

WE COUNT

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Acknowledgement

The 'Africa Life Story Project' is yet another platform for BasicNeeds to reach and be reached by a cross-section of audiences from Africa and the world as a whole. It seeks to make use of the rich learning we have built through the testimonies of individual mentally ill people (and other stakeholders of our work such as carers, traditional healers, and our partner workers) to share with everyone of you reading this magazine, especially everyone of you that has a responsibility and a duty to give people suffering mental illness and epilepsy and their carers and families a chance to experience a better life devoid of stigma and discrimination. Through this medium, we hope to inform, educate and communicate to you and challenge you to do something today for thousands that are affected by mental illness either as being ill themselves or directly related to the mentally ill.

In this issue, we share here with you a collection of stories of people involved in the Ghana and Tanzania Programmes of BasicNeeds. This has been possible through the collaborative efforts of

Policy Research Project Officers in Africa, from the Accra and Northern Ghana Programmes of Ghana, Tanzania and Uganda. We would like to pay respects to the invaluable support of Shoba Raja, the Director of Policy and Practice, Lakshmi Mohan, Life Story Coordinator, Jane Cox, BasicNeeds Director for Corporate Services, and Dharshana Karunathilake which has been very useful in producing this final piece. We equally acknowledge the ideas and support of the Founder Director to this project.

It has been quite an interesting experience producing this maiden edition and we will appreciate feedback from all readers about how we can improve on the quality of the magazine. These will be featured in the subsequent editions from our readers.

Enjoy reading it.



Peter Yaro
Chair of Panel



Bernard Alando
Coordinator - Africa Life Story Project

Our Vision

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

Our Mission

Our mission, therefore, is to initiate programmes in developing countries, which actively involve mentally ill people and their carers and enable them to realize their basic rights.

Message from Founder Director: Chris Underhill

Each and every one of us has a life story; at times consisting of our greatest moments of happiness and some of our most difficult moments.

This magazine contains the life stories of four people who have suffered from mental illness or epilepsy. Stories are drawn from our different programmes in Africa. To really understand a life story of a person you must really listen! My young colleagues from Tanzania and Ghana (Northern Ghana and Accra) have done a wonderful job of bringing out the stories of four remarkable people.



As the stories unfold, the individual and their life become clearer to us but also so do the lives of those people in the community who support the people concerned and, indeed, sometimes oppose them. All of life's drama is here: the really difficult moments and some of the happiest.

THE STORY OF FADILA NASHIRU



Alando Bernard

We
Thank
God

Foreword

Fadila Nashiru sits in the arms of her mother behind their house. There is a look of shy seriousness on her face. Her clothes are a little too big for her. Her eyes are large and vulnerable and tight curls of hair cling to her broad forehead. Fadila has just returned to the friendship and the excitement of school through the support of BasicNeeds, having had to discontinue her studies when she was in her nursery class due to epilepsy, which brought hardship to her family. She now feels happy and loved again as her illness is controlled.

Introducing Fadila

Fadila Nashiru is a six year old girl who suffers from epilepsy. She lives with her parents and younger brother, Mudasri, in Sakasaka, one of the poorest communities in Tamale, northern Ghana, in their extended family home. She is a nursery school pupil but had to stop schooling due to frequent attacks of epileptic seizures. Nashiru Mumuni, her father, is a farmer and a shea nuts dealer (the shea tree is an African tree, whose seeds yield shea butter, used as food and in manufacture of soap and body lotions). Amatu Nashiru, her mother, sells bread at the main transport station in Tamale. Nashiru first heard about BasicNeeds at Aboabu market where there was a drama performance by Gub-Katimali drama troupe, one of BasicNeeds' partners.

That First Day

“That day, I was lamenting to a friend in the market that I have exhausted all avenues I thought could treat my daughters sickness, when we heard that some people had gathered near the market site and were discussing mental illness. My friend encouraged me to go and listen; maybe I could learn how to manage my child’s sickness. When I joined the crowd I saw that they were staging a play about a mentally ill person being maltreated by a trader in the market for worrying her, but later when the mentally ill person’s condition improved he came back to the trader, decently dressed, to buy some of her wares and the trader was ashamed. I instantly felt encouraged that my child could also be treated if I took her to the Psychiatric Unit as they recommended at the end. Though they asked the carers of mentally ill people to step forward I didn’t do so because I was concerned about what the larger society would say when they hear that my child is epileptic.

Deep inside me, I had made up my mind to take my child to the Psychiatric Unit.”

Fervent Support

At a consultation much later at Ti Sampaa (the Community Psychiatric Unit) during the participatory evaluation of BasicNeeds’ Northern Ghana programme, Fadila’s father, Nashiru, was one of the candid and communicative carers who spoke about the relief BasicNeeds had brought to his daughter and his entire family. He was so impressed with his daughter’s improved condition that we became interested in hearing more of Fadila’s experience and possibly documenting it as it also drew attention to the impact of BasicNeeds’ work with mentally ill people and their carers under the Mental Health and Development programme. A few weeks later, Nashiru came to the BasicNeeds’ office seeking financial assistance to enable them to send Fadila back to school. BasicNeeds supported him with an amount of 500,000 cedis (about £31) under its Sustainable

Livelihoods programme. Lance, then Programme Manager of the Northern Ghana Programme and now adviser to the programme, asked me to follow up on Fadila and write her story. I sought permission from Nashiru and he agreed that I could document Fadila's story.

How it All Started

Nashiru narrates that, one day, he and his wife went to do farm work at Bugya, a village near Walewale in the West Mamprusi District of the Northern Region of Ghana. Fadila was at home with a babysitter. On their return, the babysitter brought Fadila to them and asked them to have a look at her condition. They saw that Fadila's eyes were wide open and twisted to the left, and her whole body was stiff. Initially, they thought it was convulsions and started giving her the mixture of herbs neighbours provided to revive Fadila. She was unconscious for about eight hours after which she regained consciousness. After that incident, she experienced occasional dizziness, which

sometimes made her fall to the ground. This has affected her left arm and her right leg. Nashiru and his wife returned to Tamale as Fadila's condition did not improve and she was admitted to a major hospital in Tamale for two months during which her condition improved. When Fadila was discharged, Nashiru and his family returned to their farm at Bugya near Walewale since it was still the farming season. But two months after their return, Fadila's condition became worse and she collapsed. She was taken to the medical centre at Nalerigu in the East Mamprusi District of the Northern Region of Ghana where she was hospitalised for four days. Since then Fadila has suffered relapses from time to time. They then resorted to traditional healing as treatment at the hospital was yielding no positive results.

The Search for Treatment

Nashiru Mumuni admits that he has spent a lot of money in his desperate search for treatment for Fadila's illness. He said that at the Tamale Teaching Hospital, for instance, he paid 150,000 cedis to settle hospital bills (about £10 - a lot of money for a man like Nashiru especially in the farming season). At a traditional healer in Diare, a village in the Northern Region, he offered three fowls and 100,000 in cash totalling about 150,000 Cedis (£10), but while they were still at the traditional healers home, Fadila relapsed and they had to return home. They were also told of another traditional healer at Kperiga, a village near Walewale in the Northern Region. There again they were asked to bring four goats, four fowls and 150,000 in cash, totalling about 600,000 Cedis (about £36), but that also did not yield any results. At yet another traditional healer in Sinsina, a village near Daboya, the healer requested a white ewe, half a piece of cloth and some cash, but Fadila's condition did not get better.

Nashiru lamented that: "I have spent so much money getting locally available treatment. This has worsened my economic situation but I never gave up."

Tears and Loneliness

During this period, Nashiru's neighbours showed no concern about his child's sickness. They prevented their children from eating and playing with Fadila because they thought that the disease was contagious and could infect their children. This left Fadila lonely and crying..

"Some family members even advised me to divorce my wife because the disease could be a curse in her family, they said, but I did not heed this advice because I believe in God and I know God makes things happen in ways we find difficult to understand. Even though I almost got convinced at a certain point, I just stayed calm and always prayed to God to guide me and protect my family."

Fadila's mother, Amatu, feels Fadila is worth more than

anything they have been able to acquire in life. She says while they were at the hospital in Tamale, she would cry the whole day and remain without food because other children were dying, and she was afraid that Fadila might also die. She does not regret that they have spent so much money and time on her. She is very grateful for Fadila's life and her improved condition now. Recounting some of Fadila's experiences, Amatu said it took Fadila a long time to start walking and just when she had begun to take a few steps, she fell sick and sat back on the ground. And it was a long time before she could walk again.

BasicNeeds' Intervention

Fadila was first seen by Dr. Asare, a psychiatrist, at the Tamale Psychiatric Unit on the 29th September 2003. She was diagnosed with Grand Mal Epilepsy (GME) and was given treatment. Her condition has since improved drastically. Amatu said that when she saw other children going to school, she felt disheartened that Fadila was at home, hence, their appeal to BasicNeeds to support Fadila's education. Fadila returned to school, to Future Leaders, an early Childhood Development Centre, on the 23rd February 2004 and now looks neat and more cheerful than before.

When asked how he feels about BasicNeeds' intervention, Nashiru expresses his feelings in these proverbial words: "When someone clothes you, he covers your nakedness," meaning BasicNeeds has saved his family from shame. He adds, "In all these years of my life, I have never seen an organisation so helpful to the downtrodden and so caring towards them. I pray that God will help you to help us."

Reflections and Comments

Nashiru's family has suffered so much humiliation as a result of Fadila's illness. It was thought that Fadila's illness was contagious, so parents warned their children not to go near Fadila or eat anything from her house. In Ghana it is common for children to stay together, play together and eat at each other's homes. It is therefore humiliating for a parent and a child when children avoid their company and refuse to eat their food. From his own narration it can be deduced that now that Fadila's condition has improved, and she has been supported to go back to school, I can see hope transplanted in Nashiru's family. In terms of treatment, the impact has already started showing on Fadila's physical and mental health. The extended family, and the community as a whole, have now started relating better with them.

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

Community Volunteers

Volunteers are people who are well known in their communities. Many of them are members of the Community Based Disease Surveillance volunteers' groups who have an appreciable knowledge of community health issues. Interested in the eradication of disease in their communities and in community development, they are more than willing to work with people with mental illness. They are recruited based on their level of commitment and dedication and they work closely with the Ghana Health Service and BasicNeeds' other development partners, Amasachina Self-help Association and Gub-Katimali Society. They undertake home visits to monitor the progress of treatment of mentally ill people and the livelihoods activities they engage in.

Epilepsy

Epilepsy is the most common brain disorder in the general population. It is characterised by recurrence of seizures, caused by outbursts of excessive electrical activity in a part or the whole of the brain. The majority of individuals with epilepsy do not have any obvious or demonstrable abnormality in the brain, besides the electrical changes. However, a proportion of individuals with this disorder may have accompanying brain damage, which may cause other physical dysfunctions such as spasticity or mental retardation.

(Sources: Foundation and Techniques in Psychiatric Rehabilitation NIMHANS Essential Psychiatry Edited by Nicholas D.B. Rose, The World Health Report 2001).



What a Miracle

Dokuruğu Adamı Yahya

Foreword

Awolu Ziblim made his living operating his uncle's tractor, ploughing village fields and transporting crops and goods. At the end of one work-crowded day, he was resting, out in the open, when in his dream he felt someone forcibly holding him down. He resisted, struggling to be free, and finally, woke up, disoriented. This incident took place six years ago and ever since, he has been suffering fits.

It was the onset of epilepsy. In articulate words, Awolu captures his situation, his illness, and says how epilepsy is not a sickness for weak-willed people. He had to give up work and seek treatment. His family was deprived of an income. His customers were put to hardship sourcing other tractor operators. Then he describes the nature of the illness itself. How it comes on with no prior symptom, no forewarning. The shame of it.

BasicNeeds had arranged treatment for mentally ill people at the Gushiegu Hospital, northern Ghana. Awolu received

free treatment and drugs. Today, Awolu is not only well, but also back at work, enjoying the effort and energy he devotes to it.

This is Awolu's Family

Awolu comes from Danso-Wulanyili in Zei, a village nine kilometers from Gushiegu. He has four siblings. Alhassan and Bugli are his brothers. Sugri and Ayisha are his sisters. Awolu is married to Ashetu and they have three daughters; Zahara, Lamnatu and Amina. Awolu belongs to the Dagomba tribe, from the warrior clan. However, today, Awolu is a tractor operator while Ashetu is a housewife. The other members of his family are farmers.

A Popular Person

“Before my illness I was a tractor operator”, said Awolu, talking of life before epilepsy. “I operated the tractor for my father’s brother, Braimah. I used the tractor to plough farmers’ fields in our village and in surrounding villages during the rainy season. I also used to transport farm produce and other goods to the villages in the dry season. This made me a very busy and popular person in the community.”

The Day it Started

Giving an account of how his illness started, Awolu said, “One day we returned from the farm after a busy time, and after supper decided to rest in the compound because it was airier there than in the room. I was dreaming and it occurred to me as if I was experiencing the presence of a person I could not identify. This ‘person’ came and held me firmly down. My colleagues managed to run but I could not. I was helpless and lay there kicking and struggling for help until I finally managed to wake up. Since that incident, I have

been falling, for the past six years now.”

Contact with BasicNeeds

Awolu reveals that Tamimu (staff member of Ghana Health Service and community volunteer of BasicNeeds) introduced him to BasicNeeds. His brother, Alhassan, agreeing with Awolu, said that an announcement had been made inviting anyone with any sort of mental illness to come to the hospital on a specific date to see a specialist. Alhassan talked to Tamimu about Awolu and he encouraged him to bring Awolu to see the specialist. “We went to the hospital on the stated date and, true to the announcement, the specialist examined Awolu and gave him medication free of charge,” said Alhassan. Awolu thinks he is suffering from epilepsy because he has fallen on a number of occasions. The psychiatrist’s report also revealed that he is suffering from Noctus Parvus, a kind of epilepsy in which the seizures occur only at night. He was given Tegretol, 200mg.

Articulate Reflections

“My sickness affected many people. In the first place, I was out of work because I thought it wise to get treatment before going back to work. This seriously affected our family’s income since it has not been easy to get an honest person to operate the tractor while I sought treatment. Farmers and traders who depended on my services had to turn to other sources amidst the difficulty of finding reliable tractor services as our tractor was the only one in the village then.

As a matter of fact, it is not good for anyone to suffer from this sickness. No man deserves this. This is because it can occur without prior warning as in my first experience. Supposing you are with friends, as we were, all resting in the compound, and this happens, you wake up stunned and confused. It disgraces and humiliates you. If you don’t have a strong heart you may contemplate harming yourself, for example, attempting suicide.”

Treatment’s Progress

According to Awolu, he realised the tremendous improvement in his condition after he started taking the medication prescribed by the psychiatrist. “I am still on medication and will continue so long as the drug is available,” he vowed. “I was asked by the doctor to take my medication at night. The drugs are good for me.”

Awolu is back operating his uncle’s tractor. “Operating a tractor is what I have learnt to do for a living. I can say I am a professional in that sense. In the dry season when there is less farming activities I go hunting for antelopes, quails and the like. I derive a lot of satisfaction from that. I am also able to exercise myself because I flex my muscles in the process of hunting.”

A Supportive Community

Awolu's illness had been a matter of concern to the family and the entire neighbourhood. According to Braimah, they have had no problems whatsoever with their neighbours. He said, "In fact, this was a problem for the whole family and the community. Our neighbours were concerned about his condition and recommended many traditional healers we could consult for treatment. The consultation fees of some of the traditional healers we visited ranged from 10,000 cedis (about £0.6) to 20,000 cedis (about £1.20). The fee you pay at the end of your treatment depends on whether you recover or not. We consulted about ten traditional healers in total. Some of them took two fowls while others took fowls along with goats and sheep, or cash. The search for a cure ended when, through the work of BasicNeeds, we were able to see a specialist at the Gushiegu Hospital."

Tamimu explained that most families with relatives suffering from mental illness, end up in

poverty because they spend all their resources seeking a cure for the person who is unwell.

It Tells me You Care...

"But for your intervention," Awolu said of BasicNeeds' support, "things would have been different. It was timely. Your work with me did not end with the doctor you brought. Tamimu constantly visits me and that is even more encouraging. This motivates me to fight the illness and I tell you, I think I am through with it."

"It is heart-warming to have you come all the way from Tamale to listen to me share my experience. This community does not even seem to be part of Ghana. I am honoured. It tells me you and your organisation care, what a miracle!"

Writer's Reflections

Awolu is a cheerful man. He is very interactive and connects so well with his kin and with members of his community. A hard worker, Awolu defied bad weather and went to the field about thirteen kilometres from Zei to work. He was busy ploughing when we arrived at Nabulugu, a small farming community, with just three houses. It was a difficult terrain to travel on. But it was worth travelling all the way to listen to him tell his story in the presence of other family members. At the end of the day, he was happy, felt cared for, felt human and could smile because he had gained hope again.

***Written by: Dokurugu Adam
Yahaya,
Community Mental Health
Officer, BasicNeeds Northern
Ghana.***



I believe
in the
Holy
Quran

John Kilaue

Foreword

Adam Mohamed used to work on his own farm where he cultivated cashew nuts, coconuts and millet. He was a good farmer, a good man, his family says. In those days, many years ago, he took an active interest in politics too. He was a youth leader in Tanzania's ruling political party.

Mental illness started as shyness that overwhelmed him. He preferred isolation and exclusion to the company of people. One day, he left his family and home and retreated to a jungle, five kilometres away from his home where he spent 20 years, occasionally emerging from the underbrush to get himself some food from neighbouring homes.

Treatment and awareness have transformed Adam. Today, fifty-five year old Adam Mohamed is recovering from twenty-four years of schizophrenia. His self-care habits have improved. Aware of the need for continued treatment, he personally visits

the hospital every month for his medicines. The community, reaching out a welcoming hand, invite him to gatherings and traditional dancing.

Life before the illness

Adam was born into a family of nine. Before his illness he was married, but was later abandoned by his family because of his illness. He is a father of seven children, although five of them have passed away. Two daughters are alive. They are Sofina and Shabia.

Sofina and Shabia are married and have children. They live in a nearby village. Sofina has a son and a daughter, Zamda and Yassin. Adam loves his grandchildren very much; they pay their grandfather regular visits now that he has recovered.

Pointing his finger to a small plot located just a few metres from us, Adam says, “That is my plot, I want to build a house there and then get married.”

“Before my illness, I used to do a lot of things. I was the chairperson of the ruling party’s youth wing. I also used to farm cashew nuts, coconuts and millet, but when the illness came I stopped everything.”

His married life had been far from happy. As he says, “I married my first wife. We were blessed with three children. All of them passed away. We divorced and I married my second wife. We were blessed with two children. One of them passed away. We too divorced and later I married my third wife. We were blessed with one daughter but my wife deserted me when the illness started.”

Slowly, in a low-toned voice, Adam says, “I love reading the holy Quran. But if you are lazy about reading the book you forget everything. I used to love politics. My illness has made everything fade away.”

Piecing Together His Life

Adam does not remember what happened to his life. His brother, Ibrahim, says, “Adam used to be a very good man, we used to live together harmoniously, but it all started abruptly. He started feeling shy. He could not face people anymore. He started covering his face and became restless and spoke in a low voice. We took him to several

traditional healers for two years, but nothing happened. After that he deserted his house for the bushes.”

It was a small jungle five kilometres away from his house. Sometimes Adam used to walk out of it to collect food for himself from neighbouring houses and then return to the jungle. Life went on like this for twenty years.

His sister, Amina, says, “Prior to his illness, my brother was a very good man, hardworking, a lovely man. My brother was bewitched by a neighbour who used to have an affair with my brother’s wife.”

His daughter, Sofina, says, “His second wife caused all this. She used to have an affair with another man, a man who later bewitched my father. All the blame should go to his second wife. Without that affair my father wouldn’t have been like this.”

Treatment for the First Time

When BasicNeeds campaigned for mental health awareness in

Mahuta under its programme of Mental Health and Development, Counsellor Namgugu, a well-known local politician with strong convictions and an open mind, became closely involved. He prevailed upon the reclusive Adam to join in the field consultation BasicNeeds organised for mentally ill people, carers and community members.

Counsellor Namgugu then moved Adam to his own house where he lives as a part of the Counsellor’s family. The dearth of mental health services in Tandahimba District urged him to look elsewhere for treatment. He took Adam to the Newala District Hospital, fifty-seven kilometres away, where, for the first time, he was diagnosed and treated. Adam was diagnosed with chronic schizophrenia and he was prescribed an injection of Fluphenazine Decanoate which needs to be taken once every month. Namgugu says, “It is after two weeks that Adam started showing signs of improvement. Namgugu tells us, The medicine is very powerful, you need to eat enough food.”

Namgugu provides Adam with enough food so that the medicine does not overcome him. Namgugu says, “This is the farming season, so sometimes we come back very late from the farm. I have paid some money to a local hotel so that Adam can get his food there when we are absent from the house.”

Namgugu says, “Adam’s situation is improving. He can take a shower, wash his clothes, visit friends and ride his bicycle. After the second injection probably things will be even better.”

From Isolation to Integration

When we arrive at Namgugu’s house, Adam is not there. He is in a nearby village attending his friend’s funeral. After almost half an hour, Adam returns on his bicycle. He smiles and greets us.

Namgugu and Adam enter our car to visit his family. We get there in fifteen minutes. Adam enters his mother’s house to bring us chairs. He says, “You are our guests. According to our culture I have to make sure that you are comfortably seated.” All the

people there laugh a little and the conversation goes on.

People have come from far-away villages to witness Adam’s miraculous healing, but Namgugu says, “There is nothing like a miracle here. It is all about care, access to treatment and re-integration. Now Adam is invited to attend a funeral, he is asked to join in traditional dancing. Until I see Adam independent, I won’t rest. He has stayed in the bushes for twenty years. Why shouldn’t I accommodate him for a year or more?”

Writer’s Reflections

Twenty-four years of severe mental illness and twenty years of isolation mark Adam’s life. Access to treatment has brought dramatic change to Adam’s life. His life story is just a revelation of how fundamental the right to treatment and support is to the recovery of mentally ill people - just like other patients.

Written by: African Mlay
*Research Policy & Advocacy,
Officer, BasicNeeds Tanzania.*

Schizophrenia

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. Schizophrenia's cause is not known, but it may be related to a hereditary disorder in metabolism. 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.

Schizophrenia is found approximately equally in men and women, though the onset tends to be later in women, who also tend to have a better course and outcome of this disorder. Schizophrenia causes a high degree of disability. In a recent 14-country study on disability associated with physical and mental conditions, active psychosis was ranked the third most disabling condition by the general population, higher than paraplegia and blindness. A recent study showed that 30% of patients diagnosed with schizophrenia had attempted suicide at least once during their lifetime. About 10% of persons with schizophrenia die by suicide. Globally, schizophrenic illness reduces an affected individual's lifespan by an average of 10 years.

sources: Foundation and Techniques in Psychiatric Rehabilitation NIMHANS Essential Psychiatry Edited by Nicholas D.B. Rose The World Health Report - 2001).



John Kihawe

One more chance

Foreword

For four years now, twenty-three year old Pili Akili has had bipolar affective disorder. Her middle-aged mother, Rose Akili, care-worn from the years of caring for Pili Akili, knows practically every traditional healer in her district of Newala (about 100kms from Mtwara, southern Tanzania). She has taken her daughter to some of them, her weary efforts dampened by the cure that proved so elusive. Had she the resources she would perhaps never have given up trying. But with her husband's desertion, the sole responsibility of three growing children and a cashew farm that yields insubstantially, there is never enough time or money to invest. The family's finances are insecure.

Pili used to be in secondary school. Her illness, however, drove academic goals out of reach. Her concentration suffered and achievement became impossible. She talks of being reduced by mental illness, with no standing

in her community, her voice not important enough to be heard. What hurts her most is her abandoned education, her poor performance, her failure to achieve. Tears rush down at the memory.

Defeated by Illness

Pili is a twenty-three year old young woman who lives in the village of Nangwala in Newala district. She is frequently disturbed by mental illness. Pili has been diagnosed with bipolar affective disorder and prescribed Fluphenazine Decanoate injections. She is frequently in the manic state accompanied by restlessness and moments of sadness and extreme happiness.

Pili's illness has made it difficult for her to achieve her expectations in secondary school. Because of it, she could neither follow her teachers properly nor attend classes regularly. As a result she was not able to obtain good grades, which would have enabled her to proceed with further studies.

We fixed up the appointment with her family through SHIKUM, our partner organisation. As we arrived there, we sought Pili's permission to document her story and take her photographs. She granted us permission.

While narrating to us her academic aspirations, she suddenly burst into tears saying, "I feel so bad that I didn't achieve what I have always wanted. This is because every time examinations approached the illness would not stop disturbing me. This made it difficult for me to achieve my expectations. I am determined to pursue my studies if I am given one more chance."

Overwhelmed by Care

Pili's mother is Rose Akili. Her husband abandoned her nearly six years ago. She is the mother of three children, Pili, Farida and Hamza. She is a woman in her mid forties. She looks so exhausted and overwhelmed by her job of care giving. She knows almost every traditional healer in the district. She says, "As carers, we don't have a choice. We do try any alternative remedies we can find. The problem is money. I have taken Pili to several traditional healers. Her illness still keeps relapsing."

Easy Access to Treatment

One of the components of BasicNeeds' Mental Health and Development Programme is the capacity building of health workers. This is because in this region we have only a handful of trained mental health nurses. To address this gap, BasicNeeds trained general health workers in mental health management, that is, diagnosis, prescription and counselling. So in every dispensary and health centre, you will find at least one trained staff member who can undertake basic diagnosis and prescribe drugs for mentally ill people. The training was very intensive and it was done with the help of a consultant experienced in psychiatry.

For the very first time, mentally ill people can access diagnosis and treatment at a nearby health centre. Pili gets her drugs from the Newala District Hospital, the health centre closest to her home. When we met Pili for the first time about six months ago at a field consultation with

mentally ill people, she was psychotic. But now, six months later, she has recovered slightly and regained enough insight to reflect on her life.

The Place, The People

We arrived at Nangwala in Newala district at around 2 pm. The district is located about one hundred kilometres from the town of Mtwara. It is about the same distance too from BasicNeeds' office in Mtwara. The Makonde people dominate the area. The languages spoken here are Makonde, the vernacular language of the place, and Kiswahili, the national language of Tanzania. Everybody can speak Swahili here.

The area is dry and relatively cold and water shortages are the order of the day. The inhabitants depend on rainwater, which is usually piped from wide, deep round wells normally drilled in front of their houses. These wells have the capacity of storing water for about nine to ten months. The water is for domestic use, including washing and cooking. A family without a

well is considered very poor. The predominant activity is agriculture and the main cash crop is cashew nut.

The houses - most of them - are constructed in the most common and cheapest way. Grasses are commonly used for thatching and the walls are plastered with clay or mud. Houses, usually, contain two bedrooms and one big room in the middle used as a living room. The kitchen and the bathroom are constructed in the backyard. Firewood is used for cooking on a triangular stone cooking stove called 'mafiga'. People's staple food is bread made from maize or cassava flour or a meal made out of it, commonly called 'Ugali', a stiff porridge, eaten with beans and/or green vegetables, mainly amaranth and the leaves of the cassava and pea plants.

Meeting Pili

We arrived at Pili's home at about 2.30 pm. Pili was then resting in her room. Her younger sister walked in to let her know that she had some visitors. She

came out and brought some chairs for us and set them under a big tree, which provided us enough shade from the burning midday sun.

Pili is Recovering

"Ever since I have started taking drugs from the hospital, I am doing well, only that I feel dizzy and tired, especially when I take the drugs. I have stopped taking the medicine for about two weeks now. Look, the drugs are making me very fat. I don't hear voices any more, I do settle in one place instead of walking aimlessly down streets."

What is it Like Being Mentally Ill

"Hearing disturbing voices, just wanting to walk aimlessly, roaming the streets till midnight and making noise everywhere. I felt restless, I couldn't settle in any one place. When I was in this situation, my younger brother, Hamza, would forcefully tie my arms and legs with rope. I struggled very hard to resist them tying me up, and sometimes I tried to tear the ropes away, as a result of which I

got repeated attacks of chest pains. My mama would just stand there watching sadly. Look, the scars left by healed wounds in my arms and legs.”

“I remember one time my mama took me to a traditional healer. The healer wrote an Arabic text on white paper with red ink, then dissolved the paper in a bottle of water and instructed me to drink the solution.”

Living with Illness

“A mentally ill person in this community is almost nothing in front of people. He or she is useless and nobody will dare listen to you when you are mentally ill. As for me, I don’t care about what they say. I do a lot of things on my own. I cook, fetch water from the well, wash my clothes, take a shower and, sometimes, I go to the farm.”

Aspirations

“I would like to go on with my studies or pursue vocational training. People keep telling me that if I go back, my illness will relapse. I wish I could be doing something now, because if I

don’t, my life will be even tougher.”

“I have tried several times to apply for a job with no success. They keep telling me that nobody will accept me with my poor grades. I think I should go in for self-employment like tailoring, or something like that. I think about re-sitting my secondary school examinations, but who will pay my school fees for me? My mama is so overwhelmed by my brother and my sister. My daddy doesn’t seem to care about the family.”

“**W**e have a small cashew farm, but as you can see, this harvesting season we are expecting almost nothing from the farm. My mama had no money to buy sulphur (a pesticide normally sprayed on cashew nuts to prevent pests from destroying them) and she didn’t have enough time to attend to the farm because of my illness.”

“I will continue taking the medicine according to your advice. Please keep visiting us.”

Pili, her mother and her younger sister escorted us to the car.

Reflections

This life story unfolds the treatment mentally ill people receive from close relations. Pili was tied with ropes, her legs and arms tied, causing pain and wounding her body. Such practices contravene human rights and more so, the right to be treated equally. Of equal importance is the knowledge gap in the community about handling aggressive mentally ill people. These are issues which need to be addressed constructively.

Pili's story also informs us about the dynamics of medication to mentally ill people. Pili says the drugs make her feel dizzy and tired. Apparently she has not taken her medicines for about two weeks now. This can lead to relapse. Equally important is the need for the close involvement of a relative or friend in monitoring and ensuring that patients adhere to medication.

The story informs us about poverty and how it may relate to

mental illness. Pili's mother could not attend to her farm effectively last year basically because of time constraints. She had to spend much of her time taking care of her daughter. Above all, she could not afford to purchase vital materials for the farm. This has ultimately led to poor production in her cashew farm. As a result, she cannot pay her daughter's school fees to sit for her examinations.

In this life story we are told about how, Pili accesses treatment for the first time at a nearby health centre, whose staff have been trained by BasicNeeds. This is an evaluation of the BasicNeeds' programme of Mental Health and Development by a beneficiary, a service user. It is about hearing evidence about BasicNeeds' work from mentally ill people themselves, told by them in their own words. This is possible only when they are given a chance to speak up about their thoughts and aspirations.

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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, first, because of the associated risks like suicide, and second, because of the existence of very effective treatments.

(source:

Foundation and Techniques in Psychiatric Rehabilitation NIMHANS Essential Psychiatry Edited by Nicholas D.B. Rose The World Health Report - 2001).

Notes

BasicNeeds' Mental Health and Development Programme

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.

A series of extensive consultations with mentally ill people, their family members, carers and partner organisations led to four main areas of action.

- 1) Empowering mentally ill people and building their capacity to become involved in development activities.
- 2) Improving access to mental health services through community based programmes.
- 3) Enabling the right to work.
- 4) Tackling stigma, discrimination

and exclusion from their communities and from mainstream development.

This led BasicNeeds to develop 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.

Field Consultation

A basic premise for a BasicNeeds' engagement is that it should initiate

the active participation and involvement of people with mental illness and their families in their own development. Each field consultation is coordinated with organisations whose activities are community based (CBOs) with whom BasicNeeds enters into a partnership. Participants are mentally ill people, their families, CBO staff and individuals and groups from the village or community. These consultations are in the nature of programme planning, using a participatory research approach with people with mental illness and their families. BasicNeeds has developed a set of Topic Guides with enough room and flexibility to cover diverse field situations.



Partnership

BasicNeeds enters into partnership with a wide variety of community based organisations (CBOs) to implement its model of Mental Health and Development. It works on the firm belief that mental health is a development issue. Therefore, it takes not just the mentally ill person, but, his or her family, the community, non-governmental organisations and the state into consideration. Vital to any development work. BasicNeeds' partnership of organisations renders services to people with mental illness. BasicNeeds builds its work drawing heavily on the skills of its family of partner organisations. Together, they initiate programmes in developing countries, which actively involve mentally ill people and their carers and enable them to satisfy their basic needs and their basic rights.

Traditional Healers

BasicNeeds works with and through a broad spectrum of stakeholders, and among them are traditional healers. We at

BasicNeeds find ourselves listening, rather than talking, being taught, rather than teaching and drawing lessons from the rich experiences of traditional healers throughout Africa.

Participatory Evaluation

Resource persons from outside the organisation are called in to assess the work of the organisation with set terms of reference. In BasicNeeds, during participatory evaluation, users of its services or beneficiaries are invited along with the staff who carry out the programme. They set the tone for the process, prepare the terms of reference and conduct the evaluation with the help of resource persons who write down the proceedings. They measure their own progress under the organisational umbrella and also assess and acknowledge the role of the organisation in terms of services rendered. Dissent and negative comments are permitted, even encouraged, all of which form part of the learning and growing experience for BasicNeeds.

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