

Fighting Stigma in the Battle Against HIV

By Mecstar Chisi

For some people living with HIV in Malawi, access to quality healthcare services is a big challenge especially in the rural areas. Stigma and discrimination remains an obstacle in the fight against HIV in the country.

For a long time Marriam Kibu, 48, of Katsakaminga village in Dedza district who has been living with HIV, never thought of living again. The torture she experienced in her community was just beyond her imagination. The behavior and the negative attitude towards her prevented Marriam from accessing drugs in the community.

"I have suffered a lot. Not because I did not accept my situation, but the stigma was just too much for me to bear in the community. So, I chose to stay in doors for a long time," she said.

Following the ordeal Marriam then joined Umodzi support group. This was after she was approached by some concerned people who advised her to join the group for counselling, psycho-social and peer support.

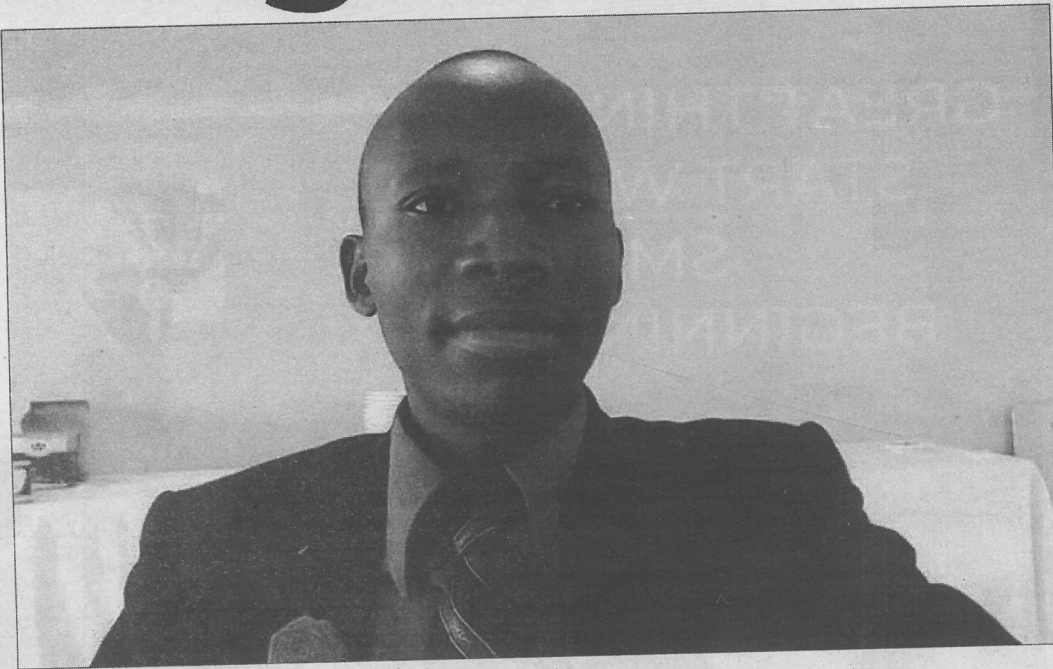
"Some friends living with HIV visited me after observing that my health was deteriorating. They advised me about the importance of associating with peers at the support group. It was very difficult for me to follow the idea, but long at last I settled for it, and since then my life has changed completely," she lamented.

However, our needs were not completely met until the support group was introduced to the Citizen Science Community Led Monitoring and Advocacy (CS-CLMA) project, locally known as "Kalondolondo wa Nzika" being implemented in Kasungu and Dedza districts, by the Malawi Network of Religious Leaders Living with or Personally Affected by HIV and AIDS-MANERELA in partnership with the Network of Journalists Living with HIV (JONEHA). The project is funded by Bill and Melinda Gates foundation through International Treatment Preparedness Coalition (ITPC)

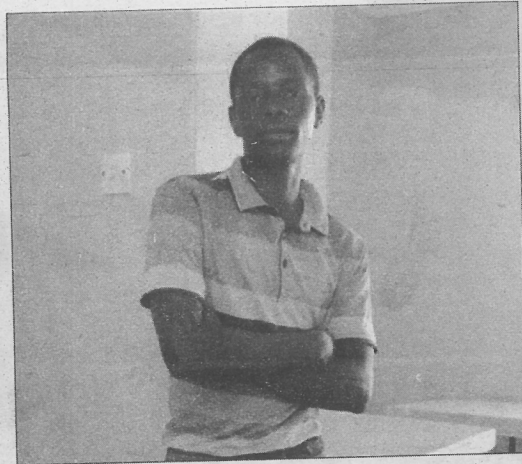
What is CS-CLMA?

CS-CLMA which started in Malawi in November, 2020 is an initiative adopted from the International Treatment Preparedness Coalition (ITPC) model that moves from models of "data extraction" to "data democracy" by combining community led interventions including Community Led Monitoring (CLM), implementation Science and a novel methodology called "Life mapping". Citizen Science acknowledges that people are experts in their own lives. It pivots away from the notion that academic research and analysis is the only legitimate knowledge creation method. The name signals democratization of data collection and analysis, empowering participants and respecting their expertise.

Community Led Monitoring is a process where communities take lead to routinely monitor



Clement Phiri



Chifuniro Misomali



Mirriam Kibu

an issue that matters to them by identifying their top priorities, creating indicators to routinely track those priorities, collecting data, analyzing result and sharing the insights with wider groups of stakeholders. CS-CLMA systematically collects and analyses qualitative and quantitative data. The data is used for monitoring trends along the HIV Cascade and to inform targeted action, that will improve the quality of HIV services. The data is collected by an organized group of community members on various aspects of HIV prevention, Testing, Care and Treatment services. The main project purpose is to identify entry points to improve quality and increase access of people living with HIV to ART treatment, care and support services in Malawi amidst the Covid-19 Pandemic. CS-CLMA is guided by principles of education, evidence, advocacy and engagement.

How has the project benefitted people living with HIV in Dedza district?

Marriam happens to be one of the beneficiaries of the project

after joining Umodzi support group. She explains how the CS-CLMA project has changed her life and other people living with HIV in her community.

"I can proudly say that the coming in of the project has changed our lives. Firstly, we accepted that living with HIV is not the end of our lives. Through the project we have learnt that as citizens we have the role to monitor the quality of HIV prevention and treatment services. We are able to contribute towards addressing the challenges that we face in hospitals when accessing services. So, we no longer experience frequent sicknesses as before. This is because we know the importance of adhering to Antiretroviral drugs (ARVs). I can share with you that we feel healthier and stronger than some of the people who don't know their HIV status, know their HIV status but are not on treatment or are on treatment but don't know their viral load," she enthused.

Another beneficiary Chifuniro Misomali, 22, from Katama village, Traditional Authority Kachere in the same district,

said the project has been an eye opener not just to people living with HIV but everyone in their community.

"At first people living with HIV did not know what to do when faced with various challenges regarding their positive status but through the program we have managed to reduce issues of stigma and discrimination. The majority of community members now have a deeper understanding that people living with HIV can also contribute positively to the socio-economic development of the country," he said. Alice Madambo, a beneficiary from Traditional Authority Kachere, Mthandidzi village in Dedza said MANERELLA+ in partnership with JONEHA have trained them on how to collect data from the community.

"At first, we did not know that we have to participate in all activities that are relevant to our quality service delivery at the facility. So, we demand that drugs are made available all the time especially the ARVs and Bactrim. This is a role that we have been practicing from the onset of the project. Thus; we

are very optimistic that through this kind of project the country should be able to end AIDS by 2030," said Madambo.

How has the Journey been since 2020?

Clement Phiri who is data supervisor for MANERELLA+ under the CS-CLMA project in Dedza district said the project has helped to increase the number of recipients of care including those going for HIV testing.

"The project has been very impactful. When COVID-19 was at peak, there were some restrictions at the hospital and people living with HIV were also affected. But through advocacy, engagements and trainings under the project things have changed. People can go anytime at the facility to access HIV Testing Services (HTS). It has also helped to reduce stigma and discrimination against people living with HIV," he said.

Phiri indicated that the project has also helped people living with HIV to realize their rights, potential and how they can address the challenges they face in society.

"Recipients of care have benefitted a lot from the CS-CLMA project as it has improved their well-being considering that they are now living a happy life unlike in the past. It has also reduced stigma and discrimination in the community including faith settings. We are striving to completely eliminate HIV related stigma and discrimination," he retorted.

The CS-CLMA project also targets vulnerable groups like key populations and women most affected by stigma and discrimination. HIV-related stigma has been defined by UNAIDS as negative beliefs, feelings and attitudes towards people living with HIV, groups associated with people living with HIV (e.g. families of people living with HIV), and other key populations at higher risk of HIV infection, such as people who inject drugs, sex workers, men who have sex with men, and transgender people. According to "Getting to the Heart of Stigma and Discrimination in Malawi"; a study conducted by Prime Health Consulting and Services in conjunction with the International AIDS Society between 2021 and 2022; though having declined over time by between 2-10% across variables between 2012 and 2016; stigma in Malawi still remains a major challenge among communities. Findings from this study have demonstrated that internalized HIV stigma in Malawi is pervasive and intersects with other forms of stigma to affect the quality of life and health outcomes for people living with HIV.