

WE COUNT

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Editorial

Welcome to the second edition of the 'We Count' magazine. The maiden edition was a success providing general insight into the situation of people with mental illness.

This edition features four stories from three African Countries. These are true life stories of those who suffer mental illness in Africa. It is our hope that through their "voice" as mentally ill people you will understand what it is like to be poor and mentally ill in Africa.

In this edition the stories reveal how cultural perceptions on mental illness lead to choices in the search for treatment for the mental health conditions that people suffer. Communities that have a wide variety of socio-cultural belief systems provide even wider range of choices for cure. In some cases choices made are not good as the stories will reveal. Large amounts of family income are spent on some choices that offer little or no relief. The near absence of bio-medical African mental health units in government health services in all the countries that BasicNeeds serves has created a challenge in responding effectively to the myriad mental illnesses that plague people in poor and hard to

reach communities. Sufferers, their primary carers and families are forced to desperately explore for sources of a cure within and beyond their environs and will do anything to get their dear ones back to normalcy, even to the detriment of the very people they are trying to help.

This and following editions, just as the first one, seek to break the silence of the suffering of mentally ill people and their families. We aim to inform, challenge and motivate all to think about mental illness, the thousands who suffer it and the hundreds of thousands affected by it.

Share the word! Lead the struggle! Make a difference today by talking about mental illness to your family, friends, work colleagues and all, especially those who care to listen. Then after this, think of what you can do to improve the well being of mentally ill people.



Peter Yaro
Chair of Panel



Bernard Alando
Coordinator - Africa Life Story Project

Vision

Our vision is that the basic needs of all mentally ill people, throughout the world are satisfied and their basic rights are respected.

Mission

To initiate programmes in developing countries which actively involve mentally ill people and their carers/families and enable them to satisfy their needs and exercise their basic rights. In so doing stimulate supporting activities by other organisations and influence public opinion.

Privacy

All the stories featured in this issue were freely and willingly constructed with the expressed permission of the mentally ill people and their families. This publication is purely to educate the wider society about mental illness and challenge them to treat mentally ill people with dignity.

Message from Founder Director

I am delighted to welcome this second edition of We Count! The editorial team and the writers have once again demonstrated their passion and conviction in bringing to us the real voice of mentally ill people. Almost every story mentions extreme cruelty meted out to people with very severe illnesses. At least in two of the stories we hear the frightening ring of shackles binding people to their communities in extra judicial actions reducing the liberty of the mentally ill person and the dignity of all those involved. The people in the stories struggle with the twin conjunctions of needing to make a living and needing to understand and then manage their illness. We are exhorted by our Editor to join them in the struggle - to make a difference. I think we must if we are to make the world a better more humane place..



THE STORY OF FAMBE BIWAGA

Written by: Irene Among, Programme Coordinator, BasicNeeds Uganda.



Irene Among

The sound of shackles



The Silence is Broken

It is a cold morning in Kaseta Primary School and a group of over eighty people have congregated for the first participatory data analysis workshop¹, four months from the commencement of BasicNeeds² Mental Health and Development programme in their parish³ in Hoima District. The workshop begins with a brainstorming session on the concepts of ‘data’ and ‘data analysis.’ There is silence in the room as participants; mentally ill people, carers and Village Health Team members think about what these concepts could mean.

The silence is broken as Fambe and her mother walked into the room. The sound of shackles on Fambe’s legs fills the air. Fambe is probably in her mid twenties and stands 5’ 5” tall with a graceful stature and beautiful in her own right. On this particular day, she dons a pink dotted dress, around which she wraps two colourful pieces of the ‘*kanga/lesu*⁴. My attention drifts to Fambe’s aging mother whose face portrays years of worry. As I ponder my next move to get the session moving, my thoughts drift

to the agony this family has suffered as dreams they must have so dearly held for their daughter were dashed by her unexpected illness. But then again, at closer look at the two, I marvel at how now with access to reliable treatment, they have begun to pick up pieces of their lives.

Well, I am reminded of the purpose of our gathering and forced to continue with the workshop, I refocus my thoughts, but I determine that we must listen to Fambe and her mother.

Dignity, a Human Entitlement

During the lunch break, I share my thoughts with my colleague Susan, and we decide to talk to Fambe and her mother. Susan speaks Alur, one of the local languages in the North Western part of Uganda, understood by Fambe and her mother. We observe some kind of communication between Fambe and her mother which, another person would not know if the two understand each other. What is for sure is that Fambe’s mother understands the needs of her daughter.

Susan starts the conversation by introducing herself and seeking their permission to document their story and take photographs. She explains that their story will help us to design interventions to help Fambe and other people in her situation. She adds that it will also help us to communicate to the world that people like Fambe, despite their illness, are entitled to human dignity like anyone else. Fambe's mother grants us permission and the interview begins.

A Mother's Devotion

Fambe is the fourth of her mother's five surviving children born sometime in the 1980s. Fambe has one sister and three brothers. When asked about her age, Fambe, whose memory has since been eroded by her illness, can only wring her fingers. Fambe lives with her mother and two siblings. Her aging mother of about seventy years continues to devote her remaining energy to providing a home and other needs to her tormented child.

As Illness Begins, a Marriage Ends

In 1998, life smiled upon Fambe and she got married. However, this bliss was brought to an abrupt halt when she got her first attack of mental illness just seven months into her marriage. Fambe's husband did not know how to care for his sick wife. His only solution was to send her back to her maternal home.

An account by Fambe's mother reveals that Fambe's illness started by her talking to herself and fearing that people were following her wanting to kill her. At this time, Fambe and her maternal family were living in the village of Kasatu located in Akworu sub-county in Nebbi district. One day while in the garden she started screaming that people wanted to slaughter her. To protect herself from these "evil people" Fambe disappeared from home for a week. She was found in the village of Boro in Nebbi district, fifty kilometres from home by a Good Samaritan who took her in.

At the Good Samaritan home Fambe had another attack of illness, during which she mentioned the names of her grandparents who fortunately were known to the Samaritan. A message was sent to Fambe's grandparents who later re-united her with her family.

Traditional Healing

Fambe's parents were peasant farmers sustaining their entire family of five children with meagre proceeds from their farm. In their quest to help their daughter, Fambe's parents took her from one traditional healer to another in West Nile region of Northern Uganda. *"My husband was a farmer and we didn't earn that much, we spent most of our earnings on finding help for Fambe,"* says Fambe's mother. Fambe could not be helped by traditional healers. However, her parents kept hoping that some day they would find a good witchdoctor who could help their daughter.

A More Secure Place

Due to the insecurity in the Northern part of Uganda

perpetrated by the Lord's Resistance Army (LRA)⁵ in the 1990s the family was forced to move from Nebbi District to a more secure area, they moved to Rwengabi village in Hoima district over 180 kilometres from Nebbi district. Once again a Good Samaritan gave Fambe's family a piece of land on which to construct shelter. The family got in touch with a whole new set of traditional healers and the cycle was repeated all over again.

In God's Hands

Unfortunately, this search for treatment came to an abrupt halt when Fambe's father, the family's breadwinner, died suddenly in October 2003. Fambe's mother laments that her life became harder. She now had to fend for her family and cope with Fambe's situation on her own. She was hardly able to work due to her daughter's state which required constant attention. Whenever possible, she cultivated her small piece of land or did casual labour in the village, for which she is paid very little. *"I could not afford to pay the traditional healers, so we gave up the visits to traditional*

healers and left Fambe's situation to God," she adds, attesting her Catholic faith.

"I Was Concerned for Her Safety"

As fate would have it, Fambe's situation continued to deteriorate. She began stripping and running nude in the village, laughing unnecessarily and eating garbage. *"She even ate her own faeces!"* adds Fambe's mother in a very sombre tone.

"I often got so worried when she ran off in the village and something bad would happen to her. So we bought shackles which I clipped together every time I noticed that she was about to run. I didn't tie her up because she was a bother, but because I was concerned for her safety. I only thank God that the people in the village know me and when Fambe runs away, they bring her back home without doing any harm to her."

"It Was Like a Dream"

Fortunately for Fambe, one of the Village Health Team (VHT) members trained by the BasicNeeds project was a personal friend of her late father. *"Fambe's*

father was my friend. When he came to settle in Kaseto, I gave him three acres of land, which his family is still using," says James Olema. In tribute to his friend, James felt compelled to ensure that Fambe benefited from the new mental health initiative in their parish. He ensured that Fambe got medicine for the first time from the outreach clinic. *"It was like a dream! My daughter had never taken modern medicine for her condition!"* adds Fambe's mother. Fambe was diagnosed with schizophrenia. At the time of the interview, Fambe had attended all three outreach clinics and received free medication, and was scheduled to see the Psychiatric Clinical Officer the next day, for the fourth time.

The VHT member has this to say, *"When I first met Fambe three years ago, she would wander naked in the village, she would laugh all by herself and go to the toilet wherever she was sitting. I have seen a marked improvement since she started taking medication from the mental health outreach clinic. Fambe now wears clothes and can visit the toilet on her own. Although she*

still wanders off and still wrings her fingers, it is not as bad as before.”

Fambe’s mother has this to say, “...although the drugs weaken her a lot, I am persistently following the instructions for her dose and ensuring that she takes the medication. My daughter has improved a lot and I am sure that she will continue to be better.”

“It is only Mungu, God, that gives me hope that Fambe will lead a better life,” adds Fambe’s mother. Fambe cannot talk, but murmurs. She smiles and when hungry, or wants to move, she signals her mother who now understands her daughter’s “sign” language.

A Hopeful After note

Four months after the story of Fambe was first written, the Development Research Training team (DRT, a partner of BasicNeeds Uganda) paid a visit to Fambe and her family. On a hot Thursday afternoon, the team drove four kilometres and walked another kilometre through a small village path to Fambe’s home. This house

is shared by the entire family; and is surrounded by lush gardens of sugarcane, beans, maize, potatoes and cassava.⁶ This particular Thursday, was also the outreach clinic day at Kaseta Health Centre II, and Fambe had not made it to the clinic for her monthly review. Instead, one of the Village Health Team members had picked up Fambe’s medication for her. One could probably attribute her absence to the long distance to the health centre. Fambe’s aunts who were at home during the visit told the team that Fambe’s mother had gone to the grinding mill to have her corn ground. They also commented that the Village Health Team member responsible for visiting Fambe had not reminded them of the next clinic day.

But the Shackles are On

During this visit, Fambe had improved, she looked brighter and healthier; she even mumble some greetings to the team in her local language. Her relatives reported that she was beginning to communicate verbally with her family. *“Initially she never used to ask for food, and even when you*

placed food in front of her she would just look at it. These days however, when hungry she asks for food,” stated her aunt. *“It seems this medicine has some appetite-inducing vitamins. We are surprised she can ask for food,”* exclaimed the Village Health Team member. Even though Fambe has begun recognizing people, she occasionally forgets her relatives. She still wrings her fingers continuously. According to her aunts the shackles on her legs have been left on for ease of identification in case she strays off during relapses.

Writer’s Reflections

Fambe’s story makes one reflect on what it means to be a woman, internally displaced and mentally ill. One wonders what the first year of moving from home in Nebbi district to a new place must have meant for Fambe and her family. Did the host community take them in or did they have to face the double stigma of being ‘intruders’ and coping with the ‘disgrace’ of having a mentally ill member in the family?

networks are vital in helping families and mentally ill people cope with their situation. Indeed Fambe’s mother appreciates the fact that the community brings Fambe back home whenever she wanders off.

Fambe and her family were all delighted when her dream of having a family of her own had been met. Sadly this came to a halt when Fambe was sent away from her matrimonial home because of her mental illness. It is for this reason that BasicNeeds recognizes the importance of gender differences when designing programmes that respond to the different needs of men, women and children. And, in measuring the impact of our interventions, we seek to understand what difference we have made to the lives of different categories of people.

The lack of livelihood options and stigmatization by neighbours often puts mentally ill people and their families in a state of hopelessness. This situation calls for a focus on treatment and rehabilitation.

Schizophrenia

Globally, 24 million people have schizophrenia. Mental and behavioural disorders are common, affecting more than 25% of all people at some time during their lives.

Schizophrenia is a serious mental disorder marked by irrational thinking, disturbed emotions and a breakdown in communications with others. Schizophrenia is the most common form of psychosis, a serious emotional or mental condition that makes a person unable to function in society. The cause of Schizophrenia's is unknown, and scientists currently relate it to a metabolism disorder thought to be hereditary. Others add that the environment also has an influence. Biochemical imbalances in the brain, which influence how we think and feel, are also known to be a cause.

People who develop schizophrenia often have a history of unhappiness and emotional stress in early childhood. Later, frustration and disappointment may contribute to the development of schizophrenia in a person who is predisposed to it. The condition can, however, arise in people from a stable family background too.

Sources: Foundation and Techniques in Psychiatric Rehabilitation - NIMHANS, Bangalore India.

Essential Psychiatry - Edited by Nicholas D.B. Rose
The World Health Report - 2001

THE STORY OF MAXWELL NAANUMA

Written by: Alando Bernard, Documentation and Learning Officer, BasicNeeds Northern Ghana



Alando Bernard

Now I
can ride
a bicycle



Breaking Barriers

We visited Maxwell Naanuma on the 7th July 2005 at his family home in Oribile, a village about five kilometres away from the town of Lawra. As we set out, we thought that we were going to meet with Maxwell's immediate family. It turned out that almost all the elders of the Oribile community came to his home to meet us.

The BasicNeeds Northern Ghana team learned more about Maxwell's situation after a participatory review meeting with mentally ill people and their primary carers in the Lawra community. The team was touched by his situation. In an earlier outreach camp⁸ and a field consultation⁹ with mentally ill people and their carers, we found Maxwell in shackles. The Participatory Review Meeting was the third time we were meeting him. Maxwell had shown such remarkable improvement, so that the Community Psychiatric Nurse who visits him felt Maxwell could now be freed from his shackles, at least around his ankles, which had made walking difficult for him.

At his home almost all the elders in the community gathered to meet us. Family members explained to us that a traditional healer had put the shackles on him partly as a form of treatment and also to prevent him from causing harm to other people. Something he had done before. To remove the shackles, they said, certain rituals had to be performed and these entail financial responsibilities. The traditional healer also needed to be convinced that Maxwell was now stable for the ritual to take place.

The Community

Oribile is a small community located about five kilometres from Lawra. The entire community consists of about ten households. The households in the area are subsistence farmers. Some of the women also brew pito (a local alcoholic drink) as an additional source of income. They have a nucleated settlement pattern with homes about 200 metres apart, the space between is used for farming activities. The area lacks a lot of basic amenities such as schools, sanitation facilities, electricity, potable drinking water

and good roads. Oribile is typically a rural community where people still uphold their communal spirit, values and cultural beliefs. There is a sense of community among the people as could be seen during our visit to Maxwell's home.

It was gratifying to us that his family and the elders of the community agreed to consult the traditional healer who put the shackles on about their removal.

This is Maxwell

Maxwell is a twenty four year old young man living with his family at Oribile. He suffers from psychosis and was shackled because his family claims that he is very destructive when not tied up. Maxwell was a second year student at the Kwame Nkrumah University of Science and Technology in Kumasi when he became ill. He appears a gentle and reserved person who does not talk unless he is asked a question. It takes a closer look to notice how fair and good looking he is. But rural hardship and his illness have almost robbed him of his natural looks.



How Maxwell's Illness Started

Suone, Maxwell's carer and elder brother, talked to us about the factors that led to Maxwell's illness at a field consultation in Lawra on the 7th of April 2005. He gave us the following narration.

"My brother completed his schooling at Nandom Secondary School and gained admission into the University of Science and Technology in Kumasi. Even though I am poor I managed to help him with some of the things he needed. One day he came home and reported to me that he saw a colleague student having sex

with a lady in their room and that when he advised them to stop, his friend threatened to destroy him. I advised him to report to the school authorities about it. He went back to school and came back with this illness.”

Search for treatment

“He appeared well when he was brought home from school. Then one day he took his Bible with him and got lost. We found him three days later, looking disturbed, and we took him to the Lawra hospital. He was admitted for a few days and discharged. He was prescribed some drugs, but the drugs did not seem to work for him, so we pursued traditional treatment.

Our search for treatment from traditional healers was very expensive. Some of them took goats, sheep, cloths and money. It drained all our resources and we just could not continue that way. We went as far as Burkina Faso in search of treatment. Maxwell’s condition was deteriorating almost every day.

Confined by the shackles

One day he was beaten by a mob on grounds that he had stoned a motorist. He was arrested and thrown into a police cell. It was during this incident that I was directed to see Kakraba Mensah, a psychiatric nurse. He gave Maxwell an injection and also gave him some drugs to take. His condition got better but occasionally he would become violent. That’s why we put him in those metal shackles.”

During this same field consultation, Maxwell participated in the exercise called ‘My World’ where a mentally ill person visualises the constitution of his world. He had this to say about his situation during the discussions, *“The shackles are my world.....”* A very moving statement indeed.

Freed from Bondage

BasicNeeds’ visit and earlier contacts were a welcome opportunity for Maxwell, a relief that has long eluded him. He gets a chance to leave the four corners of his dark room and given the opportunity to talk and share his

views. Maxwell has also had the privilege of consulting a psychiatrist who treated him in his own community through outreach clinics without the hassle of having to travel far from home.

According to Kakraba Mensah, the Psychiatric Nurse who has been attending to Maxwell, he is now lucid and regaining normalcy, the latter being a process that will

take some more time. What he needs now is medication that has a sustained effect. He also needs to be freed from his shackles and treated normally like any other person in the family. If not, he might think a lot about his condition and relapse.

BasicNeeds supported Maxwell to access the treatment that he needs to facilitate his recovery. In addition, BasicNeeds supported Maxwell's family with 150,000 cedis (about £9) to perform the necessary



rites in order to remove the metal shackles from Maxwell's feet and hands.

The shackle-free Maxwell now speaks out: *"The chains were removed on 12th December 2005. We took the money BasicNeeds supported us with to secure my release. I feel free now that the chains have been removed. Now I can ride a bicycle. I could not bath properly because of the shackles but now I do. Now my family members include me in decision making. Formerly they used not to. They asked for instance whether I was interested in the gardening they were doing. I told them I was interested and now I have joined them on the farm."*

Maxwell smiled broadly and remarked, *"All I can say is thank you to Mr. Kakraba who has been so caring and concerned about my health. My brother Suone has also done very well and a big thank you to BasicNeeds too for the support and ensuring that I am free from my shackles."*

The burden of care giving rolled away

Suone says the entire family is happy that the chains have been removed, *"Maxwell now helps us on the farm. At first I could not even go out because I was always thinking of what would happen in my absence. I could not sleep well because he used to shout and disturb. Now, we all sleep well. He is now able to take his own medication. If even I am not there, he is still able to administer it accurately as prescribed."*

Family Support and Care

According to Suone, the family has been very supportive in finding treatment for Maxwell. They have spent so much money trying to access traditional treatment and paying for property Maxwell has damaged in the course of his illness. Putting him in shackles was the only way they knew to avoiding further destruction and the embarrassment of having to bail him out of police cells.



Our visit revealed that a lot more needs to be done to fully integrate Maxwell back into his family. He still sleeps in a small thatched room in which farm produce are kept. The room has no window, only a tiny opening at the top right corner to allow limited ventilation. He does not have the privilege of changing clothes, the only thing he had around his waist was a dirty old wretched pair of shorts made out of jeans or twilled-cotton cloth. The room he used to sleep in is now occupied by his younger

brother, Domonwor. The shackles around his feet have cut deep into his skin and left a permanent scar. He looked like he had not bathed for a long time. It is indeed a pitiful situation for Maxwell.

Reflections

Maxwell has suffered a serious setback in his life due to mental illness and this hurts him a lot. His anger and aggression towards people stem from this setback in life. His plea to have his shackles removed is because he feels well enough and wants to go back to his studies. This is ample demonstration for his yearning to catch up with life and the years that he has lost to the illness. It is clear that ignorance, stigma and poverty have contributed to the worsening of Maxwell's condition. The family's fear of gods and curses contributed to Maxwell's woes. The family was reluctant to make a commitment whether to remove the metal shackles or not, because, the traditional healer had said it was part of the treatment which cannot be removed until some sacrifice was made to the gods.

Psychosis

An acute or brief psychosis is a more severe form of mental illness, it usually starts suddenly and is brief in duration. Thus, most sufferers recover completely within a month and do not need long-term treatment. Brief psychosis is typically caused by a sudden severe stressful event such as the death of a loved person.

The typical symptoms of acute or brief psychosis are

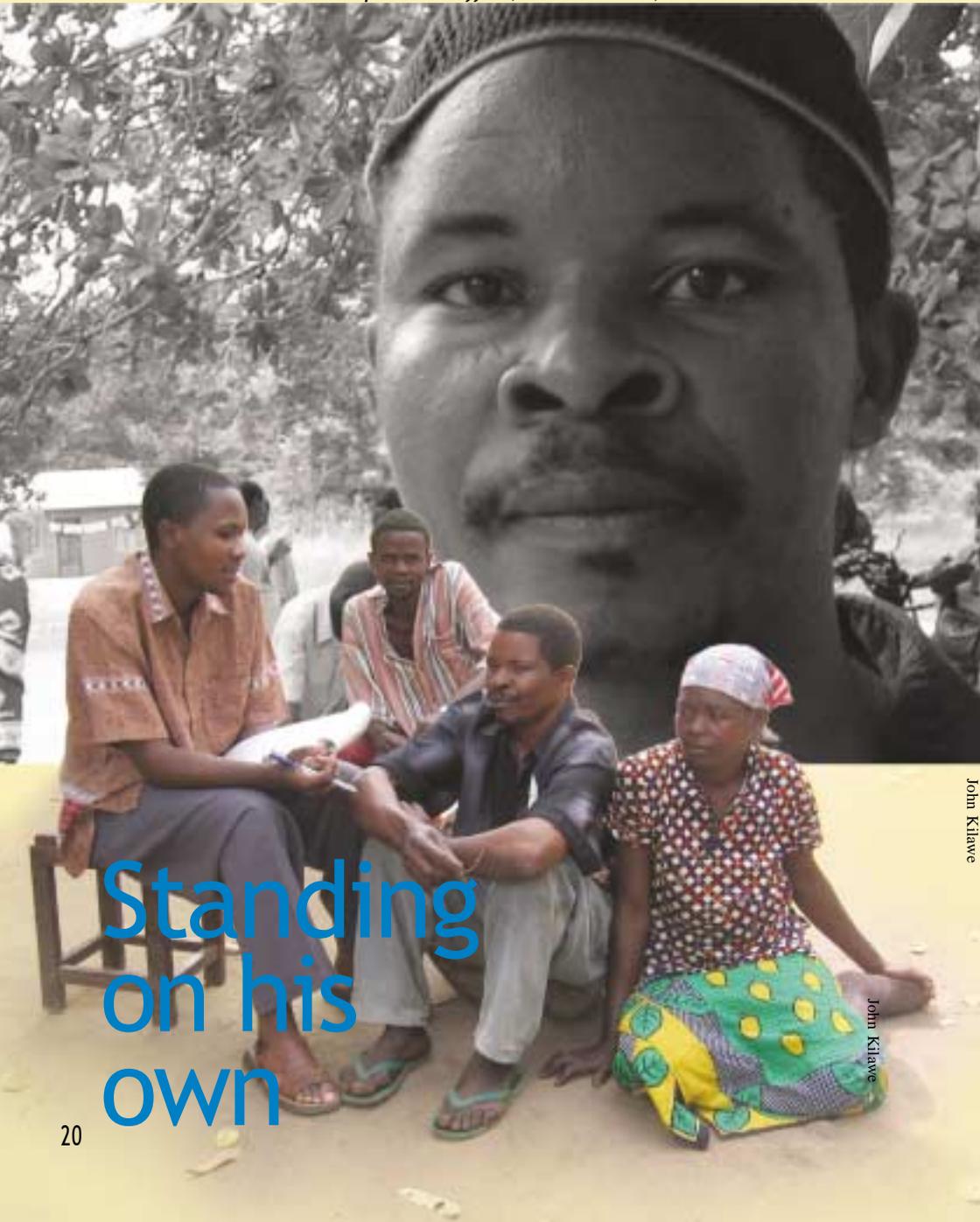
- Severe behavioural disturbance such as restlessness and aggression
- Hearing voices or seeing things others cannot
- Bizarre beliefs
- Talking nonsense, confusion, indecent exposure in public
- Fearful emotional state or rapidly changing emotions, from tears to laughter.

Sometimes, a severe medical illness in the brain can cause the acute psychosis. This condition is also called delirium. Delirium often needs urgent medical treatment.

Source: Foundation and Techniques in Psychiatric Rehabilitation - NIMHANS, Bangalore, India

THE STORY OF DANKAN RAJABU

*Written by: African Mlay, Research and Policy Officer, BasicNeeds Tanzania,
From 1st October 2003 to 31st December 2005
Now moved to Canadian Cooperation Office, Dar Es Salaam, as Governance Advisor.*



Standing
on his
own

John Kijawe

John Kijawe

Introduction

In the small village of Temeke in Masasi District¹⁰, there lives a man called Dankan Rajabu. Dankan has been suffering from mental illness since 1997. He has improved dramatically ever since he started accessing treatment at a near-by health centre at a monthly outreach clinic facilitated by BasicNeeds just a few kilometres from his village. The health centre is called Mkomaindo Hospital. It is about ten kilometres from Temeke where Dankan lives. He can also access his medication through another outreach clinic organized by BasicNeeds and the district hospital in a near-by village called Nangose. Nangose is about five kilometres from the village of Temeke.

Life's Downturn

Dankan was a soldier in the Tanzanian People's Defence Forces (TPDF). When his illness started, at that time he was stationed in the semi-autonomous, Tanzanian island of Zanzibar. According to him, his illness started with headaches, sleepless nights, loneliness and a fear of people - even those he knew, including his

friends. He was admitted to a psychiatric hospital in Zanzibar where he was diagnosed with schizophrenia. He was put on drugs but was later laid off his job in the army and sent back to his village. In his village Dankan could no longer access the medicines he was given while in the army. This caused him to have a serious relapse.

Dankan did not avail for treatment in his village, except from traditional healers. Dankan says, "Traditional healers were good, but expensive."

A Sketch Background of Dankan

Dankan is an orphan, is married and has two children, Rehema and Lailati. When we arrived at his house, Dankan was in his cashew farm doing some weeding.

It was getting to harvesting time and with the season approaching Dankan was expecting very low yields from his farm because he had not sprayed sulphur, a pesticide, on his cashew crop.

“Alternatively I have cultivated maize and cassava,” he says.

“I Can’t Forget That Day in My Life”

Dankan Narrates his story “It all started suddenly in 1997, when I was serving in the Tanzanian army in the semi-autonomous island of Zanzibar. I was taken to a psychiatric unit in Zanzibar where I was diagnosed and given medication. I recovered slightly and returned to my job. Later I relapsed and it was decided that I give up my job. I was sent back to my village where I have been staying till now.”

Dankan was taken to several traditional healers. He says the medicine he got from traditional healers was helpful but expensive. “One traditional healer demanded 20,000 tsh (about GBP £8.92) from me as an initial fee,” Dankan says. “Some of the traditional healers used to admit me in their clinics for medication.”

“I remember one night I escaped from a traditional healer. It was midnight and I was roaming in the farms. Some of the villagers, who

mistook me for a thief, arrested me and beat me severely until my whole body was covered with blood. They later took me to a police station, only to discover that I was mentally ill. The police took me to hospital where my wounds were treated. I can’t forget that day in my life.”

“How did you feel when you were mentally ill?”

“I had sleepless nights, I heard voices, I saw unknown people coming to me, and I feared even the people I know. I felt like walking out at midnight.” Dankan replies

“Are you on medication? Is it helpful to you?”

“I am generally doing well with the medicines I am taking. I normally take my drugs every evening. In case I forget, my wife is always there to remind me.”

“The medicine makes me hungry and very tired. I just want to rest when I take the medicine.”

Dankan’s wife says, “Before he started the medicine his situation was very bad. Dankan used to walk

out at midnight and this compelled us to tie him up with ropes to prevent him from getting out. Now that he is on medication, he no longer feels shy. He does not wander around or hear voices any more.”

“What is it like living with mental illness in your community?”

Dankan laments “Living with mental illness in this community is about isolation, rejection and loneliness. The community perceives mentally ill people as useless. Being mentally ill in this community means you are less respected. Nobody bothers to listen to a mentally ill person.”

BasicNeeds Brings Stability

Dankan has been a part of BasicNeeds’ initiative of Mental Health and Development ever since it started its implementation in the Mtwara Region. As a result of his faithful attendance, he has achieved stability. The first contact between BasicNeeds and mentally ill people and their families was through a series of field consultations in early April, 2004. Before that, BasicNeeds had

met with Ward and Village leaders for awareness creation on mental health issues, followed by the training of health staff to enhance access to treatment.

Dankan’s Aspirations

Dankan has started building his own house. He took us to see his house. It is a very small, beautiful house. “This is the work of my hand,” Dankan says. “My younger brother has also assisted me in making the bricks. Hopefully we shall make it.”

Dankan is also looking forward to doing some petty business. He is now working hard, to persuade other mentally ill people to go to hospital for diagnosis and medication.

Reflections

A mentally ill person in a rural set-up faces a number of problems, ranging from hunger and stigma due to lack of treatment. Dankan says his medicines make him feel hungry. This is because some medicines side effect is an increased appetite. In a setting with serious food shortage, patients usually withdraw from

their medication, because it is hard to take these medicines on an empty stomach. This highlights the importance of access to income to meet basic needs such as food. Dankan has been assessed by our partner in Masasi District and he will be assisted with a small grant through BasicNeeds' Sustainable Livelihoods programme.

The practical support that Dankan's wife provides emphasizes the need for family support in assisting the patient in taking medication. Family support is quite fundamental in the recovery of the patient.

Mentally ill people do have aspirations. Such aspirations include the desire for self-sufficiency and respect. It is important that along with medication they are supported to realise their aspirations. One of the benefits of BasicNeeds' intervention is that Dankan has stabilised after accessing treatment. He is now working as a result of his controlled condition.

Earning an income is a practical way of overcoming the stigma against mentally ill people. Dankan has started doing some productive work. He sometimes works as a casual labourer earning about 500 to 1000 tsh (about GBP £0.44) a day.

Dankan was beaten when the villagers mistook him for a thief at midnight. This highlights the plight of mentally ill people in the community, the miseries they experience, and the need to address them.

Now Dankan has almost assumed the role of counsellor to other mentally ill people in his village. He has been persuading his friend, John, who is also mentally ill to attend the health centre for diagnosis and medication.

Sustainable Livelihoods

BasicNeeds' income generation programme is a strategy for self-reliance wherein a mentally ill person can make a renewed contribution to the family and the community and earn for themselves a sense of self-worth. The programme is designed to support economic regeneration by enabling mentally ill people and their families to return to work or supporting them in income generation activity. This is normally done in partnership with other development organisations. The development organizations offer assistance through loans and through linkages with available government micro-credit schemes and other development projects. Training is imparted, helping them to use the employment opportunities available to them. They are supported to function effectively and consistently in their activity or trade. BasicNeeds also assists partner organisations in establishing contact and gathering information regarding existing local market conditions and the possibilities they hold for mentally ill people.

Thus a virtuous circle is created, bringing people back into work as they recover and assisting recovery through going back to work and earning. Meaningful work that makes a visible contribution to a person and the family's wellbeing, reduces the impact of poverty, promotes stabilisation and recovery, transforms the way a mentally ill person is seen both within and outside the family, reducing prejudice and isolation.

Source: Sustainable Livelihoods Paper by Anil K. Patil and Nicholas Colloff

THE STORY OF SOMOE HUSSEIN

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“My Father
Is
My Anchor”

Evening in Lubangala

Somoe Hussein lives in the village of Lubangala in a small cluster called Kilindu in Tandahimba district.¹¹ Somoe has been mentally ill since 1997. She is a widow and a mother of three children. The area where she lives is congested with mud houses roofed with thatched grasses. A few metres away from the houses, you can see cashew nut trees with flowers, a sign that the harvesting season is approaching. It is also the dry season in this small village during which there is shortage of water supply in the area. So you can see a lot of women carrying buckets of water on their heads. The water is fetched almost five kilometres from their houses. It was already evening when we arrive and some people were coming back from their farms which are located several kilometres from their houses.

Sustaining Life

As we arrive at her home, Somoe was carrying her one-year-old son in her arms. It was not difficult for Somoe to recognise us. It echoed in her voice as she said, *“Oh! It is you people from BasicNeeds. A*

very warm welcome.” This is because Somoe had previously met some of the BasicNeeds’ staff at the patients’ review for our Sustainable Livelihoods Programme. BasicNeeds has a comprehensive Mental Health and Development Programme in the area. Somoe was assessed for stability, the success of her treatment and the activities she could undertake to sustain her life. Somoe loves farming but she does not have the basic tools like a hoe or other farm inputs. So BasicNeeds, through its partner organisation, the Tandahimba Farmers’ Association, will give Somoe things like a hoe and some farm inputs. The partner will also offer her on-the-job training in the farm on how to tend her crops in August.

Somoe goes inside to bring us chairs and after that we start our conversation. Normally before undertaking such an activity we will have fixed an appointment with the person whose life story we are writing. Before starting the process we normally seek the patient and the

family's permission. In this case Somoe and her family agreed.

Illness Overcame Her

Somoe looks very calm with a very bright smile. She is thirty six (36) years old. Her illness started way back in 1997 when her husband died. Her husband left her with a daughter and a son. The daughter is Rehema and the son is Mustapha. Her youngest son is not her late husband's son. Neither Somoe nor her brothers are certain about the identity of father of her youngest child.

As the illness overcame her, a good friend took Somoe to the Ligula Regional Hospital, and after a long stay in the general wards she was finally referred to the psychiatric unit where she was diagnosed with Bipolar Affective Disorder. Ligula is the regional hospital for the Mtwara Region. The psychiatry unit where Somoe was referred to has three staff members. She was admitted to one of the ten beds in the ward. The hospital offers no food, so when a patient is admitted there relatives are supposed to bring food.

Medication was prescribed for her and she was sent back to her village which is located about eighty kilometres from the Ligula Regional Hospital. She finished her first dose of medication, but she could not go to the hospital to collect her second dose because of the distance and irregular transport between her village and the Regional Hospital. Consequently she was forced to withdraw from the medication, a situation which worsened her illness.

Somoe's Anchor

Due to frequent relapses her father decided to ride his bicycle to the Regional Hospital to collect medication for his daughter. Somoe loves her father very much. As she put it during our conversation, *“My father is the anchor of my life. At his age he tirelessly goes for my medication.”*

Insights into Illness

“My illness started with headache and chest pains. I used to move out of the house in the middle of the night and shout a lot of words and hear controversial voices. Now

that I am on medication my health is all right. I don't hear voices any more," says Somoe

"In most cases Somoe's relapses have occurred in the months of July and August. During this time we used to be very careful with her. One good thing about her is she doesn't harm her young child," says Hussein Khamis, Somoe's father.

"Somoe was a good lady. The illness caused a sudden change in her. She started collecting rubbish and insulting almost everyone she came across," says Juma Khamis, her stepfather.

"We really don't know the cause of her illness. We just think it is a disease from God. Due to frequent relapses we tried several traditional healers but there was no remarkable improvement," says Asha Mfaume, her mother.

"I visited four traditional healers, all of them said it is a disease caused by evil spirits. They gave me some herbs to chew. They said the herbs would chase the evil spirit away. They told me to pay

them in kind - a basket of rice and one white dove. Another healer played a drum, then slaughtered a goat and gave me the blood to drink," says Somoe.

"Traditional healers' medicines have not considerably improved my daughter's condition. I am happy that BasicNeeds has made it possible for us to collect her medicines from the near-by Mahuta health centre. It is difficult to travel such a long distance to the Regional Hospital to collect my daughter's medication. I used to pay 8,792 tzs (about GBP £3.92) for it. Now I am told I don't have to pay anything for the medication," says Hussein Khamis.

A Good Future

Somoe aspires to be a good farmer. She is on the list of potential beneficiaries of BasicNeeds' Sustainable Livelihoods Programme. She keeps three chicken. She would like to see them increased to six. She says, *"Look here, my brother, when you are born a woman in this community there is nothing you can become other than a farmer.*

I don't have a farm but I will ask one of my fathers. I will farm maize and cassava. My main problem is that I don't have a hoe and other farm inputs."

She also aspires for a good future for her children. She does not remember the father of her youngest child. Her other two children are staying with their aunt, Habiba Khamis, in the town of Mtwara. Rehema is in the sixth standard and Mustapha is in the fourth. Somoe says,

"My son, Mustapha, is very intelligent. I am sure he will make it to secondary school. I think the government will employ him as a teacher or something. As for Rehema, she is not quite as intelligent as her brother, but I hope both of them will make a better life. I don't know exactly what will happen to them but I am praying hard for a good future for my children."

Reflections

Somoe's life story brings out new knowledge about the experiences and aspirations of mentally ill people.

Carers are desperate for treatment - Somoe's father used to travel 160 kilometres to and from the Ligula Regional Hospital on a bicycle to collect medicine for his daughter. This kind of care builds hope in his daughter. He is her life's anchor, she says.

Mentally ill people have aspirations - Recognition of the aspirations of mentally ill people assists the process of their recovery. Somoe would like to do farming and build a future for her children.

Gender - Being a woman is a factor in the determination of a person's status in the community and finally, her mental health status.

Mental health services - Somoe's father travels 160 kilometres to and from the hospital, point out the chronic shortage of mental health services in the district. Now that Somoe's father can collect drugs at the near-by health centre four kilometres away, it is a big relief for him and the community.

Bipolar Affective Disorder

Bipolar disorder is one of the affective disorders, or disorders of mood, a type of mental illness. The affective disorders include a wide range of abnormalities, from mild states to severe and even life-threatening conditions. Mild forms are relatively common and usually self-limiting, but the more severe forms, while less common, are very important to note, first, because of the associated risks like suicide, and second, because of the existence of very effective treatments.

Bipolar disorder affects two people in every hundred. Men and women have an equal chance of developing it. It is most common in people in their twenties and it is believed to be caused by a combination of factors including genetics, biochemistry and stress.

Characterised by episodes of extreme mood swings, from depression and sadness to elation and excitement, bipolar affective disorder and other affective disorders place an enormous burden on society and are ranked as the fourth leading cause of burden among all diseases, accounting for 4.4% of the total Disability Adjusted Life Years (DALYs) and 11.9% of total Years Living with Disability (YLDs.) One of the particularly tragic outcomes of these disorders is suicide, one of the common and avoidable outcomes, around 15-20% of depressive patients ending their lives.

Source: Foundation and Techniques in Psychiatric Rehabilitation - NIMHANS, Bangalore, India

Notes

1. Participatory data analysis is a session facilitated by BasicNeeds in which mentally ill people, their caregivers and community health volunteers meet to analyse information emerging from programme implementation, life stories and individual files of mentally ill persons. This process yields new insights into the programme from the point of view of community level stakeholders. A typical session has about thirty to fifty people in attendance.

2. BasicNeeds is an international non-governmental organisation promoting the place of mentally ill people in development with both practical programmes and advocacy strategies. Its vision is that the basic needs of mentally ill people throughout the world are satisfied and their basic rights are respected. At the heart of the work of BasicNeeds is a way of working, a model uniquely designed and developed, a new initiative in mental health and development. The key feature of its programme of **Mental Health and Development** is that the voices and opinions of

mentally ill people and all stakeholders form the core of its planning and development. BasicNeeds has developed a series of modules to tackle the most important challenges and barriers as perceived by mentally ill people. **Community Mental Health:** to provide appropriate mental health care and treatment to mentally ill people living in the community.

Capacity Building: to build the capacity of mentally ill people, their families and partner organisations in order to involve them in the development process. The programmes have already demonstrated a capacity for economic regeneration. Thus a virtuous cycle is created, bringing people back into work as they recover and assisting recovery through going to work and earning.

Sustainable Livelihoods leading to self-reliance and social integration: to support mentally ill people and their families to earn an income either through returning to work or by involvement in income generation activities. **Research:** to research the situation of mentally ill people in the

community, to begin to tackle the lack of awareness of mental health issues within the wider community and institutions including the government. Underlying all work in this area so far has been the careful collection of life stories and ensuring that mentally ill people and their experiences are central in the research process.

Administration: to provide an efficient administrative service in support of BasicNeeds and its supporting partners, including financial and evaluation services, taking our resources as close to the field as possible

3. **A parish** a parish in Uganda is a collection of villages.
4. **The kanga/lesu** is a traditional piece of cloth commonly used by women in East Africa
5. **The LRA** is a rebel group based in Northern Uganda. The agenda of this rebel group is “ethnic cleansing.” They claim that the Acholi race has been infiltrated by traitors and they need to cleanse it. They also claim to oppose government dictatorship; but it is not known whether they intend to capture power. The insecurity the LRA has caused is however

not only confined to the districts occupied by the Acholi, but has also spread to neighbouring districts, including Nebbi.

6. **Cassava** is a tropical root tuber requiring about eight months to mature. Cassava is very significant in Africa because of its numerous uses. It is a staple food and the roots are prepared very much like the potato. It can be peeled and boiled. This can be pounded or dried, pounded and ground into flour. It can also be used to prepare local foods for the people in different regions of Africa. Starch is made from it for domestic and industrial use..

7. **The Sustainable Livelihoods** module in BasicNeeds’ Mental Health and Development programme, developed out of partnership, working directly with mentally ill people, their carers and community-based development organisations. “One of the main reasons that people find it hard to accept mentally ill people as equal members of their communities is that they do not see them as capable of contributing to the household or the community. In

poor rural communities the ‘value’ attached to an ability to earn income is great and often is the defining factor for a person’s standing within the family.” (Sustainable Livelihoods Paper by Anil K. Patil and Nicholas Colloff).

8. Outreach clinics are the same as health outreach camps as they seem to be referred to in other countries where BasicNeeds works, for instance, in India. BasicNeeds supports the camp financially by paying for the cost of transport and fuel, the day’s main meal and the allowances for the psychiatrist, other health workers and volunteers. The Community Mental Health Unit, under BasicNeeds’ Mental Health and Development Programme, organises outreach clinics every quarter, in March, June, September and December. Outreach clinics are organised in hospitals and health centres and at other more central locations where psychiatric diagnosis, treatment and counselling are provided to poor mentally ill people, especially those living in remote rural communities

without access to psychiatric facilities.

9. A field consultation is the starting point of BasicNeeds’ Mental Health and Development Programme. The first step towards composite health and development. Mentally ill people, their carers and other stakeholders like medical staff and BasicNeeds’ partner organizations participate in this initial exercise in a new area. Usually the facilitator leads the group towards an open and candid discussion of issues that impinge on their lives. They are encouraged to sketch their world, spell out their needs and mark a way forward.

10. Masasi district is one of the districts composing the Mtwara Region of Tanzania. It is one of the districts in which BasicNeeds work in Tanzania.

11. Tandahimba district is one of the districts comprising the Mtwara Region Tanzania. BasicNeeds works in this district.

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