

ZAMBART anti-stigma success stories: testimonies from the community

KITWE ANTI-STIGMA 2009 REAL LIFE SUCCESS STORIES

1. Story of Mrs. Evelyn Musonda (Pseudo-name) - EFFECTS OF REJECTION & ISOLATION

I am a widow with six children. My husband died of TB and Karposis sarcoma. Two years later I was also found with TB and I was being looked after by my relatives who were not so willing to do so for fear of catching TB, my own mother threw me out of her home and asked me to live with my young brother who also was not willing to nurse me for the same fear. I had nowhere to go, but my sister in law offered that I be looked after in the chicken run. I had no choice but to occupy what I was offered. I lived in isolation and fed among the ducks in that place and I continued to take my TB pills. Meanwhile my relatives called me all sorts of names and I lost respect and dignity. Worse still my own mother did not even want to come near me even her visits were rare and conversation with me was from a distance.

During the rain season my "room" (the chicken run) was leaking so much that at one time I was forced to spend three nights outside in the open. This was very depressing for me to the point that I felt like dying than to continue living this way. My brother was angry with me saying that I should get back in the chicken run for fear of people viewing my action as negligence on his part. I asked if I could join them in the house at least to sleep in the kitchen, my brother refused saying that he did not want his family to catch TB.

My friends who visited me felt very sorry for me. They then informed the home caregivers at the local clinic who visited my brother's home to see the living conditions I was subjected to. My brother was very angered and embarrassed by this visit and appealed to my mother to take me with her, but she still refused. I was taken to be nursed by my friend by now I also had herpes zoster. She promised my relatives that she was going to do her best to nurse me back to good health God willing. The home caregivers were also very supportive by giving me food supplements among other help until I felt well again. Eventually, I also took an HIV test which turned out to be positive, I did not despair in spite what I went through. I completed my TB treatment.

As I speak now I am very well and in good health. My appeal to all out there is that; please never stigmatize anyone with TB, it is a curable disease and if nursed and supported TB patients can recover fully and contribute positively to the community.

As a result of my experience I decided to join the local health centre as a volunteer treatment and an adherence supporter so that I can be useful by encouraging and supporting others in a similar situation

as I was and also to teach other community members not to stigmatise those suffering from TB because it is an airborne, preventable and curable disease which can be caught by any one. I therefore urge everyone to be supportive to TB patients in every way possible.

Mrs. Musonda's story is a very touching one. Her experience could be one; many others in our communities are going through. TB though a preventable and curable disease, can impact negatively on the infected person leading to stopping treatment and thoughts of despair if subjected to stigma such as she experienced. TB is curable even in HIV infected people.

Mrs. Musonda is in good health and works as a volunteer treatment and an adherence supporter at Chimwemwe clinic.

2. Story of Mrs. Godfridah Chulu (Pseudo-name) - EFFECTS OF ISOLATION

It was in the year 1997 when I was found with TB and I was put on TB pills. When my relatives learnt about my condition they did not receive the news well. I was given my own room and feeding utensils.

Though I was in my own room, no one bothered to clean it or even to wash my beddings. During meal times my sisters used to send my children to bring the food to me young as they were, because my sisters did not want to have any close contact with me for fear of catching TB and rather thought it was okay for my children to do so.

As time went by one of my sisters decided to leave me to go and live with my mother. I remained with one of them who did not nurse me as expected. My sisters' actions led me to think I was very sick and that I was not going to recover at all. I also thought there was no need for me to continue taking the TB pills.

My experience led me to join the local health centre as a volunteer TB treatment supporter and caregiver where I encourage and support TB patients who might be in a similar situation as I was and also to teach the community members not to stigmatise those suffering from TB because it is an airborne and curable disease which can be caught by any one. I therefore urge everyone to embrace TB patients and support them in every way.

Mrs. Chulu remains in good health and works as a volunteer treatment and caregiver at Chimwemwe clinic.

3. Story of Mrs. Kalembe Kafyuke (Pseudo-name) - EFFECTS OF DESERTION

I once suffered from TB, and when my relatives learned that I had TB; they ran away from me. A cousin that I lived with decided to leave me alone with my children. My cousin's action was out of the fear of catching TB and the thought of me dying under her care. I begged her to call my aunt (her mother) to come and nurse me, but she refused saying that she did not want her mother to die of TB; as she was so sure I was dying and it was just a matter of time.

In the beginning I was not worried because I knew that people die from various causes among them malaria, cholera and so on and not just TB. With time I lost so much weight and I thought I would indeed die, this was depressing for me. I received a lot of encouragement and support from the health care providers and as a result I followed their advice and took my TB pills in right doses and right time for the whole duration of eight months. I thank God that none of my children got TB as a result of living with me under one roof.

As a result of my experience I decided to join the local health centre as a volunteer treatment supporter so that I can be a useful instrument to encourage and support others in a similar situation as I was and also to teach other community members not to stigmatise those suffering from TB because it is an airborne, preventable and curable disease which can be caught by any one. I therefore urge everyone to embrace TB patients and support them in every way.

Mrs. Kafyuke's story is one that is commonly experienced by many in our communities. TB though a preventable and curable disease can have serious and

negative impact on the infected person such as depression which might lead to unnecessary loss of life when the infected person like Mrs. Kafyuke is subjected to stigma such as she experienced.

Mrs. Kafyuke continues to enjoy good health and works as a treatment supporter at Ndeke clinic and one of the anti-stigma community facilitators.

4. Story of Ms. Mulenga Chileshe (Pseudo-name) - BENEFITS OF DISCLOSURE

I had a cough for more than a month and I used to feel very weak and I could not do much physically. I went to my local clinic where sputum was examined to rule out TB. I was treated with a variety of antibiotics, but with little or no improvement. After sometime, I sought a second opinion at the hospital where a chest X-ray was done and I was found with TB.

I was started on treatment for it. Taking the TB pills for the first two months was not particularly easy but I continued until I took a complete course for eight months.

I feel disclosure of my TB status to all my relatives made it a lot easier for both them and me. They were very understanding and as a result I received a lot of encouragement and support from all of them. No one treated me like an outcast at all. They all treated and cared for me very well throughout my treatment until I recovered fully.

Learning from my experience I encourage everyone out there with a TB patient to be very supportive and caring to them as you know TB is an airborne and curable disease which can be caught by any one. Do not stigmatise anyone with TB.

Ms. Chileshe's story is one experienced by a few in our communities. It is very important to disclose to our friends and relatives our health status in order to receive the understanding, care and support we need when we are found with TB. Ms. Chileshe is now a treatment supporter at Ndeke clinic.

Story by Saliya Mumba, Chofoshi, Mwanachama

Kwali umulwele weshina Iya 'Rosemary Mumba' nemyaka iya kufyalwa 46 years mumushi mwa Mwanachama. Takwali ukwishiba bwangu ukutila alilwele pantu balupwa lwakwe bale mutwala mun'ganga ukufwaya umuti wacikaya; uko baile ikata bawishi kaice ukutila ebamulowele. Kwena kwali ukoposa inshita iitali pakuti beshibe ukuti ni TB.

Ilyo kwali ukuya bendela pakuti tulanshanye nabena, naile sanga ninshi umulwele tema nokwima iyo, kulalililafye. Nakwete ukulanda nabafyashi bakwe kwena mumashiwi nalandile, balikwete ukumfwa; nailelanda nomulwele nao alisumina ukuya kucipatala pantu aliisanga ukutila umuti wacikaya walifilika ukumuposha kubulwele akwete..

Elyo kwali kumutwala ku kiliniki, baliyamusanga na TB, nga eflyo nalebeba. Pali ino nshita, bali abasansamuka nokutasha sana pantu kwena balilwlele ukushintuka kumfwa.

Pali ino nshita, nao ale chinchishako nabambi abalepita mumafya yakulwala ukutila baleya kucipatala.

There was a 46 year old patient named RM in mwnachama village. It took long for the patient to identify the sickness as the patient was taken to the traditional healers. The traditional healer accused the uncle of having bewitched the woman. I visited the family and urged them to take the patient who was by then bedridden to the hospital. The patient was diagnosed with TB. The family was happy as the patient got better.

Today the same patient is encouraging other patients to seek early medication.

Personal Experience On Self-Stigma , By Catherine Chushi, Anti Stigma Group Member At Senama Clinic , Mansa.

Timothy Muteti is 14 years old and used to stay with his auntie. His mother passed on in 2008. He used to cough and feared to go to the clinic, fearing that he might have TB. He feared the unknown. When I visited his auntie, she told me she had a patient who doesn't want to go the clinic. She further stated to me that she tried to encourage him several times, but he refused. When I saw him, I talked to him and he told me that he had this problem for about two (2) months now. As I counselled him, I noticed some of the signs and symptoms of TB; I thus encouraged him to go to the clinic. He agreed and at the clinic they examined him and found that he had TB.

Two days later, I went to visit him and continued counselling him; informing him that TB was a curable disease, and what was needed was to take medicines as instructed by the health workers. He was put on Daily Observation by one of the family members. I also told him about the dangers/serious problems of not completing the prescribed full eight (8) months treatment. He followed my counsel and successfully completed his treatment. To this date, Timothy is fit and doing various works at home.

A TRUE STORY – BY JUDITH CHISHIMBA/SENAMA/MANSA.

On February 3, 2008 I undertook a walk in Chitakwa village to visit one bed ridden client; a widow aged 36 years and had two (2) children, one boy and one girl in the age range 9-13 years. This lady had a problem of coughing, swollen and painful legs for quiet a long period. She didn't want to go to the clinic. I counselled her on the need to get to the clinic, but all was in vain.

I returned two days later, continued with counselling and she accepted to go to the clinic. At the clinic, she went for ¹VCT from where she was tested and found to be HIV positive; her condition was not very good and she was also commenced on ART. During my home visitations, she complained of problems nausea, vomiting and skin rash; and that she wanted to stop taking the medicine that she said were causing her

¹ Voluntary Counselling and Testing

more suffering. I counselled her that stopping treatment would be more dangerous. With continued education on the benefits of ²ART, she continued taking the drugs. Two months later, her condition improved, she could walk and get out of bed, sit outside with her children. The side effects minimised. In February 2009, she attended an Adherence Counselling Training workshop organised by ³ZPCT. As a living testimony, she offered her services as an Adherence Counsellor, now volunteering her service at Mansa General Hospital to date.

SUCCESS STORY BY ALICE MWAPE. SENAMA/MANSA.

One day, while doing my normal field work of home visitation, as I passed through some neighbourhood, somebody I didn't know called me by name; so I stopped and waited to hear what she wanted to tell me. She was a distant neighbour in the locality where I stay. She introduced me to a man named Mr. Shalawambe (not real name), aged 42 years of Chitakwa village in Senama; who spent most of the day sleeping on a reed mat in his yard.

When we approached the man on his reed mat, he started crying before he could explain what the situation was like for him. I encouraged him to stop crying so that he could tell us what his problem was.

Later after calming down, he started to explain that his family members, including his wife, who had even left for her parents' home with their four children, had rejected him. Asked what his illness was all about, he said he has been experiencing chest pains, loss of weight, loss of appetite and coughing up blood for some time now.

On that day, I did some counselling and encouraged him to get to the clinic for examination; telling him what he was experiencing was very suggestive of TB, a curable disease. He accepted to go to the clinic.

At the clinic he was found to have TB and was started on TB treatment; I was assigned as the ⁴DOTS treatment supporter since he was in my neighbourhood. I continued counselling him and other community members on the negative effects of stigmatising.

Mr. Shalawambe has since completed his TB treatment and is back to his contractual works of constructions. The wife came back some months later only to find the husband was a healthy man. I talked to her and she has since rejoined the husband, who has built a big house for his family. She expressed gratitude for the help I rendered to the husband whom she thought would have died (that's why she abandoned him).

To day, this couple is working with me in the community; teaching on the bad things stigma brings in our community and encouraging families to look after their sick relations.

A TRUE STORY FROM MUTITI, SENAMA MANSA by RHOIDAH KAOMA.

² Anti Retroviral Therapy (treatment)

³ Zambia Prevention, Care and Treatment Partnership

⁴ Directly (Daily) Observed Treatment (therapy) Short course

Ba Nathan Musonda bali nemyaka yakufyalwa 50; baleikala mumushimwa Chintomfwa; tabakwete abakashi, ifyupo fyali pwile elyo tabakwete nabana; baleikala naba nkanshi yabo.

Ba Nathan bali isa lwala sana, ukufimba umubili onse. Ilyo bankanshi yabo bamwene ati ubulwele bwakosa, balisa batamfya mung'anda ikalamba, nokubabika mukayanda akanono, akashafimbilwe bwinobwino akashakwete ne cibi; elyo cabulanda yali ninshita yamainsa!

Elyo nalepita mumushi ukutandalila abalwele, nafikile pali bankanshi yaba Nathan; bansontelele kukayanda uko babatamfische; naile sanga ba Nathan bali fimba umubili onse, elyo bale moneka ababutuluka mumenso namuminwe. Naliipwishe baNathan ngacakuti kuti nabatwala ku kiliniki, bali kene ukutila amaka nayapwa. Batile lekenifye mfwe. Elyo naipwishe bankanshi yabo, batile amacinga tapaba ayakubasendelapo. Calimpafische ukufwailisha mpaka naisa lanshyanya nomulumendo umupita nshila uwasumine, twabasenda mpaka ku kiliniki. Pa kiliniki bwangubwangu babatumine ku Mansa General Hospital, pantu balilwele sana.

Bali bateka kucipatala; bankanshi yabo aba bulanyantako kuba pempula nangu bushiku bumo iyo. Ba Nathan bali basangile na TB; batampa nokunwa umuti. Baikela mucipatala pa mweshi umo nenshikupo, elyo baishile bafumya kwisa twalilila ukunwa umuti kun'ganda.

Kun'ganda elyo bafikile kuli bankanshi yabo, ba Nathan bali isa leka ukunwa umuti ngefyo babakonkomesha mucipatala. Ilyo naile batandalila, nalibpwishe ico balekela ukunwa umuti. Bangaswike abati baletina insala, pantu nga banwa umuti, baleumfwa sana insala; elyo ninshi ifyakulwa pan'ganda, bale batana kuli ba nkanshi yabo. Nale batandalila cila bushiku ukubakoselesha ukunwa umuti; nomba nga wapwa tabalelanda, baleikala fye; nabo balupwa lwabo tabaposeleko amano kuya mukubapokela umuti pa kiliniki. Balupwa lwabo baleeba ati kashishi ba Nathan balwala, kanshi ukupoka umuti kuposa inshita.

Nalikonkenyepo uku bapokela umuti ba Nathan pa kiliniki ukufikila nelyo baishile pwisha imyeshi 8 yakunwa umuti.

Pali bulelo, ba Nathan balifye bwino, bali tampa nokubila insalu, apo emilimo yabo-bali nibatelala; balupwa bali papa efyo caba kuli ba Nathan, noku bakankamba bali leka.

Year old Nathan was chased from the main house he was living in with his sister and other family members after he got sick. The time I went to see him I found he was sleeping in a poorly thatched house, which had no door. The scenario was very sad. I talked to his sister who told me that there was no bicycle to take him to the hospital. I later looked for a bicycle and took him to the hospital where he was diagnosed with TB and admitted for a month. After he was discharged Nathan stopped taking medication-citing hunger as the relatives had neglected him and could not help collect medication for him. He had also given up and said taking medication was a waste. I continued getting medication for Nathan until he completed his medication Today Nathan is doing fine and is doing a tailoring business

TRUE STORY ON MR. CHIKWANDA – MUTITI, SENAMA MANSA.

Mr Chikwanda lives in Sebyo village; he is 37 years old and has no wife. He came from Kasama to visit his uncle when sadly he fell ill and the uncle chased him from the home. He looked for a temporary shelter in the neighbouring village.

One day as I was doing my home visitation, some neighbours I had visited narrated to me how the man who had moved in the neighbourhood was always indoors, sick. I proposed we go there and see the person. We got there and found a very sick man lying on his reed mat, unable to wake up. I asked him if we could take him to the hospital, he refused saying, 'let me just die, my time has come'. There was no food or water in this house.

I visited the second day and continued talking to convince Mr. Chikwanda to get to the clinic; finally he accepted. With the help of the neighbours, we got Mr. Chikwanda to the clinic where he was admitted. Sputum samples were also collected and sent to Senama clinic. He was diagnosed to have TB and started treatment. I continued visiting him at the clinic/hospital to give him words of encouragement.

At discharge, Mr. Chikwanda continued taking his medicine from home and completed the prescribed eight months. During his hospitalisation time, I had lengthy discussions with his uncle; especially that this uncle never even on one day, paid a visit to the sick nephew.

Upon discharge from the clinic/hospital, Mr. Chikwanda was accepted back in his uncle's house and the stigmatisation that was experienced before Mr. Chikwanda's hospitalisation and subsequent diagnosis of TB, has since gone.

JOHN NGOSA,⁵ CHW OF MWANACHAMA NARRATES HIS ANTI STIGMA EXPERIENCE IN THE AREA.

As a CHW, I see people from the community with different health related problems. I service the Mwanachama community under Chief Chimese, Mansa district. My work also involves visiting the community, doing some environmental inspections.

One day as I walked through Yobe village, I found a 44 year old gentleman named Jameson Lupulwe (not real name) exchanging bitter words with his step mother. Jameson was accusing his stepmother that she was responsible for his illness. He alleged that she had bewitched him with his chronic cough as he had been coughing for the past two (2) months.

This argument degenerated into a near punch up but the on lookers managed to separate the two. Later in that week, Jameson took the case to Chief Chimese, wanting to be given a letter, authorising them to seek the services of a witch doctor to help resolve the matter. The witch doctor said the stepmother to Jameson was responsible for his illness. Surprisingly, Jameson came back to me seeking for medication.

After I interviewed him, from the way he presented his problems, I advised him to seek further medical attention as his problem sounded more of TB than what he

⁵ Community Health worker

thought it was (witchcraft). He entirely refused the idea of going to the clinic. I sought the assistance of a colleague, Joseph Mulenga, from ⁶ZRCS in the neighbourhood, to help me convince Jameson to go to the clinic for medical attention. We talked to Jameson and his family members for a protracted period till finally he accepted to go to Senama clinic. At the clinic he was asked to submit sputum samples for which he did and was diagnosed to have TB. He was commenced on treatment of which he completed the eight (8) months.

To date, Jameson is alright and his family and himself continue to be grateful that we assisted their family member a lot; else he would have died had the thought of witchcraft over taken the thought process.

AGNESS KAPUNGWE'S EXPERIENCE.

Bright Chalwe is a 33 year old resident of Fundi village, which is under Senama clinic catchment area in Mansa district. He is married with two children.

Sometime late last year, Bright fell ill, suffered a bad cough for more than a month but didn't want to go to the clinic saying he was using 'African muti' (traditional medicines). I tried to counsel him and his wife on the need to get checked at the hospital, as what Bright was experienced could be TB. He agreed and was finally found to have TB. He was started on TB treatment but again became a problem in taking the drugs; alleging those TB drugs gave him additional body pains, especially pains in the legs. I continued counselling Bright and explained that what he was experiencing would soon subside and that discontinuing medication would be more disastrous to his health, which could lead to death. I encouraged the wife to ensure that the husband took his medicine daily. Three months down the lane, Bright and the wife noticed change in Bright's life; he had drastically improved. Every time I visited them, it was all praises upon me saying I had saved Bright from dying too early.

To date, Bright is cured and encourages other community members to utilise clinic services.

BENEDICT NGA'NDWE'S SUCCESS STORY – MWANACHAMA.

I had a TB client from one of the villages within Mwanachama; she was aged 24 years. She fell ill in the year 2006. Her illness perplexed the family in that they resorted to witch-hunting.

The first witch doctor told them the one responsible for the girl's illness was the young brother to the father. Back home, the father to the girl went straight to his brother's residence where a heated argument ensued. The accused man refused the allegation; the father to the girl then suggested they go to Chief Chimese so that he could give them an authority letter to seek services of yet another witch finder. A letter was given and this family went to witch doctor Makumba in chief Kale's village, along Mansa – Samfya road. There it was revealed that the first witch doctor was

⁶ Zambia Red Cross Society

bribed (by the father to the client) to ensure that he points at the young brother as being responsible for the illness of the daughter. Doctor Makumba then wrote to Chief Chimese explaining his findings. Later Chief Chimese called all the family members, inclusive clan members (abena Chulu) and advised them what to do next. He emphasised that accusing each other in the family was not a good thing.

However, these two brothers (the father to the client and his young brother) have not fully reconciled to this date.

After this incidence I took it upon my self to visit the client's house. I talked to the father and mother of the girl on the need to take her to the hospital for investigations of which they accepted. The girl was taken to the hospital and later diagnosed with TB and started TB treatment. She was under my DOTS custody, though there was a time she defaulted for one month, she has since completed her TB treatment. She is alright and married and was recently delivered with a new baby. The client is also currently helping in sensitising community members by telling her story; emphasising that TB is curable and that people should quickly seek medical help once they start to experience symptoms of TB, rather than waste time going round witch hunting.

THE STORY OF KWANDANGALA – BY GRACE LUPUPA.

This is a story of a couple from Nyamuna village, in Senama and they only had one child. The lady was aged 64 years and the husband was in his late 70s. Both had TB and because it had taken time in illness, relatives had neglected them, including their only child; so they were left to fend for themselves in their old age, worse still in illness.

One day I took it upon myself to visit this couple but when I arrived at this household, the old lady did not want to hear anything from me; she knew that I was coming from the DOTS Treatment Supporters' group. I returned for the second time, she asked me exactly why I was so persistent on their household. She said I should just leave them alone, if it is dying, they were going to die; because their family members had neglected and abandoned them. Despite this kind of reception, I took another try for the third time; this time around, she accepted my visit and gave an appointment to see her the following day.

On the material day, we discussed at length the many problems she went through with her husband; including reasons why she had stopped taking TB medication. After a protracted discussion, I encouraged her to get back to the clinic so that she could be examined and ascertain as to how her health is; she accepted this.

I also took time to visit their only child, as it was close in the neighbourhood. I took time to go through the issues we discussed with the mother and reminded her of the responsibility of taking care of our elderly and sick parents. She accepted the mistake and offered to take her mother into her house.

This time, there is no family stigmatisation; the lady is even able to do some household chores and has continued to take her medication.

A TRUE STORY AS NARRATED BY CHITONDO CHENGO – ANTI STIGMA FACILITATOR, SENAMA/MANSA.

This story of a lady named “Nalyaafya” (not a real name), 36 years old from Chabipa village (not real name). She was married to a retired civil servant and they had five (5) children and three (3) grand children. The couple had TB and HIV. The lady was put on TB treatment and later started ART, but at some stage she defaulted on TB treatment. The husband, who knew me, reported to me of the wife’s stopping taking TB drugs for no apparent reason. He said she never wanted to be taken back to the clinic anymore. She had started hating herself and everything around her. I made an appointment to see her, through the husband and she accepted. The following day in the afternoon, I paid them a visit at their home. At the start of the conversation, she declared that she was no longer interested to listen to any community health worker from any organisation. She even confessed having had chased one female community health volunteer the previous day. I could not proceed with my intended discussion, as she was clearly not in a mood to talk with anyone; so I left the place.

A few days later, again I took the trouble and courage to visit her. On my arrival, one of her daughters informed her that I had come to see her; she once more reiterated the fact that she was tired of listening to people talking about her health. She was no longer interested in health talks. Again, I could not proceed with any meaningful discussion. A week later, I went back and fortunately, she accepted my visitation and accorded me chance to discuss. We sat in their grass-thatched hut within the yard. She took the show and narrated all the negatives she could about community care givers and the organisations from which they were coming. She even went on to say ARVs were useless medication since they were not curing her ill health. You could see that she had lost her self-esteem and had little or no hope at all in her future. She even began contemplating committing suicide; as the only best solution to her situation. I gave her time to ventilate all her emotions, listening actively and skilfully later introduced the topic on different forms of stigma, the causes and its side effects on individuals and the community in general. Our discussion mainly centred on self-stigma, as I noticed from her presentation that this was the issue at hand; and it took us quite some time to come to a conclusion. Finally, she told me she would take whatever decision she would wish. I thanked her for the time and reminded her that she was still useful to her family (children) and society.

Two months later, the husband reported that his wife had restarted taking medication and that her condition (health) had drastically improved. Nalyaafya has since completed her Anti TB medication and continues on the life long ART. The husband continues to this day to thank me for my persistence, which has saved his wife.

Isolated by family -Shared by anti stigma facilitator Choma

I once visited my sister in Namwala District of southern province. In my sisters household was a nephew to her husband who was a TB patient. The patient was

isolated from the rest of the family. He used to sleep in a pantry outside the house and had separate eating utensils.

I explained to my sister and her husband how TB is transmitted and how it cannot be transmitted through sharing eating utensils. I also told them about stigma and its effects on the patient.

The patient was asked to move back to the main house. The couple appreciated my visit. Choma

It is possible that we can stop stigmatisation- being faithful and positive

This incident happened in 2009 at new kalundu site and service where one couple stays. It so happened that a neighbour to one anti stigma facilitator (the wife) observed that the health of her husband was deteriorating. She suggested to the husband that the couple goes for Voluntary Counselling and Testing (VCT). The husband refused to go for VCT. The wife went for VCT without informing the husband. She however told him the outcome of the test, which was positive. The husband became hostile towards the wife and started mistreating her. This went on for a long time until the anti stigma facilitator visited them.

During the visit the facilitator talked about stigma to the couple. As she talked to them she could see that the husband was interested in what the anti stigma facilitator was sharing. He did undergo VCT at a later date, his test results were positive. The Husband later apologized to the wife for having mistreated her as he realized that he was stigmatizing her. He is now the best home based care man and the family is once again a happy. Choma

Self Stigma - Shared by anti stigma facilitator Choma

Mr X lives in one of the compounds in Choma. Mr X had been hiding whenever taking his medication as he did not want anyone to know that he was on treatment. This was until one anti stigma facilitator talked to him about stigma and disclosure. He is now open about his condition and does take his medication at church in public. Choma

When I had TB – as shared by Mr C . Anti stigma facilitator,Kitwe

I had TB and but continued to go to the traditional healer – I was chased from employment and my wife ran away from me I moved to another town where I was again chased by a relative I had gone to to seek solace from I moved in with another relative who again chased me because he felt I was coughing a lot and would infect his children I had no option but to look for a shack where I stayed until I joined a support group where I am now a leader and assisting TB patients.

TB In The Family as shared by Anti stigma facilitator Mansa

After my husband's death I got very ill I did not know what was wrong with me I continued visiting the clinic where I received treatment which did not make any difference. People looked at me as having cleansed myself. People used to tease me. I later went to another doctor where I was diagnosed with TB. I received treatment and recovered. Later on it was my eldest son who had TB after which the youngest

also had TB. My experience of being cured of this condition has encouraged others who look at me.

TB In The Family- as shared by Anti stigma facilitator Mansa

My son of two had TB. This brought a lot of confusion in my family. My in-laws accused me of being promiscuous this caused me to separate with my wife. Because my son had swollen glands on the sides of the head I also attributed the sickness to my wife whom I accused as having been promiscuous.

My son later got cured and is currently doing his fourth grade. I am now back with my wife

My son accused me of witchcraft in law. This is after he went to a traditional healer who told him so- I later asked that I go with him to the hospital with his brother. He was diagnosed with TB and was admitted for two weeks.

After leaving the hospital he never came to see me – I am told he has recovered and has gone to the fishing camp. I am yet to confront him.

Rejection - as shared by Anti stigma facilitator Mansa

I had a client who showed signs of TB when I reached her home I found the person had been isolated the person would be left without food the whole day. I took sputum and she was found with TB I informed the family about the condition- she was rejected further I continued taking medication to her until she gained strength and was able to go to the clinic on her own. Mansa

2. I had a person who was rejected when he had TB. The patient was isolated until the day he died. People had to call me when I was not even a relative. I approached the family members who later on decided to contribute towards the funeral. Mansa

3. In a certain township there lived this lady who attempted commit suicide by jumping into a well at a ne

I WAS DIAGNOSED WITH EXTRA PULMONARY TB- as shared by Anti stigma facilitator Kabwe

In 1989 the month of May I suffered from TB. At first I didn't know it was TB, since I had very few signs and symptoms associated with my illness. It so happened that I had developed constipation for sometime. In due course I was forced to take some traditional concoction, which led me to suffer from severe diarrhoea and vomiting. I developed pneumonia and was hospitalised at the University Teaching Hospital in Lusaka for a period of 1 week. Unfortunately the doctors could not come up with a precise diagnosis pertaining to my illness. I was told that the xray showed a slight sign of infection but I could not be commenced on TB treatment.

On 25th May 1989 my brother decided to take me for further investigations in Botswana where I was hospitalised at a private clinic in Gaborone.

I was diagnosed with ETB. It was discovered that I had some fluid in the stomach the fluid was drained and I was put on TB treatment immediately. The sad part of it was that I was only being visited by my brother his wife did not visit me despite being a health staff at one of the major hospitals. Though my brother visited me he could not come into the ward were I was admitted but opted to call me out and would only spend a few minutes with me. I was given a different kind of clothing to distinguish me from other patients.

When I returned to Zambia the only people that would visit with me were my children and my wife. My close friends and my neighbours never came to welcome or visit me. After sometime I gathered rumour that people suspected that I was HIV positive this they attributed to the fact that I previously was involved in cross border trading. It took time for people to accept me and it was only after I had regained my health fully.

Later I became involved in health related programmes and developed the desire to serve people who were found in the same situation as I was.

In conclusion I would say that for sure stigma is pronounced in our communities, we have to continue fighting it at any cost. We need concerted efforts to succeed.

I WAS NEGLECTED BY THE CHURCH AND MY FAMILY as shared by Anti stigma facilitator Lusaka

Before I was diagnosed with TB of the spine I was working for a certain church within our locality from the year 2003 to 2006.

My family rejected me when they learnt that I had TB of the spine. I was admitted to the hospital for 2 months. During the time I was admitted my brothers and sisters never visited me, it was only my wife and my neighbours who came to see me

The church were I was working stopped paying me in time they later stopped paying me my full salary, this was despite my wife taking up the responsibility of sleeping at the church as a care taker. They would give my wife any amount they wished they told her that they did not know her.

Due to the TB I unable to fulfil my conjugal rights this makes me feel so bad the only compensation is that my wife is very understanding

There is stigma in our community and it is everywhere. We need to fight it.

THEY USED TO CALL ME MAPILISI.

The time my family learnt that I had TB and HIV and was on treatment they started calling me 'mapilisi' a name derived from pills. This was in reference to the medication.

I used to feel so hurt whenever they called me this name. Later my sister who gave me this name was also diagnosed with TB and was later found with HIV. I am the one who assisted her and gave her the support during her sickness.

Thank God today I am alive and fit and able to assist those who are in need.

The story of Patricia of Victoria Falls – Livingstone.

Patricia Siloka, who lives at Victoria Falls Community in Livingstone, was once a chronically ill patient who was bedridden for some time. This meant that she could not get out of bed without being assisted by someone.

Patricia had self-stigma as she never allowed people to visit her for fear of them laughing at her and gossiping about her because she had lost a lot of weight and had a terrible odour due to the bed sores that she had developed. The family too stigmatized her as no one wanted to sit near her or talk to her. Patricia's husband even left her and went and started staying with another woman in a different community.

Patricia was then registered in the Home Based Care (HBC) programme after which she was counseled and sensitized about VCT and against stigma. She is now on ART, strong and active.

Patricia is now a very active anti-stigma advocate who has helped to form a support group at her site by the name of "Shungu Namutitima" meaning "The smoke that thunders". She has since been a role model who has come out in the open and is always sensitizing others on the Community Radio, Radio Mosi-o-Tunya on matters of stigma.

Patricia says for her, STIGMA stands for:

Still Thinking Intelligent Good Motivated and Active (STIGMA).

2. The story of Febby of Libuyu Community of Livingstone.

Febby, a resident of Maramba community was diagnosed with TB early 2008. Almost at the same time, her sister whom she was staying with in the same house was also found to have TB. Febby started the treatment immediately and tried to encourage her sister to do the same, but the sister refused because of the way the relatives and the neighbours used pass comments and behave towards them. She could not even gain courage to go to the clinic because neighbours would see her and still feared to meet some on the way to the clinic and to meet some at the clinic itself. People shunned visiting Febby and her sister and avoided passing near their house. Name calling was increasing by each passing day which included, "Amankowesha," meaning "infected" and "utujili jili" meaning that someone was infected by drinking a local brew similar to Dry Gin and whisky which is popularly known as "Kachasu" in local language.

A few months later unfortunately, Febby's sister passed away as a result of no treatment due to stigma. Febby however, was still determined and with the encouragement from her caregiver, she managed to finish her TB treatment.

Febby overcame stigma and is now busy sensitizing other TB patients within the community and at times, she is found at the TB corner at Maramba clinic telling her part of the story to others.

Sharing of cups as shared by Anti stigma facilitator Choma

Morgan Nsemu a former TB patient and now an activist at Shampande Clinic reports on how TB patients could not share cups provided at the clinic. 'each one would come with their own cup for fear of transmission' he says. He has continued sensitizing patients at the TB corner about transmission and says he has seen significant change especially for patients who are already on treatment and have attended the sessions.

Family disputes - as shared by Anti stigma facilitator Choma

One woman diagnosed with TB was chased from her matrimonial home. This was after the family to the husband discovered that she was on treatment. In their explanation they said the woman was promiscuous and did not deserve to be with their relative whom they felt she was going to infect with TB and HIV which they said was the same.

One of the Anti Stigma Facilitators visited the family and talked to them about TB transmission and the link between TB and HIV she also talked to them about the effects of stigma.

The family reversed their decision to have the woman chased from her home and have since been supporting her.

Neglected Child- as shared by Anti stigma facilitator Choma

Florence Beenzu shared a story a child who was neglected by her aunt. The guardian was a sister to her mother who is a business lady. Florence discussed the plight of the child with the aunt who decided to take her to the clinic. 'The day I went to the aunt to the child I found the child sitting by the brazier and shaking, the child clearly had a fever'. The aunt later took the child to the clinic where he was diagnosed with TB and HIV. The child was put on treatment and is now better. He is now better and is able to collect medication on his own.

The mother who is also HIV positive is forever grateful and has told other people about me who visit Florence at her home.

My Uncle Had TB as shared by Anti stigma facilitator Choma

Gibson Mulobela an anti stigma facilitator and member of the Traditional Healers organization. He reports that he took in his uncle who was on TB treatment. when at home his family would interact with his uncle and would eat with him but in his absence they would give him separate eating utensils and isolate him. This prompted the uncle to decide to leave. When he learnt about what was going on Gibson called all his family members and discussed TB transmission and stigma with them.

The family members have since changed their attitude towards his uncle who is now happy to stay.

Shunned by friends and family - as shared by Anti stigma facilitator Choma

Mary miyoba shared a story about a grade seven child who was being abused by her stepmother. The child was HIV positive and sickly. His friends did not want to sit next to him in class. When she visited the child's parents she discovered that the child was

isolated even at home. When confronted the father said he did not know that the child was being abused and also that the child was on TB treatment. Mary then discussed with the father and the stepmother on the negative impact that stigma had on the child.

The child was taken to the health center by the stepmother where he received further treatment on other ailments. The boy got better and has since qualified to go to grade 8.

Stigma Beyond Treatment- as shared by Anti stigma facilitator Choma

One of the participants shared how a guardian to a former TB patient came to enquire whether it was safe to live with a TB patient who had completed medication. The anti stigma facilitator shared on the basic facts of TB and also discussed stigma related issues.

The guardian has since continued staying with the former TB patient and is supporting him as he is on ART.

Child denied ART - as shared by Anti stigma facilitator choma

One facilitator shared how a child was denied access to ART because the grandmother thought the child's sickness was caused by witchcraft. The grandmother attributed the death of both parents to the child to witch craft. One of the facilitators approached the grandmother to the child and advised her on the importance of taking the child for an HIV test. After resisting for some time the grandmother finally accepted to take the child for the test. The test was positive and the child was put on ART. The child's health has improved and she has started going back to school.

Stigmatized by family - as shared by Anti stigma facilitator Choma

Family members stigmatized one young TB patient after discovering that he had been diagnosed with TB. The family members gave the young man separate eating utensils and isolated him. No one used to interact with him. This scenario was brought to the attention of an anti stigma trainer who is also a TB Treatment Supporter. The facilitator approached the family and had a group counseling session where amongst other things stigma and its impact on the patient was explained. The family has since changed their attitudes towards the patient.

Chased by family- as shared by Anti stigma facilitator Kabwe

One young lady's parents chased their daughter after she became ill. The parents accused their daughter of having brought the sickness on her self as they claimed she had been promiscuous. One anti stigma facilitator encouraged the woman to test for TB. The woman was diagnosed with TB and later did an HIV test, which came out positive.

The woman's health has improved and she has since gone back to her parents. The woman has not told her parents who leave in another town about her status but has continued to collect her medication and is being supported by the anti stigma facilitator.

Chased By Wife- as shared by Anti stigma facilitator Kabwe

One woman from a community in Kabwe barred her husband from sleeping in their bedroom after he was diagnosed with TB. The wife explained to one of the facilitators that what prompted her to chase the husband from their matrimonial bedroom was because she felt he was going to infect her and the unborn child with TB as she was pregnant.

The anti stigma facilitator explained the mode of transmission of TB and the impact of stigma to the couple. After the counseling session the wife's attitude changed and she became supportive to the husband. She would even collect medication from the clinic on his behalf. The man has since completed treatment and came to thank the anti stigma facilitator for bringing peace in the home.

TB In The Workplace- as shared by Anti stigma facilitator Lusaka South

Franklin Munsanje is a Community Health Worker at Kanyama clinic, Lusaka.

When diagnosed with TB, a man in Franklin's community feared losing his job with the security firm he worked for, and asked Frank to visit his employer and talk to him about TB and try and persuade them to let him keep his job.

After the visit to see his boss, it was agreed to call a meeting with the man's co-workers to acknowledge the situation and bring it out in the open. During the meeting, Frank talked about some of the facts and fears about TB, as well as the social stigma surrounding the disease. The aim of the talk was to try and spread the right knowledge about TB: how it is contracted and treated, and also how it is not contracted. This open discussion with a fellow member of the community helped to counter some of the rumours and myths that circulate and spread through informal networks such as those in the work place.

The man eventually negotiated set sick leave from his job, which remained secured. Frank was encouraged to make a return visit to the security firm to follow up on his talk and visit some of the families of the workers to find out if his message had got through to networks beyond the workplace.

My Experience Of Being A Community Health Worker On ART as shared by Anti stigma facilitator Lusaka South

Judith Msiska is an Anti Retroviral Therapy (ART) Counsellor working in Chawama health centre Lusaka.

One of the challenges Judith faced was establishing trust when trying to discuss stigma issues with HIV positive community members at the ART clinics she visits as a counsellor. Why should they listen to her? Judith is open about her own HIV-positive status and has faced stigma herself as a result, but uses her own experience as both her reason and her material for teaching people about TB and HIV stigma. Yet on one occasion, some people were cynical about her openness and attitude to being HIV positive. People were asking, 'but how do we know you're really HIV positive?'. The next week, Judith brought her ART medication with her to the clinic. She showed them the pill. They said, 'how do we really know that is ART?'. She showed them the bottle; she asked someone to read the label out loud so that they would know it

wasn't just a headache tablet, and then she sipped some water and took her medication in front of them.

Teacher -one of the participants who is a teacher and a counselling and guidance teacher at her school talked reported that she talks to students at school, different age groups and different techniques. The Key messages that she shared are on TB transmission.

A health worker shared how one landlord who evicted a tenant because she was HIV positive and had TB is now a TB patient and shared her regrets for stigmatising the tenant despite advice from the health worker

Children affected by stigma, either in real cases or in their customs and relations e.g. if a student coughs he/she accused of having TB. Children stigmatised if parents have TB/HIV a child can be isolated.

She observed that School groups such as anti-AIDS clubs are good transmission vehicles for getting messages back to parents and incorporated into family life.

Girl Encouraged To Take TB.

One girl within the community was coughing a lot. She kept on taking different cough remedies but the cough never went away. One anti stigma facilitator encouraged her to test for TB but she got very angry with him. The anti stigma facilitator did not relent in doing this but continued to encourage the girl until she went to the clinic where she was referred to the main hospital. The girl was diagnosed with TB and is now on treatment and is better.

TB + Pregnancy

TB stigma and an unplanned pregnancy attract a lot of stigma. Her mother chased one youth from home when she was found to be pregnant and later diagnosed with TB. The mother warned the girl that her step father was not going to accept her in the house considering that she was not his child and had the two conditions.

One of the anti stigma facilitators who is a neighbor to the family took the girl in and encouraged her to continue taking medication. The girl is much better and her mother has started visiting her she has also requested that the girl returns home.

Chased From Home.

Alice Mwape reported that a man approached her after making a presentation who told her that he had been chased from home after he became sickly. Alice advised him to seek medication as he was coughing a lot. The man went to the clinic where he was diagnosed with TB. Alice then went to the family and talked to them about TB and HIV. The family accepted the man back home and he has since continued on treatment and is recovering.

'I Would Have Started Taking Medication A long Time Ago'

Agness who is one of the trained anti stigma facilitators reported that she had a client who refused to seek medication because he was stigmatized by his family. The family isolated him as he was sickly and coughing. The facilitator encouraged him to go to the clinic. He went to the clinic and was diagnosed with TB. The man started taking medication and is thankful to the anti stigma facilitators.

Isolated

Sophie shared a story about a young woman who was isolated by the family 'the woman was given her own eating utensils' says Sophie. The woman was sleeping in a small house that did not have a door. Sophie advised the women to go to the clinic. She was diagnosed with TB and was put on treatment. Sophie further had an audience with the family. They thanked Sophie for her effort and accepted the patient back into the household.

Demon Possessed

Matildah shared a story about a family who attributed the sickness of their relative to demons. Matilda took the patient to the hospital where she was diagnosed with TB. Upon learning that she was diagnosed with TB, the family started stigmatizing her. Later on Matilda talked to the family about TB Transmission, The effects of stigma and how to look after a TB patient. The family took her in and her health has now improved.

Denied by own family

'My brother was contemplating chasing his wife and marrying another woman' This was shared by Bridget who went to see her brother who leaved in another town after learning that he was diagnosed with TB.

His wife gave him separate eating utensils and he was sleeping in a separate room. Bridget talked to the family about TB. They started sharing eating utensils and admitted him into his bedroom. He is still however been counseled as he is still thinking of divorcing his wife.

Isolated by Family

Mr X is a widower and has 3 children. He stays in a family house with 11 other relatives in one of the local residential areas. His rejection started when he started coughing and losing weight. The family members decided to put him in his own room away from others and his children. This they said was in order to protect his children and others from contracting TB and dying.

Rita visited the family and educated them on TB transmission she also talked about stigma and its effects. The family's attitude changed after the discussion.

Mr X successfully completed his TB treatment and has continued taking ARVs. He is now running a business and is looking after his children and is living happily with his relatives.

I Am Now A Public Speaker

'My success story is about myself' says Tyson Moonga. Tyson is one of the trained anti stigma trainers in Livingston. He tells the meeting that it was very difficult for him to talk about TB/HIV in public. He proudly says he has clients whom he has discussed TB stigma and the importance of treatment and they have since been adhering to medication. He says his family stigmatized one of his clients until Tyson had an audience with the family members after being told about the situation. He discussed with the family the effects of stigma. The family changed their attitude towards the patient and have that he has since been adhering to medication. Tyson also says he shares anti stigma messages at the local church he attends.

Denial + Rejection (no success)

In one of the local communities there was a woman who was pregnant. The woman was tested positive during the routine antenatal tests. At that time her health was alright.

After delivery the woman got sick and was later diagnosed with TB.

'The woman was my client under the Home Based Care Programme' says Grace Sianga.

During the time that she was sick the husband did not want other people to know of her sickness. Neither did he want her to take her TB drug. She would only take her medication in the absence of the husband. This caused her to deteriorate, as she was not adhering to medication.

The husband became very hostile towards the woman until she lost hope. This was despite the anti stigma facilitator taking the woman to the clinic for psychosocial counseling. The woman became depressed and later died at one of the General Hospitals in Livingstone.

Success After Focused Group Discussion.

'After the TB Stigma training I was able to recognize some of the forms of stigma and other related issues' says Lungowe Akufuna.

In one house hold there was a TB patient who was isolated. No one was allowed to enter the room where the patient used to sleep. The children were not allowed to come near him even when he was outside the house.

I felt it necessary to invite the aunt to one of the focused group discussions where we talked about TB transmission and stigma. She later on confessed that she did not know that what she was doing was stigma as she thought it was the only way of protecting the others from being infected.

I was glad when I made my follow up visit I found the family having breakfast together with the patient the room where the patient slept was well cleaned and the beddings washed. The Aunty the patient also explained that she was collecting medication on behalf of the patient from the clinic.

Poem By Grace Muvwimi Sianga.

STIGMA

STIGMA STIGMA STIGMA

Where did you originate?

Where did you come from?
Where did you get your power?
Where did you get your influence?

STIGMA STIGMA STIGMA
Why are you so cruel?
Where there is medicine
You cause people to stop taking it
Where someone had purpose to live
You come in making them loose it

STIGMA STIGMA STIGMA
You are in all institutions
In hospitals, in churches, in schools, in colleges, in shops and markets
You are found everywhere.

STIGMA STIGMA STIGMA
I hate you because when people are on medication you cause them to stop.
They loose hope when you are present.
You cause them to die faster than illness or disease.

STIGMA STIGMA STIGMA
Your consequences are the worst.
Drugs can control HIV
And a person can live long with the virus present
TB can be cured if a person adheres to treatment
But you stigma – you have no mercy

NOW WATCH OUT –
I WILL TALK ABOUT YOU
UNTIL YOUR CRUELTY IS UNDERSTOOD BY EVERYONE.
SO THEY CAN RESIST YOU. UNTIL YOU CEASE TO EXIST.