

KAWEMPE

Home Care Initiative

Providing Comprehensive Holistic Care
to HIV&AIDS, TB and Cancer Clients

Five case studies of clients

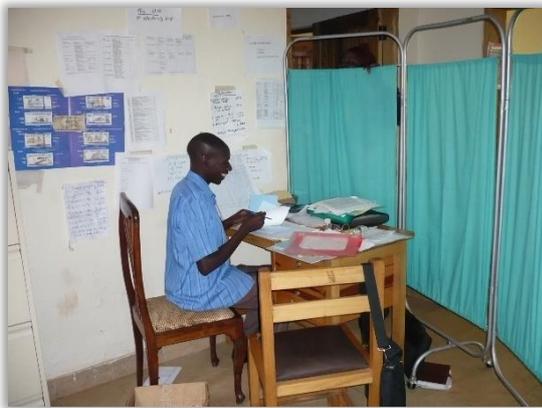




KHC

Kawempe Home Care Initiative (KHC) is a community based organization providing holistic comprehensive care and support to disadvantaged people living with HIV&AIDS, TB or cancer in Kawempe Division in Kampala, Uganda. KHC is providing education for children who are orphaned or vulnerable and empowering clients through income generating programs.

Kawempe Home Care Initiative's aim is to provide holistic home care to people living with HIV/Aids and to prevent further spread of HIV in the community. KHC is run by a dedicated team of experienced medical staff and volunteers, many of them at the same time clients of the project. Support from friends through grants and donations made it possible to set up the project and to keep it running.





The fact that Kawempe Home Care Initiative is not only taking care of the medical side makes it special. The family based approach is also taking care of psychological, emotional and social aspects occurring with the illnesses.



The majority of clients are women who are in most cases also the caretakers of the family. To illustrate the living conditions and circumstances of the clients some of their stories are presented below.



Client Stories

Case 1

Sarah

At the beginning of 2007 I fell so sick that I was locking myself up in a room. I had lost all my hope of being able to take care of my two children and I felt so ashamed. One day a Community Worker of Kawempe Home Care Initiative in Kasangati knocked at my door. First I did not want to open, because I did not want to see anybody. But then she convinced me to let her in. We talked and she counselled me and I understood that there can be help. Since then I am a client of Kawempe Home Care and I have improved a lot.



I live in a small room with my children. My sister lives in the house next door. With her I have an agreement. I work for her as a house girl and in return she is paying the rent for my room. She is also supporting me with food and soap. But my sister is also very poor and there are days when there is simply no food available.



I used to work in a small restaurant as a waitress when I became sick. In April 2007 my weight was only 20 kg, I hardly could move anymore and was bed ridden. I didn't want to see people anymore and I was frightened to realize that I was seriously sick. I was afraid to get help from outside and thought I was going to die soon. When the community worker convinced me to go for treatment I was too weak to walk. I had to be carried to Kasangati Outreach Clinic. There I was tested HIV/Aids positive.

I am not yet on ART because I have a strong CD4 of 500. From July 2007 on I started going to Kawempe Home Care Initiative for counselling. I was coughing heavily that is why the doctors



there advised me to go for x-ray. Thanks to them it was found out that I also have TB. I now take TB drugs and anti malaria medication since September 2007 which I get from Kawempe Home Care. After I developed some leg problems the doctors and nurses changed my medication. I am feeling much better now and can walk around by myself.



John and Christine are my children that live here with me in this small room with all our things and two beds. They are 7 and 5 years old. Both of them are tested HIV negative. Although John has reached the right age he is not going to school, because I can not afford the school fees. I am hoping that Kawempe Home Care school fee program will assist me. I really would like to send my boy to school. My biggest hope is to get better soon to be able to get a job and look after my kids.





Case 2

Christine



I am 30 years. I live with my husband John in Wakiso District, not far from Kampala. We are both clients of Kawempe Home Care. My husband was very sick, but now, thanks to Kawempe Home Care, he went out to look for a job, repairing bicycles.

When we got our first child we were still in a good relationship. But then I found out that my husband was dating

another woman. I decided to go back to my parents. After a while John came and wanted me to come back. My parents also advised me to go back. I obeyed and went back to live with him. Since then we have a good relationship. I got 7 more children. They are now aged between 13 and 1 year. Kawempe Home Care Initiative is paying the school fees for the second eldest, so far the only child that is going to school.

Our story was that my husband was feeling sick more often and became bed ridden for a whole year. I convinced him that we both should go for counselling and testing at Kasangati Hospital. He agreed and we went for testing in December 2007. The result was that he is HIV/Aids positive. He was put on RAV. He is now going to Kawempe Home Care Initiative for medication once a month.



The doctors from Home Care also visited him frequently when he was very sick and helped him to save his life. The Community Antiretroviral and Tuberculosis treatment Supporters (CATTs) still come to visit us regularly although it is a long foot walk for them because we live in a bit of a remote place.

I myself was also tested HIV positive although I was not feeling sick. I went to Mulago Hospital and a test showed that I have a high CD4 of 549, which means my immune system is still quite strong. Therefore I am not supposed to start RAT. The only thing



that I developed so far is herpes. You can still see the marks here on my back. I also go regularly for a medical check up at Kawempe Home Care.



I am a member of a women's group who collect money and give it to one of the women as a grant. While my husband was bedridden I got this amount of money and installed a tap on our property from which I was selling clean water from National Water to the neighbours. We would like to get a big water tank from which we could sell water. The problem of the area is that there is a dwell but if it rains heavily the water is polluted. But nowadays sometimes the water bills are too high and we can not cover them by selling water. I also raise some chicken to secure some food for the family.

The water from that tap I also used for brick making. In front of the house you still see a big heap of left over red bricks. With the bricks we were able to build our own house which is not yet fully finished. We bought the plot for the house before my husband got sick. I sold the surplus of the bricks I produced and from that money we could afford buying iron sheets for the roof of the house. Now that I know that I am tested positive the doctors of Kawempe Home Care advised me to stop making bricks because it is too exhausting for my body.



We are proud that we have our own home and my husband can now start working part time since he recovered well from his sickness thanks to Kawempe Home Care.



Case 3

Muhammed



My name is Muhammed and I am sharing this small house with my family. My family means my own 7 children, my sister and her three children. I am HIV, still very weak and shaky but I now manage to get up and walk around on my own thanks to Kawempe Home Care. It is only two weeks that I am able to do so, before I was bed-ridden for 4 weeks and the doctors feared for my life.

I used to be a business man. I was selling fish. In Entebbe, where I was living I used to move around with my bicycle selling fish. My wife was working in the same business. In January 2007 she fell sick. We both lost our jobs because of that and after a disagreement she left and went to Kampala. She was tested positive of HIV/Aids and died in June 2007 at the age of 44 years.

Shortly after that I was also ill and therefore shifted to my sisters' place in Kampala. I took all the children with me. My sister had heard about the Kawempe Home Care Initiative in her District. That is why I went to the Voluntary Counselling and Testing at the Kawempe Home Care. They gave me the result and that's how I learned that I was HIV positive. By that time I was really very sick. The doctors found that my CD4, my immune system, was extremely low, it had reached one. Healthy people have a DC4 of around 1000. My condition was very severe and I was bedridden for several weeks. The doctors and nurses of Kawempe Home Care Initiative made sure I go to the scanning. The scanning showed that I have abdominal TB.

After that they started with my TB treatment. Two weeks later they assisted me on starting the ART [Antiretroviral Therapy]. I was fighting for my life but the doctors





from Kawempe Home Care came every day to look after me. Slowly my condition was improving. Every Wednesday I am now going to the open counselling day of Kawempe Home Care Initiative in the neighbourhood where I get my daily antibiotics and multivitamin medication for free.



My children mean a lot to me. There are 5 girls and 2 boys, aged between 18 years and 4 years. They all have been tested at the Kawempe Home Care Initiative and so far been HIV negative. All in all 12 persons now live in my sister's three room house made of bricks. The older children are sleeping on mats, the small children in 2 beds, close to their aunt. I sleep in a separate bed where my sister was

able to take care of me when I thought I could not get up anymore. My sister is a very important person to me since she advised me to go to the Kawempe Home Care Initiative. Besides that she is giving all of us shelter and is also farming on a small piece of land to provide some food.

My biggest worry is that my children might not go to school. I pray everyday that the drugs help me to get stronger so that I can start working again. I want to stay and work in Kampala because there is no reason to go back to Entebbe since my wife died. My biggest wish for the future is: "I want my life and my children to go to school."



Case 4

Jennifer



My name is Jennifer. I used to sell Cassava chips and fried sweet potatoes to support my 4 children. In addition I was attending a course to learn hairdressing but was not able to finish it. I often fell sick for quite a while but so far I could cope with it. But in October 2007 I developed high fever, the joints were aching, I was coughing and went to Mulago Hospital. A blood

test showed that I am HIV/Aids positive.

My husband died already in 2000. I had separated from him before because he had affairs with other women who abused me. One day a cousin called me and said that my husband is now very sick. He was tested IV/Aids positive but refused to take medication. I decided to take care of him. He had to go to the hospital daily but shortly after I went back he died.

I went for HIV/Aids testing already at the end of the 90ies but never got any results, either I was not told the result or the blood sample got lost. Therefore, I was discouraged to go for further testing and counselling. Today the counselling is much better at Kawempe Home Care. My late husband had started to build a house for us but did not finish. In 2003 I managed to get at least an iron roof and shifted to that house in Kawempe where I live now with three of my children.



My second eldest boy is cooking, taking care of me and at the same time he is looking for a job. The other boy is in school and Kawempe Home Care Initiative is paying the school fees for him. My youngest daughter is in a boarding school and has found some sponsors for that. Everyday life is not easy for us. In this small house there is no toilet and using the one of the neighbours is my biggest concern because they do not like that. Another problem for us is food. We are supposed to eat things like fruits and



greens the doctors from Kawempe Home Care advised us but we often can not afford this.



My plan for the future is to raise chicken and sell them but I do not have enough money to start a small business. Besides that there is water entering the house during heavy rains and there is not enough room for all the children. Therefore my eldest daughter, Nuru, is staying with her aunts in a different part of Kampala.

After counselling by Kawempe Home Care I went for screening and it was found that I have TB. The doctors put me on TB treatment. After I will have finished this I want to start with ART.. My brother died when he was on RAV and TB treatment at the same time so my fear is that both would be too much for my body. But the CATTs assist me taking the drugs. Except the eldest my children have not been tested for HIV/Aids. I am convinced that the youngest is not infected.



Case 5

Nuru

Nuru is Jennifer's eldest daughter.



At the moment I am working as a Community Volunteer at the Kawempe Home Care Initiative. I got to know that I was positive when I was 14 years old. All my siblings are healthy but have not been tested, they are scared to go for testing because of the injection.

I was born in 1986 as the first child of Jennifer and Kizito. I went to Bat Valley Primary School and later to a High School where I completed O and A level. Already then I fell sick frequently. In 1995 my parents divorced and my mother went to her parents. I grew up looking after my siblings while different women stayed with my father.

In 1999 my father fell sick and became bed ridden in January 2000. My mother then took me to a boarding school and went back to look after him. Two weeks after she went back he died. I remember my father as a very quiet person but who would suddenly beat his wife and us, the children. Until his death he did not accept that he was positive. He always thought it was typhus. He died at the age of 33 years.



After that my mother took up the responsibility to look after us. Their relatives abandoned us and my mother had to sell most of our household things to buy food and to cover the school fees. I was sick on and off as far as I can remember. One day my aunt took me to VCT. But aunt and mother did not tell me the result. I got thinner and thinner until I almost died in June 2006. I was rushed to the hospital, a blood test was done and there they told me that I was HIV positive. First I was shocked but then I started with the RAT in March 2007.



A friend told me about Kawempe Home Care Initiative. I went there and started to work as one of the first volunteers there in August 2007. I am not staying with my mother because there are not enough facilities and not enough space in the half finished house.

Instead I am staying with my aunts in a different suburb, Wandegeya. But I am not really happy there because my aunts stigmatise me. Stigmatisation is a big issue. My mother does not experience this because I am there to talk to her once she feels down. I give her a lot of psychological support. These skills I learned through Kawempe Home Care Initiative. Myself I am suffering because the aunts do not really socialize with me. I am cooking for myself and I am supposed to use my own cutlery and cups. I often feel lonely because they stigmatise me.



My wish for the future is to become a counsellor for people with HIV/Aids, especially for adolescents. It is a good experience for me to work in the Kawempe Home Care Initiative and I really enjoy being one of the 'Angels' going out into the community and informing the people about the opportunities Kawempe Home Care is offering for their families. I would like to

give more psychosocial support to children in the community who are stigmatised like I have experienced it. I would love to start a course at Makerere University for Guidance and Counselling but at there moment I am lacking the money for the fees.



Summary – Kawempe Homecare makes a difference

The cases show extend and influx of HIV/Aids infection on families' lifestyle in urban areas of Kampala. KHC tries to ease the devastating influx sickness can have on individuals, families and the community.



KHC offers voluntary counselling and testing and tested last year 505 members of the community of whom 39% were HIV/Aids positive. The centre offers medical consultations in form of home visits, clinic visits and hospital visits.

Three counsellors do the pre and post HIV counselling, ongoing counselling, positive living, disclosure counselling and bereavement support. They test patients

also at home and encourage clients to bring along their spouses and children for testing. Mohammed's 8 children e.g. all went to testing and were found negative what gives the family hope.

Community ART and TB Treatment Supporters, in short CATTs, are trained in drug adherence support and monitoring, home based care, nutrition and hygiene. The CATTs go out into the community and identify sick people suffering in their homes, suggest testing and enrol them if eligible. Sarah was profiting from the persistent effort of the volunteer who found her suffering, weak all on her own in her small room.

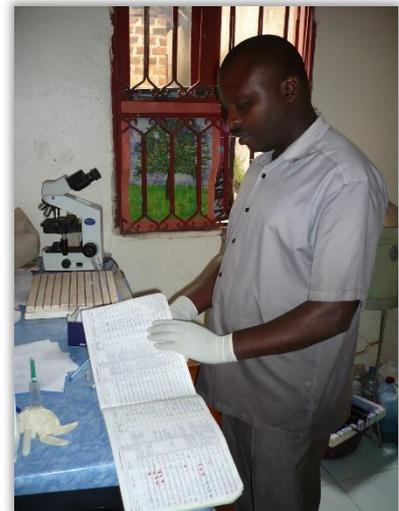


The patients are in different clinical stages. Mohammed and Sarah's condition had worsened to stage 3, what means bed ridden with opportunistic infections. In that stage the most important service Kawempe Home Care Initiative is offering is the home based care. Two days of the week are scheduled for routine home visits and emergency visits on a daily basis as the need arises.



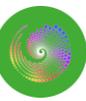
The team of clinicians comprises of 1 doctor, 1 clinical officer, 3 nurses and 1 laboratory technician. Mohammed was visited daily for a long and difficult period of time. Part of the medical service is also palliative care to all the clients with pain and distressing symptoms, especially cancer clients.

A laboratory at KHC conducts basic laboratory tests including Malaria and Tuberculosis testing. All clients are tested for TB since it is assumed that 50% or more clients with Tuberculosis have HIV. Jennifer was counselled and first her TB is treated before she starts with ART. Voluntary testing is offered also to pregnant women for the Prevention of Mother to Child Transmission (PMTCT). Should Christine become pregnant again she has a good chance not to transmit HIV to her newborn.



With the KHC approach the multidisciplinary team comprising of clinicians, counsellors and community care givers is able to take the whole lifestyle and living conditions of the patients and the relatives into consideration. Besides the drug adherence support, for ARV, TB therapy and nursing care the community volunteers provide also a great deal of social support. A youth network the 'Angels' embark on door to door sensitisation. Like Nuru, herself positive, who is one of them, it gives them at the same time strong support through the activity of helping others in a similar situation.

KHC also identify children who are not able to go to school because of the socio-economic situation in the family caused by the sickness. If they pass the Kawempe Home Care Initiative criteria their school fees are covered by the project. One of Christine's and Jennifer's children are now able to continue with their schooling. With the increase of funding KHC would like to extend this service in future. Social support service is also given in form of nutrition support, grants and micro finance loans and the promotion of income generating projects.



Nearly 84,6% of KHC expenditures have been spent on operational costs covering the active support of Mohammed, Sarah, Christine and her husband, Jennifer, Nuru and many more in the community through medical and social support.



Kawempe Home Care (KHC) Initiative was founded by a group of devoted health professionals and as the first months of their existence shows they can make a difference with the help of this holistic approach.

Moved by Love





Impressum
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