing the bag of biscuits from poti’s hands and poti resisting. Eventually john takes the bag of biscuits. I was disappointed to see this two-faced behavior. In front of me, john appears to be the supportive nephew, however behind my back he is taking full advantage of poti. I see them leave together, poti holding the oranges and john holding the biscuits. John gestures that they are going to sell the oranges and make money. I leave it at that.

I continue up the road to say bye to casserra and her family. I walk into her yard and they are eating the oranges I got for them yesterday. She gives me her address and phone number. Says if I can to send something for them from the Netherlands, but above all please pray for them. I told her that I could not promise anything but would try my best. I hug her, the two beautiful children, and her husband goodbye. They really are a sweet, humble family, and if I could, I would do everything in my power to make their lives a little better.

I then say bye to ana and her daughters. We hug, and I leave.

On my way back to the radio station, I see poti and john still walking together. This time, john is holding the oranges. I got the feeling that poti had little control over this situation.
Thesis Summary:

**The Mad Struggle**: A Case Study on the Duties and Difficulties of Informal Care for Mentally ill Individuals in a Resource-Poor Township in South African

In spite of South Africa’s national policy to protect the rights of mentally ill individuals, a lack of adequate resources, feasible planning and commitment, have meant a gap in the mental health care of affected individuals. As a consequence, the burden of care is increasingly felt by the informal caregivers of mentally ill individuals.

“The Mad Struggle”, is entitled so because of its double meaning. Firstly it depicts the suggestion that mentally ill individuals struggle in their daily lives, and secondly it attempts to convey the inconceivable notion of a vicious cycle in which the already resource-limited family members become even more burdened by often bearing the sole responsibility of taking care of these individuals.

By means of a case study, the aim of this research was to identify the main actors of informal care and to describe the mechanisms involved in supporting mentally ill individuals in the South African Township of Platfontein. Using qualitative research methods, the lives of two case study subjects locally described as mentally ill, were investigated for a duration of 10 weeks. Insights into the daily activities and relationships present in the lives of the case study subjects were gathered using participatory observation and semi-structured interviews with the subjects and 23 informants consisting of family, friends, community members, and community leaders. Results indicate that the responsibility of informal care weighs most heavily on the family members of mentally ill individuals. While the presence of a clinic does provide access to health care, informal care is most commonly provided in the form of social support, consisting of commodities such as food, money and shelter. A limited record of emotional support was identified. In this research, several factors hindering the efforts and willingness of informal care were also identified. Personal hardships, stigmatism, and unrealistic rules and regulations set by the health care system in place limit the amount of support mentally ill individuals in Platfontein receive. The gap in mental health care in combination with the factors hindering informal care efforts seem to take its toll on the heavily burdened family members taking care of their mentally ill relatives and thus further perpetuate the cycle of poverty that is already very present in the Platfontein community.

Through the use of qualitative research methods and presenting the data by means of ethnographic passages written by the researcher, this thesis aims to provide a deeper, and more humanized account of the issues surrounding informal care for mentally ill individuals in a resource poor setting, such as Platfontein South Africa.