Talking points – community models of care

Main messages:

- *Patients demand community models of care that remove the obstacles they are facing to access ARVs. It often costs a lot of time, effort and money in resource-poor countries to collect drugs. It discourages many to keep taking their life-long treatment.*
- *Community models of care are an efficient way to manage growing cohorts of HIV+ patients in ways adapted to the realities of the places where the pandemic strikes hardest.*
- *Community models of care are a key tool to allow scale up for HIV care. They relieve already overwhelmed health systems in high burden countries, therefore making it possible to not only initiate more people on treatment but also to keep more and more patients on an effective treatment*

What is patient-centered care?

It is an approach that puts the patient at the heart of the health system, instead of asking the patient to jump through hoops in order to access and retain in health care. Concretely, it means that patients realities and constraints are taken into account, and the health care is adapted to those realities.

Flexibility of the health system is a key factor that allow a patient-centered approach to care. It is especially important in the fight against HIV as the large majority of people live in resource-poor countries (only 6.5% of HIV+ people are in the developed world; 71% of the total live in sub-Saharan Africa). Most of those countries have weak health systems that cannot manage millions of chronic patients.

Examples illustrating patient-centered approach:

- Adapting opening hours of clinics to the schedule of the patients. MSF does it in several adapted models, such as night clinics to reach commercial sex workers; early morning hours to allow people who work to access care...
- Letting people have a three or six month supply of their daily ARV drugs instead of the usual one-month supply. This lessen the burden in term of time and money to go to the clinic and get their drugs (but pharmacy regulations often prevent this simple measure to be implemented)
- Getting where people in need are: for example MSF in KwaZulu Natal province of South Africa organizes door-to-door HIV testing.
- Listening to what challenges the patient faces in clinical consultation or counselling sessions and work out realistic solutions together

What are community models of care?

They are a model of care that illustrate the patient-centered approach, by addressing the barriers that stable patients on ART face to receive their life long treatment. It is a pragmatic response to how to deal with a growing cohort of stable patients on ART by adapting the health systems so that patients are in charge of their treatment and allowed to organize themselves in innovative ways so as to better access drugs.

Community models of care were first piloted with stable patients on ART who do not need intensive medical care. It is therefore a de-medicalization of HIV care in order to facilitate access to treatment for patients and lighten the burden that HIV is posing to already weak African health systems.

In community models of care, communities and their members are involved in the health systems decisions; community members help each other to follow their treatment. For the patient, it is a way to find strength in a group of people who share a common burden.

Community models of care cover a continuum of models. They bring treatment closer to patient's homes putting ART delivery at community-level and allow patients to play a bigger part in their treatment.

These models have one overarching principle: they separate appointments to see a doctor or nurse for a check up (which is only necessary once a year for patients whose HIV treatment is monitored by viral load count and works optimally), from the pickup of one's supply of daily antiretroviral drugs (which, depending on the context, can be as often as once every month). The delivery of drugs is organized at community level through the support of peer groups.

WHY do we need community models of care in the fight against HIV?

To have a shot at ending HIV we need to not only initiate more people on ARV, but also to keep them on ARV for the rest of their lives because it's only when people are taking the daily treatment without interruption that they stop being infectious and therefore don't transmit the virus anymore.

Stable people on ART do not need intensive medical care. Today's HIV patients who are on ARVs and adhering well to their treatment are healthy and, just like people suffering from diabetes, they want to live a regular life without having to come often to overcrowded hospitals and queue for hours just to pick up their drugs. It's also in the community that people living with HIV can find support to deal with the daily issues of taking drugs and living with a chronic illness, and not only in health facilities.

But the reality of the HIV pandemic is that the largest public health effort that humanity has ever undertaken to manage a chronic disease is fought primarily in poor countries whose health systems cannot cope with a continuous flow of patients necessitating a life-long follow up and treatment. There are huge needs, and few resources. As African health systems are already overburdened, we need to experiment with other ways to deliver adapted services to growing throngs of HIV patients. The solution is in the hands of the patients themselves.

Community models of care address both sides of the problem of treatment scale-up. From a patient's perspective, it's a matter of adapting the health services to the needs of chronic patients; and from a

health system perspective it frees up the scarce human resources to initiate more people on treatment, and make sure that people already stable on ARV don't add on to the burden faced by weak health systems.

How does it work?

In general: a continuum of flexible solutions adapted to specific context.

There is no one-size fits all: to make the most of very limited resources while responding to huge and growing needs it is imperative to adapt models to specific needs of patients and capacity of health systems. MSF has piloted several models, from more health facility-driven approaches to more patient-led approaches. Several approaches can even co-exist in one setting to fit the needs of different populations.

Appointment spacing and fast-track drug refill

A first, health-service driven strategy called appointment spacing and fast track drug refill was implemented in rural Chiradzulu in Malawi.

Patients individually attend 3-monthly for drug refill at the health facility where they get the drugs dispensed directly from a lay worker, meaning they no longer need to pass by the nurse. The drug refill can be stretched so as to provide 6 months worth of drug so as to relieve the burden and expense of regular travel for the patient.

Patients only attend 6 monthly for a clinical consultation and yearly for viral load.

Adherence clubs

This model called adherence clubs was piloted in the urban township of Khayelitsha in South Africa. In this approach, patients, led by a lay worker, gather once every two months as a group in the health facility or at a community venue (library for example) for ART distribution. The group allows for peer support and health education among its members. Patients attend once a year the health facility for a clinical consultation and viral load.

The model is being further expanded within the community by the organization of adherence clubs located in a patient's home instead of a health center.

This model is well adapted to urban environments where especially time spent at the clinic is an issue for patients.

For more information, see the specific talking points on adherence clubs.

Community ART distribution points (PODI)

Moving further along the continuum towards more patient driven strategies, we come across the community ART distribution points, also called PODI in French ("Points de distribution communautaires").

Patient individually come once every three months to a community distribution point managed by a network of people living with HIV. Lay workers of this network dispense ART to the patients. Patients attend once a year the health facility for a clinical consultation and CD4 monitoring to check how well their treatment is working.

This strategy was launched in urban Kinshasa, in DR Congo, in a context of very low ART coverage with only few health facilities offering ART, and high stigma.

Community ART Groups (CAGs)

A last model is the community ART groups (CAGs) that were piloted in rural Tete, Mozambique. In this model patients form groups in the community and the group members rotate to attend the health facility to pick up ART for the whole group. When the group member on duty returns from the clinic, he dispenses drugs to the other members in a patient's home. While a group member picks up drugs for the group at the clinic, he also gets his 6 monthly or yearly clinical consultation and blood drawing for CD4 or viral load.

This model is especially well adapted to rural environments with long distance to clinics and a tight sense of community.

WHERE are these models implemented?

The reflection started in 2007, led by MSF and several ministries of health. A continuum of strategies was developed, ranging from health service driven to more patient driven approaches. These approaches were piloted in DR Congo, South Africa, Malawi and Mozambique, but have in the meantime been adapted to other settings and by others than MSF.

Numbers as of December 2013.

In Mozambique

CAGs in rural Tete and in the capital of Maputo.

Mozambique has adopted the CAGs as national policy in and is implementing it independently from MSF.

In South Africa

Adherence clubs in Khayelitsha; CAGs and adherence clubs in KwaZulu Natal province.

Adherence clubs have been rolled out independently from MSF in the whole Western Cape province, and started to be implemented – also independently from MSF – in the Gauteng and Free State provinces.

In Lesotho

CAGs launched in 2014. MoH in Lesotho is willing to roll out the CAG model nationally.

In Zimbabwe

CAGs in Gutu and Tsholotsho.

In Malawi

CAGs in Thyolo.

In the DRC

In Kinshasa MSF has opened three PODI (distribution posts) throughout the city, enabling 2500 HIV patients to access ARVs in their community. The PODI were purposefully set up independently from public health centers, where patients are often made to pay for consultations, tests and drugs. PODIs also have retention rates of 91% after two years, and preliminary research evaluates its cost at $8 per patient per year against $27 in a public health center. In DRC, MSF is currently looking at adapting the PODI model so as to further reduce its cost and enable PODIs to be supplied by Global Fund drugs.

The situation of HIV patients in the DRC is catastrophic: less than 20% of HIV-infected people are on ARV, drug stock outs are frequent, and as a consequence treatment outcome is poor. In the MSF HIV reference hospital of Kabinda, or CHK, mortality is as high as 25%. Close to half the people who die there do so within two days of arriving in the clinic. There we see scenes we haven't seen since the height of the pandemic in the 1990's, before the arrival of ARVs. The results in retention in care achieved in the PODI are therefore all the more striking in this context.

By end 2014 there were about 2500 patients in PODI in Kinshasa.

In Guinea

CAGs piloted since 2013. Context comparable with the DRC.

WHY should we use them

Better retention in care

A 2010 study in 17 countries showed that a third of patients on ARV treatment dropped out of care within two to three years.

Patients in community models of care retain better in care than their peers who chose to stay in conventional care. In Khayelitsha for example 97% of patients in adherence clubs were still remained in care after 40 months, compare to 85% of their peers. MSF's experience shows that among stable patients on ART , over 90% of patients in the Tete province of Mozambique were still in care after four years in CAGs, 91% of members of PODI in the DRC (after two years).

Advantage for the patients: cost and time

Patients go less often to the health centers, thus lowering their travel time and cost associated.

Concrete examples:

- When she was pregnant, Mamotsileli from Lesotho had to walk for 3 hours every month through mountains to pick up her drugs. Now she gets her drugs through a CAG, whereby she takes turn to pick up her drugs with other HIV+ patients from her village. She now only walks twice a year to the facility to pick up her drugs. In Guinea, half of the patients enrolled in MSF supported health centers come from outside of Conakry, some traveling up to two full days to come to the capital to pick up their drugs. By forming a CAG they can reduce the travel time and cost enormously

- In Gutu district, Zimbabwe, a sparsely populated rural area in a country where one in 7 adults is HIV positive, most live 10 to 20 km from the nearest clinics, and some as far as 46 kilometers away. Is it really feasible to stay on treatment in these conditions?

- Quote from a CAG member, Tete: *The advantage of being in a CAG is that you can do other small jobs when you know that a group member will collect ART for you. This makes things easier*

An analysis in DRC with the Community ART distribution points also show that patients spend 3 times less money to get their drugs at the PODI than if they would have continued to get their drugs at the hospital. Patients were spending an average of 14 minutes to pick up their drugs at PODI against 85 minutes at the hospital. They also have to pay in average three times less for travel to come to the PODI than to come to the hospital.

Advantages for patients: increased peer support; empowered individuals

Qualitative studies show that community models of care, especially CAG model, increases peer support, lower perceived stigma by its members and may contribute to empowering individuals (cf story on Zimbabwe).

Another example:

- Cacilda, in a CAG in Maputo: “with the CAG, there is no problem. We meet in public to share our drugs. So what? We are not hiding!”

- CAG member, Tete: “*belonging to a group strengthens people. Moreover, being united people become mentally stronger during treatment compared to those who do it individually.”*

Advantages for the health systems: reduction of work load

A spacing of appointments as well as the use of lay workers to dispense drugs allow already overworked nurses to not waste time to distribute drugs. Instead, they can dedicate their time to those who are actually sick and need their level of skills.

With the CAG there is a 59% reduction in ART refill visits and a 43% reduction in overall clinic visits (data from 2013), which means a big reduction in health staff’s workload.

“Color” examples:

- Head nurse in a clinic in Buhera, Zimbabwe, telling me that she works till midnight to finish paperwork, waking up on her table at home with papers scattered around. She’s alone in her

rural health center where she does everything, from the woman giving birth to the child sick with malaria. Should she be burdened with dispensing drugs ? Can't her time be better used?

- Kingston Fry, 25 years old, ones of the recipients of an MSF scholarship program who trains health workers says: "When I was 15 years, my sister fell sick and we took her to Thekerani hospital, the queue was so long and there was only one clinician. We arrived at 7am and my sister died right there in the queue at 2:00pm, it was very difficult to understand. The death of my sister was due to the shortage of health care workers and I decided to become one." (context: in Malawi, two thirds of job openings in the health sector are unfulfilled because of a lack of trained doctors, nurses, lab technicians, midwives etc).

Advantages for the health systems: cheaper

Preliminary finding of a study in Khayelitsha showed that the cost per patient in conventional care was $109; versus $58 in an adherence club. Further research is being analyzed and made ready for publication.

Under which conditions can it work

A solid drug supply

This is a key enabler: if the drugs are not ready to be picked up by patients the systems cannot work. However stock outs are systemic throughout Southern Africa. MSF is currently monitoring the situation region wide and it is worrying. We are in the process of gathering and analyzing data to identify the extent of the problem and its main bottlenecks. But it is definitely a key area where efforts need to be made.

All countries where MSF works in the SADC region as well as the DRC, experience regularly too short supplies on some drugs. It is a systematic problem that cannot be fixed easily. When we experience stock outs in the clinics where we work MSF tries its best to support the health structures by providing the patients with the drugs they need. But it is clear that a systemic solution is needed involving local, national and international actors.

Investment on lay cadres

Community supported models of care rely strongly on human resources to facilitate them. Those needs can be fulfilled by well trained, supervised and remunerated lay cadres. These cadres are less qualified than fully licensed health professionals and therefore cheaper for the health system. They do fulfill a key role so, in the long term, recognizing them, training them and paying is necessary to maintain these models. An additional benefit is that those lay cadres can be recruited directly from within the community and are therefore more attuned to patients' needs.

But this remains a regrettable obstacle to a general roll out of the very efficient community models of care. Because of restrictions imposed by international donor organizations countries are reticent to, sometimes prevented from, increasing their wage bill for health and lay cadres often remain in a grey zone. MSF calls for a relaxation of those rules for resource-poor countries most affected by HIV-Aids.

Access to quality clinical management is needed with clear referral mechanism to ensure a minimum follow-up of patients.

Monitoring and evaluation are essential parts of any community supported model to ensure accountability as well as a troubleshooting capacity when confronted with patient or groups' problems.

All of these above enablers need to be well defined in a national policy to ensure the models' roll out on a larger scale. Community models of care are being progressively adopted throughout sub-Saharan Africa: adherence clubs are now officially endorsed by the South African government, as well as CAGs in Mozambique. Funding is however needed to support start up roll out of these models and ensure kick-off support, as well as financing for community based organizations who can bring these models to a higher level, by including these networks for advocacy purposes, link to income generating projects etc. For these models of care to be adopted by countries, financing needs to be secured for example by countries including them in the demands expressed to the Global Fund.

RESSOURCES

Most resources are centralized in the SAMU website: msf.org/blog/portfolio-item/cmc/

Photos:

On the database:

- Folder MSFSTO503, CAGs Mozambique
- Folder MSFSTO553, CAGs Malawi
- On adherence clubs, photos by Samantha Reinders, July 2012, ref. MSF124615 to 62
- From Zimbabwe, portraits (to go with patient's story): MSB10691 and 92

Videos:

- CAG in Malawi: https://www.youtube.com/watch?v=8DsIM_IniWU
- How do CAG work in Mozambique: https://www.youtube.com/watch?v=IIlcHanDXzI
- "Join the club" (adherence clubs) on MSF SA website: http://www.msf.org.za/msf-publications/how-to-keep-art-patients-long-term-care-art-adherence-club-report-and-toolkit

Publications:

Reports Closer to Home and PODI (in French), adherence clubs and CAG toolkits on SAMU website: http://samumsf.org/blog/portfolio-item/cmc/

Scientific publications:

Centralized on SAMU website: http://samumsf.org/blog/portfolio-item/cmc/

For adherence clubs:

- Southern Africa journal of HIV medicine: http://www.sajhivmed.org.za/index.php/sajhivmed/article/view/924/821
- PLOS One: http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0056088
- NCBI: Community-supported models of care for people on HIV treatment in sub-Saharan Africa:
- http://www.ncbi.nlm.nih.gov/pubmed/24889337

Patient stories already shared:

- "not alone anymore", Mozambique: http://www.msf.org.za/msf-publications/mozambique-not-alone-anymore
- "divided we fall", Zimbabwe: http://www.msf.org/article/zimbabwe-divided-we-fall