



Evaluation of counselling - part of the MSF OCB Project “Distribution of Antiretroviral Therapy through Self- forming Groups of People Living with HIV-AIDS” Tete, Mozambique.

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This publication was produced at the request of Médecins sans Frontières. It was prepared independently by *Miranda Brouwer of PHTB Consult*.

DISCLAIMER

The author’s views expressed in this publication do not necessarily reflect the views of **Médecins sans Frontières** or the **Stockholm Evaluation Unit**.

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ACRONYMS

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| ART | Antiretroviral Therapy |
| ARV | Antiretroviral medicines |
| CAG | Community ART Group |
| EAC | Enhanced Adherence Counselling |
| HIV | Human Immunodeficiency Virus |
| IPT | Isoniazid Preventive Therapy |
| MAC | Monitoring of Adherence in the Community |
| MoH | Ministry of Health |
| MSF | Médécins sans Frontières |
| MSM | Men having sex with men |
| PLHIV | People Living with HIV |
| TB | Tuberculosis |
| VL | Viral Load |

EXECUTIVE SUMMARY

The project ‘Distribution of Antiretroviral Therapy through Self-forming Groups of People Living with HIV-AIDS’ Tete, Mozambique’ is a continuation of MSF’s interventions in the provision of HIV care and prevention services that started as early as 2003 in Tete. Over the years interventions moved from the provincial capital Tete towards other districts and now concentrates in Changara district. The focus of the Changara project initially was to introduce community testing, and accreditation of 12 health facilities in the district for ART provision. However, after the introduction of routine VL testing for patients on ART for 6 months or more, the focus shifted more towards the counselling. The finding that a substantial proportion of the patients had a high VL of more than 3,000 copies/ml (the criteria at the time) raised questions on the **efficacy of the counselling services** and contributed to initiating this evaluation.

In addition to evaluating the counselling services, MSF has conducted a **major advocacy campaign** addressing the need for counselling in HIV care, including the potential engagement of lay counsellors. The evaluation of the Tete counsellor provides input for further discussions in Mozambique on the topic. The evaluation addresses the following specific questions:

- Where the counselling activities carried out as planned, and if not what caused deviation from the plans? What challenges were encountered and how were these overcome?
- Have the counselling activities affected the approach to people not enrolled in a CAG: do they receive counselling, by whom and how?
- How does counselling contribute to adequate action taken by patients in case of forgotten medication, threatening to run out of medication?
- Do patients with high VL have common characteristics, which could explain (partially) the high VL?
- What is the perspective of the patients with high viral load? How do patients perceive adherence? How do they perceive high VL?
- How do the CAGs contribute to adherence for patients initiating treatment and at the detection of high VL?
- What activities take place? How do the counsellors address the patients’ concerns and barriers? What support do the patients receive outside the formal counselling sessions?
- What limitations and opportunities does the counselling approach pose?
- How can the counselling approach contribute to achieve lower VL in target population?

The methodology used for the evaluation was mainly qualitative in nature to understand better how counselling contributes to patient care. The evaluator used interviews and group discussions the most appropriate method. Key stakeholders for interviewing and group discussions included the patients, the counsellors and their supervisors, health care workers at the health facilities, health authorities at district and provincial level, partners and MSF field staff. In addition, the evaluator observed counselling activities in practice. The evaluator had interviews with patients with the following criteria: (former) CAG members, Non CAG members, patients with high and with undetectable VL, and patients on Monitoring Adherence in the Community (MAC). The evaluator had an interactive meeting with all but three of the counsellors and their supervisors to receive as much input from the counsellors as possible. Analysis consisted of identifying common themes in the interviews, discussions and observed activities. The evaluator crosschecked findings in the next interview or discussion. Further analysis came from the document reviewed, mainly the quarterly reports and the results frameworks. The debriefing meetings in Tete and Maputo provided further insights and initial feedback from the field team. The draft report was shared with relevant MSF staff and the evaluator reviewed feedback from these staff members and prepared the final version of the report.

The main limitations of the evaluation were the **limited time** in the field, the need for **translation** for patients not speaking Portuguese, and **selection** of the patients by the counsellors. Not only did the evaluator spend limited time in the field, there were few opportunities to observe counselling sessions due to much reduced attendance of patients due to heavy rains and people working in their fields. The evaluator mitigated the effect of this limitation through prioritising contact with patients (interviews or observing activities). Selection bias of patients: the counsellors invited patients for interviewing. This may have resulted in selected patients that would answer ‘correctly’, or were maybe briefed on ‘correct’ answers. Patients may have given answers that they thought the evaluator wanted to hear.

Mitigation of this limitation was through crosschecking patients' contributions with other patients, the counsellors and the other interviewees as much as possible. The counsellors' supervisors acted as translators when people did not speak sufficient Portuguese. This may also have resulted in wanted or desirable translations. It may be difficult to translate certain concepts from the local language into Portuguese even if correctly translated.

The evaluator interviewed 23 **patients** in three locations. Findings from these interviews were that the counsellor is an important person for the patient. The counsellor provides support in an understandable way and has more time to do so compared to clinicians. This support is important to adhere to treatment. The counsellors explain the disease and how treatment works and what CD4 cells are and the relevance of VL. Emphasis in the treatment initiation sessions is on this explanation and on the importance of taking medication every day for life. Counsellors do not seem to verify if patients have means to know the time, to take their medication at the same time everyday.

Participation in CAGs has several **advantages** such as allowing patients more time for themselves, they receive support from other members and if they don't feel well enough to attend the health facility they will still get their supply of medication. The support they receive from each other seems limited to discuss how to stay adherent and help in case of illness. Groups seem to turn to their counsellor easily when in need for help. Some patients do **not want to participate** because they do not always trust other members to keep their HIV-status confidential; they prefer to maintain the responsibility for collecting their ARVs on time themselves; and work or travel may require an individual approach.

Patients know what to do when they forgot to take their medication, perceive taking the medication correctly as 'life returns to normal', and look upon a high VL as a lot of virus in the body. This is mostly linked to not taking medication correctly. However, not all patients were aware of what VL means, especially those that had a low or undetectable VL. The counsellor had said it was good.

The **counsellors** do their work with much enthusiasm and know their tasks well. They have a set of tools available to support their work such as plasticized flipcharts to explain what HIV does in the body. They report their activities on a monthly basis to the supervisor who aggregate the reports and send it to the patient support manager (position vacant at time of visit). In counselling sessions after identification of a high VL they emphasise more the timing of the medication than in earlier sessions. **Challenges the counsellors encounter related to patient care** are finding the patient at home during community visits, a sudden decision of the patient to discontinue the treatment, not being welcome for community visits for confidentiality reasons, and attitude of the clinicians after a loss-to-follow-up patient returns to care. **Organisational challenges** include unavailability of transport, space for their counselling work (specific for Matambo), communication with the supervisor using private airtime, a high turn over of expatriate staff, and a frequent change in the project.

The supervisors provide excellent support to the counsellors. They did receive an orientation on their supervising role but no formal training. They have limited computer skills.

Other **stakeholders** are all positive of the work of the counsellors. Health care workers and provincial authorities appreciate that the counsellors reduce the time they need to spend with patients and their community work. Some further analysis of the data and support in districts where MSF does not operate with counsellors are some of the challenges.

No common **characteristics of patients with high VL** were identified. Years on ART, ever participation in a CAG and location seem not important. Because the number with high VL is yet relatively small, further and continued analysis may reveal characteristics of patients with high VL.

MSF uses a results framework for **monitoring** the counselling activities. However, the indicators used in 2014 and 2015 have little direct relationship with the counselling activities. Counsellors do not record much of their counselling sessions therefore limiting the follow-up.

In conclusion, the counsellors' work is important for the patients and for the health care workers. The counselling contributes to treatment adherence even though this is difficult to quantify. The patients, however, do seem to depend on the counsellors rather than being enabled to solve their own problems, either individually or as groups. The counsellors are also important in support for the CAGs though do support the groups in solving their problems independently only in a limited way.

The work of the counsellors initially focused on community testing more than the counselling. The counselling approach is mainly standardised rather than tailored to the needs of the individual patient. Counselling is the same for all patients whether they participate in CAGs or not. Due to the involvement of the counsellors in CAG meetings, the CAG participants have more contact with the counsellors and may benefit from this. However, the almost similar proportion of high VL in CAG and non-CAG patients do not support additional benefit from more frequent contact with counsellors.

Patients know what they need to do when they have forgotten their medication or when their stock at home is about to finish. Their perception of the high VL is linked to the adherence perception, with most patients thinking that a high VL is a consequence of not taking the medication correctly.

Furthermore, the counselling is psychosocial support that may not be the support that patients need most. To be able to address patient's need, the counsellors need to explore the patient's needs. They have tools for identifying the most common barriers that patients face and offer ways to overcome these. The counsellors have little possibility to support patients in a practical way with transport problems or food scarcity.

The relationship between counselling and a high VL remains unclear. It seems that the focus on the time of medication only emerges in the enhanced counselling sessions whereas it seems relevant to address this already the earlier – initial – counselling sessions. Treatment failure is not the results of counselling or a lack thereof only, many factors contribute to it. A more comprehensive approach to treatment failure will provide better understanding of the reasons for failure in Mozambique and if and how counselling can reduce treatment failure. There seem to be no common characteristics of patients with high VL that contribute to the explanation of the high proportion of patients with high VL.

The counselling approach provides a good opportunity to link well with patients, and usually close to their home. The counsellors are often from the same community as the patients and therefore understand well the living situation of the patient. Currently the counsellors have limitations in implementing a patient centred approach further due to their limited skills and possibilities to identify and address patients' needs and challenges. A further limitation exists in the basic conditions present within the MoH to implement the use of (lay) counsellors on a large scale. The position is not recognised within the MoH staff structure. Basic conditions to be met for a well functioning lay counsellor involvement in HIV care and treatment include recognition of the position by the MoH including an initial training programme, continuous mentoring and supervision, material support for the tools counsellors use, and support for the counsellors to do their work: transport and other means.

Practical on-the-job training has resulted in counselling that is important in HIV care. Not all counsellors have had much schooling, however, they are still doing their work satisfactorily. Therefore educational level only is not a good selection criterion.

The recommendations resulting from this evaluation are:

1. To continue to further develop the skills of the counsellors (including the supervisors) and to support their work;
2. To adopt a more comprehensive approach to potential treatment failure;
3. To continue to work on formal acceptance of the lay counsellor position.

Further **development of skills** for the counsellors include to enable to patients and CAGs to rely on themselves rather than the counsellor, assess quality of the counselling through exit interviews, increase VL testing for patients in individual care, and to invest in the supervisors. The use of supervisors is a good practice of this project. More direct indicators for monitoring the counselling activities will make the activities more visible and track better the counselling process.

For the more **comprehensive approach to potential treatment failure**, this report suggests a framework. In addition to taking into account the counselling, the project should look into health care provider factors, into medicines factors, and into patient factors. Assessment of primary resistance is part of this approach.

To increase access to counselling for all patients in HIV care in Mozambique, acceptance that not sufficiently trained social and psychology workers are available is important and that lay counsellors can satisfactorily fill this gap. MSF should continue to **advocate for acceptance of the lay counsellors** with the MoH.

PROJECT BACKGROUND

SETTING

Mozambique is a country in Southern Africa that soon after independence of Portugal in 1975 entered into a civil war, which ended in 1992 with the Peace Agreement.¹ The prolonged civil war resulted in damaged infrastructure, including health facilities. In recent years political tension between the two main parties – Frelimo, of which the majority of the Republic Assembly consists, and Renamo – has increased again. This also affects Tete province where the project takes place even though until publication of this report it did not affect project implementation.

Tete province is situated in northwestern Mozambique and has a population of about 2.3 million.² Zimbabwe, Zambia and Malawi border the province in the west, north and east and major transport routes from mainly Malawi and Zimbabwe to the port in Beira cross the province. The development of the mining industry since 2006 has brought increased economic activity to the province and attracted national and international workers. This includes truck drivers, sex workers and higher educated workers.² Especially the first two categories of workers are at high risk of acquiring an HIV-infection or transmitting it if they already have the infection.

The health profile of the province shows a high maternal mortality and only slow improvements in child mortality.³ Communicable diseases such as tuberculosis (TB) and other respiratory illnesses, malaria and diarrhoea are prevalent and the HIV epidemic has stabilised. Non-communicable diseases are on the increase. The last HIV population survey of Mozambique showed an HIV prevalence of 11.5% in the general population, and 7% in Tete province.⁴ Provincial data show a higher prevalence in Moatize and Tete city (> 15%) compared to the rest of the province. Access to health care facilities is difficult for the mainly rural population and this results in late presentation of ill people and huge challenges for people with chronic illness such as HIV that require frequent health centre visits.

DESCRIPTION OF PROJECT¹

Médécins sans Frontières (MSF) started providing HIV care and prevention services early this century in Tete province. Until 2005 MSF was the main partner implementing these services along side the Ministry of Health (MoH).^{2,5} It was mainly the city of Tete where treatment (Antiretroviral therapy, ART) services were available.

In 2006 MoH started decentralisation of the ART services to peripheral health services, starting with the district hospitals. From very early on, MSF included counsellors into the HIV and ART services. Though initially the focus was on pre-and post-test counselling, later on counsellors worked with patients in preparation for ART initiation. Patients on ART received adherence counselling. Counsellors also traced patients lost to follow-up in the community.

In 2008 MSF initiated in collaboration with the local health authorities and the patients a model known as community ART groups: CAGs.⁶ The groups consisted of up to six patients stable on their ART and formed themselves. Each member of the group took turns to visit the health facility for a consultation for their HIV-infection and for collection of the medication of all group members. As such the members needed to visit the hospital only once every six months (if six members in a group) instead of monthly, as was the dispensing schedule of ART at the time. The CAGs resulted from discussions with patients that identified the long distance to the facility and transport money as difficulties to adhere to their ART, and also to the overwhelming number of patients attending health facilities. The CAGs saved the patients money and time, and reduced the number of patients attending the health facility therefore reducing the burden on the health system. Patients could still visit the health facility for consultation between medication collection appointments if they wished or needed to. Retention in care was high at 12 months: 98%.

MoH recognised the role of some form of psychosocial support to HIV-infected patients and especially those on ART early on in the roll out of HIV and ART services. However, because of insufficient numbers of qualified personnel, many patients remained without or received limited counselling. MSF and several other partners recruited lay people from the communities where the patients came from. Initially, the recruitment criteria for counsellors were 12th grade and some knowledge of HIV. Later on the focus shifted to using peer educators, people with HIV-infection that experienced all the challenges of HIV-treatment themselves. Criteria for recruitment changed to 7th grade. The counsellors became an important cadre in the functioning of the CAGs. The functioning of the CAG consists of monthly meetings before the next medication collection is due, the collection itself and distribution of the medication through meetings or other means. At the pre-collection meetings members discuss their challenges and do pill count for other members. Counsellors often attend these meetings and assist with problems identified by the members. As such they have a

¹ In addition to listed references, this section includes information from interviews and observations.

coordinating role. In 2011 MSF launched the CAG project for 3 years. In six districts of Tete province clinicians encouraged the patients to form CAGS when they started ART.

The number of patients tested and diagnosed with an HIV-infection remained low however and therefore MSF initiated the Changara project. The project consisted of community testing in order to increase the number of people diagnosed; link the people identified with an HIV-infection to the health facility for HIV care; encourage all HIV-infected people to participate in groups (ART or pre-ART); and retain people in care that had not yet started ART because this group had the highest lost to follow-up rate. The role of counsellors is crucial in all parts of the project. In 2014 this project expanded with the provision of routine viral load (VL) testing, and with a change of ART eligibility criteria to CD4 cells below 500 instead of below 350 as before. MSF does not only support the counsellors in Changara, but also provides support to the laboratory in the form of point of care CD4 cell counters (PIMA) and collection of samples for VL testing done in Maputo. The pharmacies receive support in quantification of ART needs to prevent stock outs of antiretroviral medicines (ARVs). MSF clinicians work with the MoH clinicians in the district to improve clinical care.

The focus of the Changara project was two-fold in the beginning: community testing and accreditation of 12 health facilities in the district for ART provision. This resulted in limited attention for the other tasks of the counsellors. However, after the introduction of routine VL testing for patients on ART for 6 months or more, it became clear that a substantial proportion of the patients had a high VL of more than 3,000 copies/ml (the criteria at the time). With the renewed criteria of high VL of more than 1,000 copies/ml the proportion was obviously higher. The proportion of high VL was equal for patients receiving treatment through CAGs and patient receiving treatment individually. These findings raised questions on the efficacy of the counselling services and contributed to initiating this evaluation.

Logical framework

The logical framework monitors the progress (or lack of) of the project. For 2014 indicators linked most to the counsellors' activities were:

- Number of people tested at community level per quarter is > 1,000
- CD4 testing is available for >90% of those tested HIV+ in community during this quarter
- > 80% of pre-ART patients retained through a community based strategy
- >90% of people eligible, initiated ART
- Average time between detection of eligible CD4 and ART initiation for people tested at community level is less than 30 days

The 2015 framework retained most of these indicators though slightly rephrased or with new targets:

- Number of people tested at community level per quarter is > 2000
- CD4 result is available for >90% of those tested HIV+ in community within one month
- Number of pre - ART patients enrolled in a community-based strategy (no target listed)
- >90% of people tested at the community and eligible, initiate ART
- Average time between detection of eligible CD4 and ART initiation for people tested at community level is less than 30 days
- >50% of new HIV patients screened TB negative start Isoniazid Prophylactic Treatment (IPT) within 1 month

PURPOSE AND OBJECTIVES OF THE EVALUATION

MSF requested an evaluation of the counselling activities in the Changara for two reasons. The first relates to the major advocacy campaign that MSF has done recently addressing the need for counselling in HIV care, including the potential engagement of lay counsellors.⁷ A high level meeting on the subject resulted in the Johannesburg declaration in which representatives from eight Southern African countries' governments, civil society, from people living with HIV (PLHIV), and donors recommend the recognition of lay counsellors.⁸ In Mozambique the National Directorate of Medical

Servicesⁱⁱ of the MoH requested MSF to join forces with the Centers for Disease Control in Mozambique to develop a job profile for this cadre. Therefore lessons from the Changara project provide timely input for the DNAM request. The second reason is the high proportion of patients on ART with a high VL. This raised the question whether the counselling provided is adequate and related to this unexpected and undesirable outcome.

The evaluation addresses the following more specific evaluation questions:

- Where the counselling activities carried out as planned, and if not what caused deviation from the plans? What challenges were encountered and how were these overcome?
- Have the counselling activities affected the approach to people not enrolled in a CAG: do they receive counselling, by whom and how?
- How does counselling contribute to adequate action taken by patients in case of forgotten medication, threatening to run out of medication?
- Do patients with high VL have common characteristics, which could explain (partially) the high VL?
- What is the perspective of the patients with high viral load? How do patients perceive adherence? How do they perceive high VL?
- How do the CAGs contribute to adherence for patients initiating treatment and at the detection of high VL?
- What activities take place? How do the counsellors address the patients' concerns and barriers? What support do the patients receive outside the formal counselling sessions?
- What limitations and opportunities does the counselling approach pose?
- How can the counselling approach contribute to achieve lower VL in target population?

Although the focus of the evaluation is the role of the counsellors and especially in relation to detection of high VL, it is impossible to isolate the counsellors' work completely from the rest of the project. Thus this report will touch upon related issues as well.

ⁱⁱ Direção Nacional de Assistência Médica – DNAM

EVALUATION METHODS & LIMITATIONS

EVALUATION METHODS

The evaluation started with a preparatory period before the actual field visit. This period consisted of a review of documents including some articles published in peer reviewed scientific journals. Annex three provides an overview of the documents used in this report. In addition, the evaluator had Skype meetings with the project coordinator in Tete and MSF's medical coordinator in Maputo, and one with the head of the cell from the Brussels head quarters.

The evaluation was mainly qualitative in nature to understand better how counselling contributes to patient care. The evaluator therefore considered interviews and group discussions the most appropriate method. Key stakeholders for interviewing and group discussions included the patients, the counsellors and their supervisors, health care workers at the health facilities, health authorities at district and provincial level, partners and MSF field staff. The evaluator developed a questionnaire (included as annex 4, Portuguese) to guide the interviews and discussions. MSF field staff provided feedback to the questionnaire.

Not all patients had an adequate level of Portuguese in which case the counsellors or supervisors acted as translators. Though this was not ideal (see limitations), it was the most practical approach also maintaining patient confidentiality. The evaluator took notes during the interviews and discussions and recorded some electronically if the interviewees agreed with the recording. The purpose of recording was to be able to listen again to the interaction between evaluator and interviewees for better understanding. The recordings are only available to the evaluator who will destroy them when the final report is accepted.

The plan for selecting patients was to approach those who attended the clinics. However, the Tete medical coordinator had asked the counsellors to invite patients with certain criteria:

- CAG members
- Former CAG members
- Non CAG members
- With high VL
- With undetectable VL
- Patients on Monitoring Adherence in the Community (MAC), with their supporter if possible

Although this may have introduced selection bias, it turned out to work well because of the very low attendance at the clinics. Counsellors also approached people in the community for meeting with people in the community. Again, this may have resulted in selection bias, but it was the best option given the rains and many people working in their fields. In the end the evaluator managed to talk to a good number of patients.

In addition to interviews and discussions, the evaluator observed the counsellors and supervisors at work: group and individual counselling sessions at the health facility and interaction with patients in the community. The supervisors do their supervision on the job: the counsellor is counselling and the supervisor observes the session using a standard tool to note down their observations. The supervisor provided feedback directly after the session. The evaluator was able to observe a few of these interactions. In the community she observed one CAG meeting, and two MAC sessions. She also went with the team to find a patient who had not attended a consultation with a clinician since initiating ART nine months previously.

Because the actual time in the field was rather short and patient interviews took more time than anticipated, the evaluator decided to organise an interactive workshop with the counsellors and their supervisors to receive as much input from the counsellors as possible. Three counsellors could unfortunately not participate for lack of transport. The evaluator had prepared a presentation with questions that the counsellors answered in groups (two groups). The presentation also contained propositions, based on the themes identified in the interviews and discussions, to which the counsellors could react and which elicited lively discussions.

Analysis consisted of identifying common themes in the interviews, discussions and observed activities. The evaluator crosschecked findings in the next interview or discussion. Further analysis came from the document reviewed, mainly the quarterly reports and the results frameworks.

Finally, the two debriefing meetings (one in Tete, one in Maputo) contributed to fine tuning the understanding of the findings. This applied also to the recommendations. The evaluator prepared a PowerPoint presentation for the Tete debriefing and adapted it for the Maputo debriefing. The presentations summarised the findings, presented the conclusions and listed the recommendations. Discussions with the people present at the debriefings resulted in better understanding and improved formulation of the recommendations.

LIMITATIONS

Limited time in the field: The evaluator only spent 6.5 days in Tete due to a public holiday (3rd February) and the debriefing in Maputo. Because flight connections between Tete and Maputo are few, the evaluator had to leave Tete on Thursday 4th. Not only did the evaluator spend limited time in the field, there were few opportunities to observe counselling sessions due to much reduced attendance of patients. The reasons for reduced patient attendance were heavy rains and people working in their fields. The evaluator mitigated the effect of this limitation through prioritising contact with patients (interviews or observing activities). To obtain adequate and sufficient input from the counsellors, the evaluator held an interactive workshop with the counsellors.

Selection bias of patients and desirable answers of patients interviewed: The counsellors invited patients for interviewing pertaining to various categories: low and high VL, participating or not in CAGs, patients under community monitoring of adherence. This may have resulted in selected patients that would answer 'correctly', or were maybe briefed on 'correct' answers. In relation with this limitation, the patients may have given answers that they thought the evaluator wanted to hear, instead of contributing their thoughts and experiences. Mitigation of this limitation was through crosschecking patients' contributions with other patients, the counsellors and the other interviewees as much as possible. The evaluator achieved this to a certain extent because of the similarity of responses from the various interviewees. Theoretically a random sampling method for patients would have been a possibility however not considered practical in the limited available time.

The counsellors' supervisors acted as translators when people did not speak sufficient Portuguese. This may also have resulted in wanted or desirable translations.

The evaluator does not speak or understand the local language, which may limit her understanding of patients' concepts. Even when correctly translated, the concept in the local language may be different from the concept in Portuguese.

FINDINGS

Figure 1 shows the general schedule of care including counselling for an HIV-infected person.

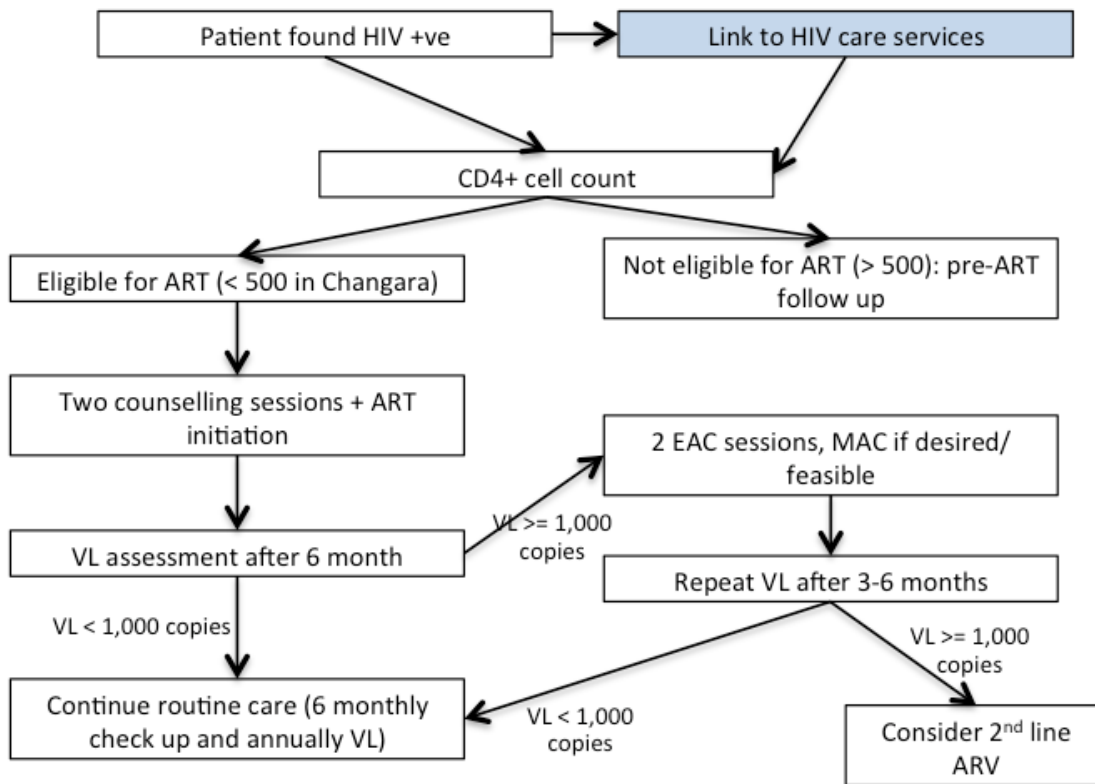


Figure 1 General schedule for follow-up of HIV infected patients on ART

Legend: ART=Antiretroviral treatment, EAC=Enhanced Adherence Counselling, MAC=Monitoring of Adherence in the Community, VL=viral load. The blue coloured activity takes place if patients are found HIV+ve in the community.

When a patient attends the health facility a receptionist welcomes her/him and finds the patients' file. In most of the facilities the counsellors conduct this activity. The counsellors conduct health education in the waiting room for the patients waiting for their consultation with the clinician. They use a flipchart, a plasticised A4 format information tool with mainly designs, to support their messages. The session that the evaluator observed was interactive in the sense that patients were free to interrupt for questions and also the counsellors asked questions to the patients. A patient that had a VL of undetectable level received a T-shirt to mark this achievement.

PATIENTS' PERSPECTIVE ON COUNSELLING

The evaluator interviewed 23 patients at three locations: Changara district hospital, and Matambo and Misawa health centre. The interviews took place with people individually or in groups of 2-4 people. With 10 (43%) people the interviews took place in Portuguese and most were women (74%). The average age was 40 years with a range from 23 to 64 years. Fifty-two per cent was married and 26% had reached 10th class in school. Five women (22% of all interviewees) had received no schooling. The mean time of knowing their positive HIV-status was 5 years with a range of 1-13 years. All patients but one received ART for a median period of 3.5 years. The range on ART was 1 to 13 years. Three quarters of interviewees participated in CAGs. The evaluator did not ask systematically whether people had had a VL assessment, however, eighteen interviewees had had a first VL assessment of which 7 (39%) had a high VL. Five of them had already had a second VL test of which 3 were still high.

The patients consider the counsellor an important person. The counsellors help patients with adherence to treatment in various ways. During the ART initiation sessions the counsellors emphasise the importance of treatment through explaining the relationship between the virus, the body's defence system (CD4 cells) and the effect of medication. This

message is repeated during patient education at the health facility and the CAG meetings in the community. The counsellor is often the first person the patients turn to if she/he needs advice outside clinic appointments. The counsellors also motivate and encourage the patients to take their medication. They inform the patients on their VL results and congratulate them if low or undetectable. The patients know how to get in contact with the counsellors through telephone or at the house of the counsellor. It appears that the patients find it easier to ask questions to the counsellor than to the clinician. One interviewee mentioned that she did not dare to ask the clinician about her problems: *“I did not have the courage”*. Patients also perceive that the counsellors provide them with more information than a clinician would, and in an easy to understand way.

Patients in CAGs have more intensive contact with the counsellors than the patients not in CAGs (individual treatment). This is because the counsellors participate regularly in the meetings of the groups in the community. This is easier to accomplish for nearby CAGs than for far away CAGs. The evaluation did not assess the frequency of contact between the counsellors and the CAGs however, should mapping of patients demonstrate a clustering of patients in certain regions, this warrants further examination.

Patients have several reasons for not participating in CAGs. The MoH guidelines stipulate that patients with tuberculosis (TB) or pregnant women should not receive their ARVs through CAGs. TB patients attend the health facility daily for their TB medication and pick up their ARVs monthly from the HIV clinic and pregnant women get ARVs through the mother and child health clinics. For pregnant and postpartum women another type of group exists: mothers-for-mothers. These take place at the health facility.

Interviewees considered that participation in CAGs had several advantages: it leaves them more time for themselves, they receive support from other members and if they don't feel well enough to attend the health facility they will still get their supply of medication. The support they receive from each other seems limited to discuss how to stay adherent and help in case of illness. Groups seem to turn to their counsellor easily when in need for help. Though this is good if they can't resolve their problems themselves, it may create dependence on the counsellor. A disadvantage of the groups is that some members go more frequently than others. They may receive payment for or being coerced into going more frequently. It was the reason why a group member had not come for a clinical check up for several months: he usually sent his wife for medication collection. Other people mentioned that not all members participated equally active in the groups because some did not always come for meetings.

Other patients do not want to participate in the CAGs. They mentioned several reasons:

- They do not always trust other members to keep their HIV-status confidential. Other group members may talk too much to people to whom they do not want their HIV-status revealed.
- They prefer to maintain the responsibility for collecting their ARVs on time themselves.
- Related to the previous point is that other group members may delay collecting the medication which would leave them with no medication. For one interviewed patient it was the reason to leave the CAG.
- Travelling a lot that required an individual approach: going to the health facility to ask for more medication during travels.

Patients know they can take the medication if forgotten. They also know that when there are only a few tablets left (most mentioned 2-3) they need to get together with the CAG or go for their clinic appointment. The perception of adherence to treatment is strongly linked to taking the medication correctly with the effect that 'life returns to normal' and that they can 'live their lives'. Not all patients know what correctly taking the medication means. For some it was taking medication every day without specifying at the same time, whereas others stated clearly that it was daily at the same time.

Patients with a high VL knew that it means they have a lot of virus in the body and most mentioned not taking medication correctly. This is linked to the perception of adherence described above. Not taking the medication correctly could be not every day or not every day at the same time. Patients did not always know that taking the medication at the same time was important. Other patients did not have means to verify the time. The importance of taking the medication at the same time every day is mentioned during initial counselling sessions, however, it appears that counsellors do not verify systematically if the patient has means to know the time. Patients had several means to know the time to take their medication: a watch, the telephone (including using the alarm for reminding), the radio, and the time that the sun goes down or when the chickens go into the chicken shed. Other perceptions of a high VL included a resistant virus,

poor treatment adherence of the sexual partner, and unprotected sex. Several women were in polygamous marriages and told that the husband did not always take his medication when he was with his other wife(s).

Patients that did not have a high VL did not always know what a VL means. The counsellor had told them that the VL was good. Other patients mentioned that the VL was to check whether the medication functioned well. Patients did not make the connection between a high VL and getting worse in their HIV-infection. Because VL testing is now routine (in Changara district), even a detectable or high VL may not yet have resulted in a worse clinical condition because of timely detection.

The evaluator asked almost all patients if they ever had run out of medication at home or whether they ever went to the health facility for refill of the medication and did not receive medication because of stock-out. All stated that they never were without medication and had never encountered an out-of-stock situation for ART medicines. However, some did encounter out-of-stock of other medicines such as for treatment of opportunistic infections. Given that MSF reported frequent out-of-stock situations it seems unusual that the patients did not ever encounter it. This may be linked to the limitation of desirable answers or selection of patients.

The evaluator asked all patients whether they had any question for her. Many did not but those that had asked clinical question (*'Can I get pregnant?'*); requested social support (*'We need food.'*); or mentioned side effects of the medication. The evaluator encouraged patients with clinical questions to present these to the clinician. One patient mentioned to receive some food support (soya), but most patients were not aware of any existing food support.

When asked how to improve the counselling activities patients mentioned: the presence of the counsellors at the group meeting; train the focal points of the groups on how to solve problems such as when a patient has too many pills compared to other members in the group (indication for missed doses); to inform the community on HIV and its care and treatment; and help in the form of a garden or a water pump would be welcome.

COUNSELLORS' PERSPECTIVE ON COUNSELLING

All counsellors observed in their activities worked with much enthusiasm and they were well aware of their tasks, which included in the health facility:

1. Reception of patient and locate patient file
2. Health education in waiting room/area
3. Counselling: before and after testing, pre-ART, Enhanced Adherence Counselling (EAC) in case of high VL, follow-up visits
4. Coordination of CAGs
5. Record and report activities (CAG register, AMA register)
6. Explanation of medical tests to be done
7. Maintenance of patient files, including filing of results
8. Participate in ART committee
9. Identify patients late for follow-up and contact (phone, home visit): medication pick-up, medical consultation, and medical tests.

Their tasks in the community included similar activities:

1. CAG meetings
2. Formation of CAGs
3. Voluntary testing in the community
4. Enhanced adherence counselling
5. Home visits
6. Forming MAC teams/groups



Figure 2 Plasticised tools for explanation of VL and CD4

7. Health education.

The counsellors have several counselling tools at their disposal, which include the flipchart and plasticised sheets to demonstrate what CD4 cells and VL means (see [Figure 2](#)). With these tools they explain well to the patients what HIV infection is, that the CD4 cells are the defence mechanism of the body and that HIV attacks this mechanism, and how medication works. They stress the importance of medication and the need to take it life long. In most sessions observed, the message seems the same all the time. There is little exploration of what the patients already know and what problems the patient encounters. Verification of whether the patients understand the message occurs through asking whether they understand. The patient usually says yes. As such the counselling sessions is mainly a transfer of information.

Though the evaluator did not observe any ART initiation counselling session, it appeared from what the counsellors told that these sessions focuses on the importance of taking the medication every day without explaining the importance of taking the medication at the same time every day. If the counsellors mention the timing, they do not explore well whether the patient has any practical means to check the time.

In the EAC counselling sessions the counsellors use a checklist with the most frequent barriers that the patients face.⁹ These include knowledge on the importance of treatment; not taking medication due to work or travel; not taking medication for cultural, traditional or religious ceremonies or believes; problems of taking medication because others around the patient do not know the HIV-status; the mental status of the patient; use of alcohol or drugs; and problems on reaching the facility for medication refill. The counsellors make a plan together with the patient on how to overcome the barriers. In the observed interaction the focus was on taking the medication every day at the same time. In these sessions the counsellors do verify whether the patient has practical means to know the time and provide them with suggestions if necessary.

Another possibility to assist patients with a high VL is to form a MAC: monitoring adherence in the community. It is a variation of the direct observed therapy common in TB treatment where the patient has someone she/he trusts who sees the patient swallow his or her medication. The counsellors offer this opportunity to patients when a high VL is detected and who forget to take their medication.

The counsellors mentioned several challenges related to their work. Some of the challenges relate to the care for patients, others are more organisational. Challenges related to patient care:

- When going out to the community, they do not always find the patient home. Patients may change their place of residence without informing the health facility, or may work in their fields. Though one could consider it rather normal to not find people at home during the day, it complicates the counsellors' work. They try to resolve this by leaving a message that they will return, agree on a specific part of the day to meet, or through simply going back to the patient's home again.
- Patients may decide all of a sudden to interrupt or abandon their treatment. The counsellor may not always convince the patient to restart, but they always keep the door open for the patient.
- Patients do not always accept home visits to maintain confidentiality. The counsellors said this was much more so for patients in individual care compared to the patients in CAGs, and as such the groups seem to be beneficial in allowing patients openness about their disease.
- Clinicians do not always attend quickly to patients identified in the community. The patient may have defaulted treatment or clinical follow-up, after which the counsellors try to identify the patient in the community. On finding and referring the patient to the health facility, clinicians may take long to attend to this patient, which may contribute to future defaulting. If the counsellor goes with the patient, attention is usually given more easily, but this is not always feasible.

Challenges related to the organisational part of their work were:

- There is not always transport available for patients that live beyond walking distance. The supervisors take the counsellors on their motorbikes; however, one of the motorcycles broke down and had been off the road for three weeks at the time of the visit. Another mechanism is that the counsellors use the car on the days that the laboratory team visits, but this is usually the day they work at the health facility because more patients attend to initiate treatment. Bicycles would allow the patients to go further (up to about 10 kilometres), however, it

does not completely solve the transport issue. Also the provision of bicycle has challenges: maintenance, spare parts, and carnetⁱⁱⁱ.

- In Matambo health centre, the counsellor does not always have a room to work from and needs to find a private space to do the work.
- For communication with the supervisor, the counsellors use their personal phone and airtime. When airtime runs out, they message the supervisor who will call the counsellors back. The supervisors receive some airtime from MSF, though is not always sufficient.
- High turn over of expatriate staff (4 in a period of 2-3 months). New expatriate staff does not always take the time and patience to get to know the project and want to start changing the routine soon after arrival.
- The approach has frequent changes anyway, due to results or findings in practice. Though this adaptive way of working has the potential to improve rapidly, it may lead to confusion on the correct approach among the counsellors or not allow sufficient time for an approach to work.

Since mid 2015 the counsellors have two supervisors, who used to be counsellors themselves. Their tasks are:

- Supervise activities of the counsellors in the community and at the health facilities
- Technical assistance:
 - Ensure adequate functioning of the testing activities (for HIV, for health)
 - Guarantee quality of the counselling
 - Cooperate with other departments in the follow-up of patients
 - Conduct on-the-job training for the counsellors during the supervision
 - Identify and address weaknesses of the counselling
 - (Assist with) development of new tools for the counselling work when necessary
 - Monthly reporting to patient support manager
 - Assist the patient support manager in the trainings and monthly meetings

The supervisors support the counsellors in many aspects of their work and the counsellors appreciate this support very much. The project only created the position of supervisor six months ago because the group became too big to be managed by one person (the patient support manager, a position filled by an expatriate until December 2015 and vacant at the time of the visit). The supervisors did receive an orientation on their role of supervisors but no additional training.

The evaluator observed the supervisors at work. When supervising sessions, the supervisor sometimes takes over the session. The supervisors explained that they do this when the counsellor provides incorrect information, because they don't want the patient to have incorrect information. However, the evaluator had the impression that the supervisor also did not allow sufficient time for the counsellors to provide the counselling in their own way. The supervisors do discuss the sessions directly with the counsellors in a supportive way, though they could give more room asking the counsellors on their perspective. They use standardised supervisory tools.

The creation of the position supervisor and the way the supervisors fulfil their role constitutes a good practice that deserves consideration in similar projects. The supervisors provide really supportive supervision, using a mentoring attitude. Their first-hand experience in counselling and their position close to the counsellors facilitates good functioning of the counsellors.

OTHER STAKEHOLDERS' PERSPECTIVE ON COUNSELLING

Health care workers and the provincial health authorities appreciate the work of the counsellors. They recognise the importance of home visits to find patients who defaulted, and the importance to patient support close to the patients'

ⁱⁱⁱ Cyclists need to register at the council and pay a small fee annually.

homes too. All are aware that the counsellors have much more time to talk to the patients than clinicians. The community testing contributed to an increase in testing in the province.

There seems to be a good relationship between the counsellors and the MoH staff. They work well together in general. Health care workers know that without the counsellors they would have to do the counselling and seem prepared to do so. At the same time, they understand well that they don't have the same time available for the counselling and certainly not for all the support the counsellors provide in the community.

The MoH recently adopted a new approach of the MoH, *prevenção positiva*^{iv}. This approach has seven components to address with HIV-infected patients such as nutrition, how to stay healthy, and consists mainly of advice. This approach is not (yet) integrated in the counsellors' work.

The health authorities would like to see more analysis of the available data on results by treatment site. This is not yet done partly because the numbers are still small and analysis is therefore not very useful.

The districts where MSF does not provide support (anymore) entrance into CAGs is reduced and the counsellors in these districts receive little support and supervision. This may jeopardise the quality of the counselling.

Partners, including MoH, often talk about integration of the counsellors' work in their activities, but in reality MSF staff does not observe this. Counselling activities are very much related to MSF only.

Chass, a PEPFAR funded support for HIV care and prevention provided by FHI 360 has Changara as one of their priority districts. Their activities may have overlap with MSF activities.

Some people questioned whether level of schooling of the counsellors is sufficient for adequate counselling, exploring barriers of patients and providing solutions. The evaluator did not find evidence for this. The counsellors used the tools adequately and receive substantial support from the supervisors and in monthly meetings. The harsh reality of Tete, maybe for the whole of Mozambique, is that there is little social work to support patients with their social problems. Although a system of social work exists in Mozambique, it is almost non-existent outside the city of Tete and even there access is cumbersome and difficult.

SOME CHARACTERISTICS OF PATIENTS WITH HIGH VL

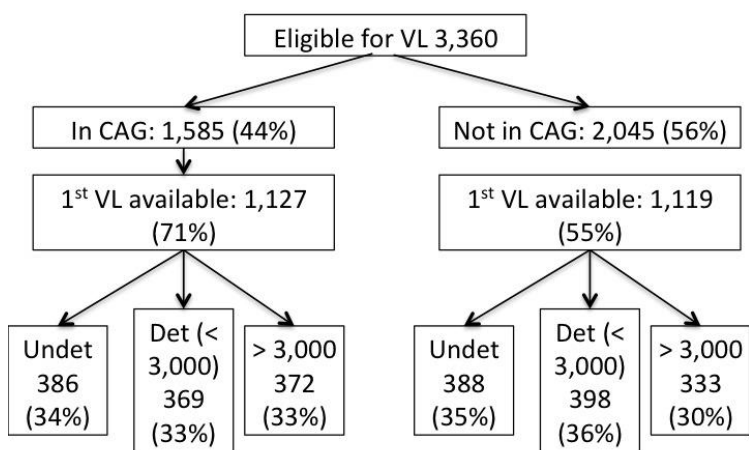


Figure 3 VL cascade at the end of 2015

The routine VL testing introduced in Changara in 2014 resulted in detection of a high proportion of patients with high VL. The VL cascade shows that at the end of 2015, one third of patients had a high VL using the cut off of 3,000 copies (see [Figure 3](#)).¹⁰ The proportions are almost the same for patients in CAG and in individual follow-up although coverage is lower in patients in individual follow-up. In this cascade MSF used the old definition of detectable VL of 3,000 copies per millilitre, however, the MoH in Mozambique adopted a different cut-off value of 1,000 copies per millilitre.¹¹ Obviously the proportion of high VL is then even higher.

These results raised questions on the quality of the HIV care provided, including the counselling. However, tough adherence is crucial for adequate HIV treatment, there are many factors influencing adherence.¹² Individual patient factors such as

malabsorption will influence bioavailability and may contribute to therapeutic failure. In Tete diarrhoeal diseases are in the top ten list of all age mortality³ and this will impact on drug absorption.

In an effort to identify risk factors for patients with high VL, the epidemiologist conducted some analysis on patients with high VL. [Figure 4](#) shows that there is very little difference between patients who ever participated in a CAG and patients who never participated in a CAG.

^{iv} Positive prevention.

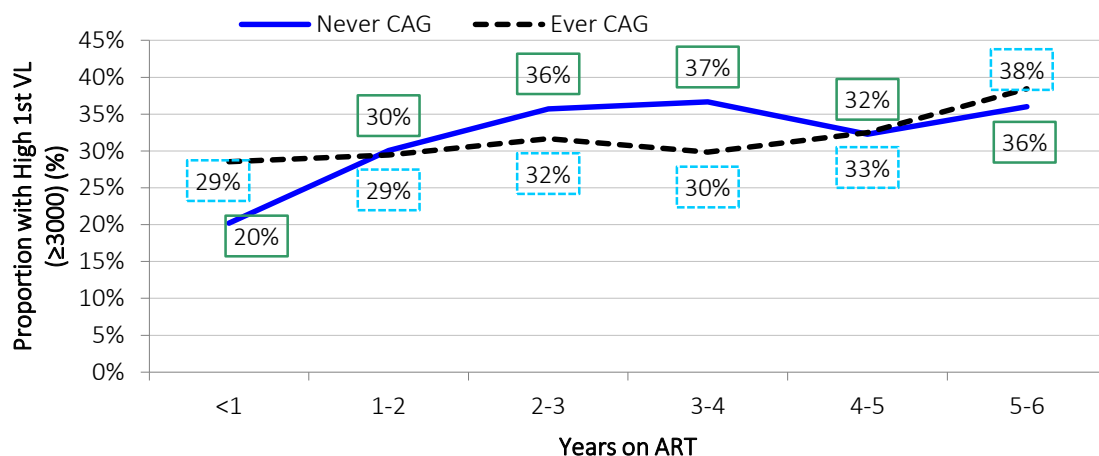


Figure 4 Proportion high VL and participation in CAG

If quality of HIV care is an issue, then one may expect that receiving treatment in a particular location may contribute to the proportion of high VL. *Figure 5* shows that there are some difference between CAG status and treatment location, however, the interpretation of the graph needs to occur with caution as some numbers are really small, resulting in large percentages.

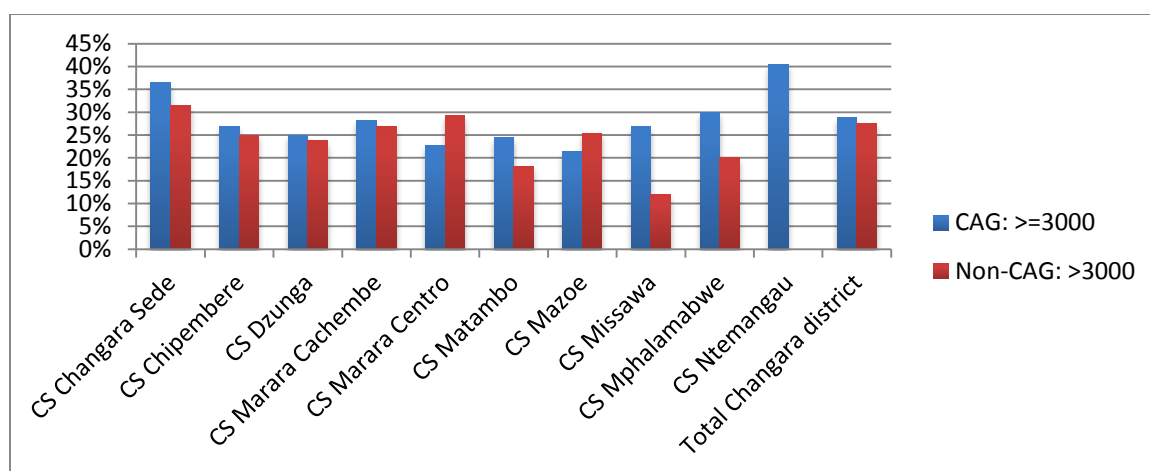


Figure 5 Proportion of high VL (> 3,000 copies/ml) by location and CAG status

Primary resistance, meaning an infected with a resistant virus, may also play a role, however levels of primary resistance in Tete are unknown.

RECORDING AND REPORTING OF COUNSELLING ACTIVITIES

The project monitors its achievements through a results framework. **Not available to the evaluator.*

Table 1 and *Table 2* present the achievements for the indicators related to the work of the counsellors.

| Indicator | Q1 2014 | Q2 2014 | Q3 2014 | Q4 2014 |
|---|-----------------------|---------|---------|----------------------|
| Number of people tested at community level per quarter is > 1,000 | report not available* | 1,679 | 4,267 | report not available |
| CD4 testing is available for >90% of those tested HIV+ in community during this quarter | report not available | 65% | 71% | report not available |
| > 80% of pre-ART patients retained through a community based strategy | report not available | 39% | 34% | report not available |
| >90% of people eligible who initiated ART | report not available | 100% | 69% | report not available |

| Indicator | Q1 2014 | Q2 2014 | Q3 2014 | Q4 2014 |
|---|----------------------|---------|---------|----------------------|
| Average time between detection of eligible CD4 and ART initiation for people tested at community level is less than 30 days | report not available | 10 | 8 | report not available |

*Not available to the evaluator.

Table 1 Achievements for results framework 2014

| Indicator | Q1 2015 | Q2 2015 | Q3 2015 | Q4 2015 |
|---|------------------------|---------|---------|---------|
| Number of people tested at community level per quarter is > 2,000 | 2,242 | 2,432 | 2,256 | 1,792 |
| CD4 result is available for >90% of those tested HIV+ in community within one month | 60% | 72% | 90% | 93% |
| Number of pre - ART patients enrolled in a community-based strategy (no target) | 204 | 190 | no info | no info |
| >90% of people tested at the community and eligible initiate ART | no info | 83% | 100% | 61% |
| Average time between detection of eligible CD4 and ART initiation for people tested at community level is less than 30 days | 14 | 11 | 9 | 15 |
| >50% of new HIV patients screened TB negative start IPT within 1 month | indicator not included | no info | no info | no info |

Table 2 Achievements for the results framework 2015

Legend for table 1 and 2: green cells = target achieved, red cells = target not achieved or report not available to evaluator; orange cells = no information available.

The indicators in the results framework have little direct relationship with the counselling activities of the counsellors and are much more related to the community testing part of the counsellors' work than their counselling. The team explained that at the start of the project the emphasis was more on the community testing than on the counselling and also that more indicators related to the counsellors' activities were included initially. When the counselling became routine, the project reduced the number of indicators. However, more visible indicators may have a role for advocacy purposes. Also, it could provide the counsellors with feedback on their work, though this may have an adversary effect as well: if – for example – VL remains high after counselling, this may demotivate the counsellors.

Some indicators are good proxies for the quality of HIV care of the whole team including the counsellors. Examples are 'CD4 result is available for >90% of those tested HIV+ in community within one month' and '>90% of people tested at the community and eligible initiate ART'.

The counsellors use various forms and registers to record their activities. The counsellors record the community testing (number tested, number positive, number referred to HF); the number of CAG (new, continued, dissolved); number of counselling sessions (EAC, MAC, various forms of other counselling); and the health education talks to do. They report these figures monthly to the supervisors who aggregate the data to a monthly report to the manager patient support. A very short interaction with the supervisors on reporting showed they had little skills in excel. Even though their calculations are limited, better skills would help them and may improve the quality of the reports.

The counsellors do hardly record the content of the counselling sessions thereby limiting adequate follow-up especially if another counsellor were to attend the patient a next time.

CONCLUSIONS

The counsellors' work is important for the patients and for the health care workers. The counselling contributes to treatment adherence even though this is difficult to quantify. The patients, however, do seem to depend on the counsellors rather than being enabled to solve their own problems, either individually or as groups.

The counsellors are also important in support for the CAGs: they start groups, support them in their meetings and have a coordinating role. Though it is not necessarily the counsellors that have to conduct this activity, it is important that someone has this role. Because of the synergy between counselling and the coordination of groups, it seems logical to add or maintain the coordination of CAGs to the counsellors' job description.

The counselling activities, though a long-standing feature of MSF's work, were initially not planned as such. The work of the counsellors initially focused on community testing more than the counselling, which evolved over time. The approach is mainly standardised rather than tailored to the needs of the individual patient. The choice for this was made because of using community counsellors with the relatively low level of schooling. However, continuous support and training for the counsellors improved the counselling and may allow a more individual patient approach.

Counselling is the same for all patients whether they participate in CAGs or not. Due to the involvement of the counsellors in CAG meetings, the CAG participants have more contact with the counsellors and may benefit of this. However, the almost similar proportion of high VL in CAG and non-CAG patients do not support additional benefit from more frequent contact with counsellors. Patients know what they need to do when they have forgotten their medication or when their stock at home is about to finish. This is probably a result from the counselling though the clinician may have explained it as well. Patients perceive adherence as taking the medication correctly and a high VL as a sign that the medication is not working well. Their perception of the high VL is linked to the adherence perception, with most patients thinking that a high VL is a consequence of not taking the medication correctly.

Furthermore, the counselling is psychosocial support that may not be the support that patients need most. There is unfortunately not one definition of patient centred approach.¹³ Commonly it involves patient participation and involvement which means that the care takes into account the patient's individual needs both physical and emotional. To be able to address patient's need, the counsellors need to explore these. They have tools for identifying the most common barriers that patients face and offer ways to overcome these. The counsellors have little possibility to support patients in a practical way with transport problems or food scarcity.

The relationship between counselling and a high VL remains unclear. It seems that the focus on the time of medication only emerges in the enhanced counselling sessions whereas it seems relevant to address this already the earlier – initial – counselling sessions. Some possibilities exist that may contribute to improve intake of medication through the counselling sessions. This includes an active approach in assessing if patients have practical means to know the time (to take medication at the right time of the day) and exploring earlier the barriers that patients may face. By addressing that earlier, one may prevent poor adherence because of travel, work or other reasons. The counsellor could also have more attention for adherence of the partner if he/she is also on ART.

However, treatment failure is not the results of counselling or a lack thereof only, many factors contribute to it. A more comprehensive approach to treatment failure will provide better understanding of the reasons for failure in Mozambique and if and how counselling can reduce treatment failure.

There seem to be no common characteristics of patients with high VL that contribute to the explanation of the high proportion of patients with high VL. Patients in CAGs have a higher coverage of VL, which is the consequence of the counsellors following up with them when it is time to do the VL assessment.

The counselling approach provides a good opportunity to link well with patients, and usually close to their home. The counsellors are often from the same community as the patients and therefore understand well the living situation of the patient. In addition, several counsellors are HIV-patients themselves and know the challenges of HIV treatment first hand. For all these reasons the counsellors are well positioned to provide a patient-centred approach for HIV-treatment. However, in the current implementation of the counsellors, they have limitations in implementing a patient centred approach further due to their limited skills and possibilities to identify and address patients' needs and challenges. A further limitation exists in the basic conditions present within the MoH to implement the use of (lay) counsellors on a large scale. The position is not recognised within the MoH staff structure and support for counsellors through supervision and mentoring is almost non-existent for districts where MSF does not provide support. Basic conditions to be met for a well functioning lay counsellor involvement in HIV care and treatment:

- Recognition of the position by the MoH including an initial training programme

- Continuous mentoring and supervision
- Material support for the tools counsellors use
- Support for the counsellors to do their work: transport and other means.

Practical on-the-job training has resulted in counselling that is important in HIV care. Not all counsellors have had much schooling, however, they are still doing their work satisfactorily. Therefore one should be careful in using level of schooling as selection criteria for the job as lay counsellor. This may limit potential candidates in certain areas of the country, and may also not contributing to selecting good candidates.

RECOMMENDATIONS

- ⇒ Recommendations 1: Continue to further develop the skills of the counsellors and support their work
- ⇒ Recommendations 2: Adopt a more comprehensive approach to potential treatment failure
- ⇒ Recommendations 3: Continue to work on formal acceptance of the lay counsellor position

CONTINUE TO FURTHER DEVELOP THE SKILLS OF THE COUNSELLORS AND SUPPORT THEIR WORK

Continue developing the skills of the counsellors will enable them to adopt a more patient-centred approach. For further development of their skills and support of their work, one can think of several possibilities:

- Develop skills to enable patients and CAGs to rely on themselves rather than on the counsellor.
- Develop skills to approach the patients in a more individual way compared to having the standard strategy for all. This will enable to more real patient-centred approach.
- Cooperate with partners to further integrate the counsellor into HIV care the system and involve other available staff in the counselling (or in part of the work of the counsellors, for example related to filing work).
- Assess the quality of the counselling not only through supervision but also through exit interviews with patients. A possibility is to have a few questions for each type of counselling session and conduct surveys asking the patients directly after the session. Once in a while surveys that ask patients a few days after the session will provide insights on how long knowledge and messages remain with the patients. Ideally these surveys are conducted independently from MoH and MSF.
- Increase the coverage VL testing of patients in individual care.
- Improve visibility of the counsellors' work by including a direct indicator in the framework. Possible indicators are:
 - % Of patients attending ART initiation counselling sessions correctly answering 3-5 key questions on exit interviews (not as routine activity, but regularly as a monitoring tool, ideally independently executed) – see previous point.
 - % Of patients with first high VL completing 3 enhanced counselling sessions (though this is an output indicator, using an outcome indicator is difficult as a reduced second VL does depend on many factors of which counselling is only one).
- Invest in the skills of the supervisors. This includes further improving their supervision skills and computer skills such as use of excel. Supervising skills would be the most important to focus on.
- Consider the provision of airtime to cover some of the telephone costs related to the counsellors' work.
- Analyse if and how to resolve transport challenges related to the counsellors' work. Possibilities include bicycles and reduce time for repairing motorbikes.

ADOPT A MORE COMPREHENSIVE APPROACH TO POTENTIAL TREATMENT FAILURE.

The approach in how to deal with high VL focuses a lot on counselling whereas a high VL, as indication for potential treatment failure, may be caused by many factors. The evaluator recommends using a more comprehensive approach using the framework below. This framework comes from the Companion handbook to the WHO guidelines for programmatic management of drug-resistant tuberculosis¹⁴ and has been adapted to the HIV context ([Figure 6](#)).

Factors contributing to poor HIV treatment outcomes

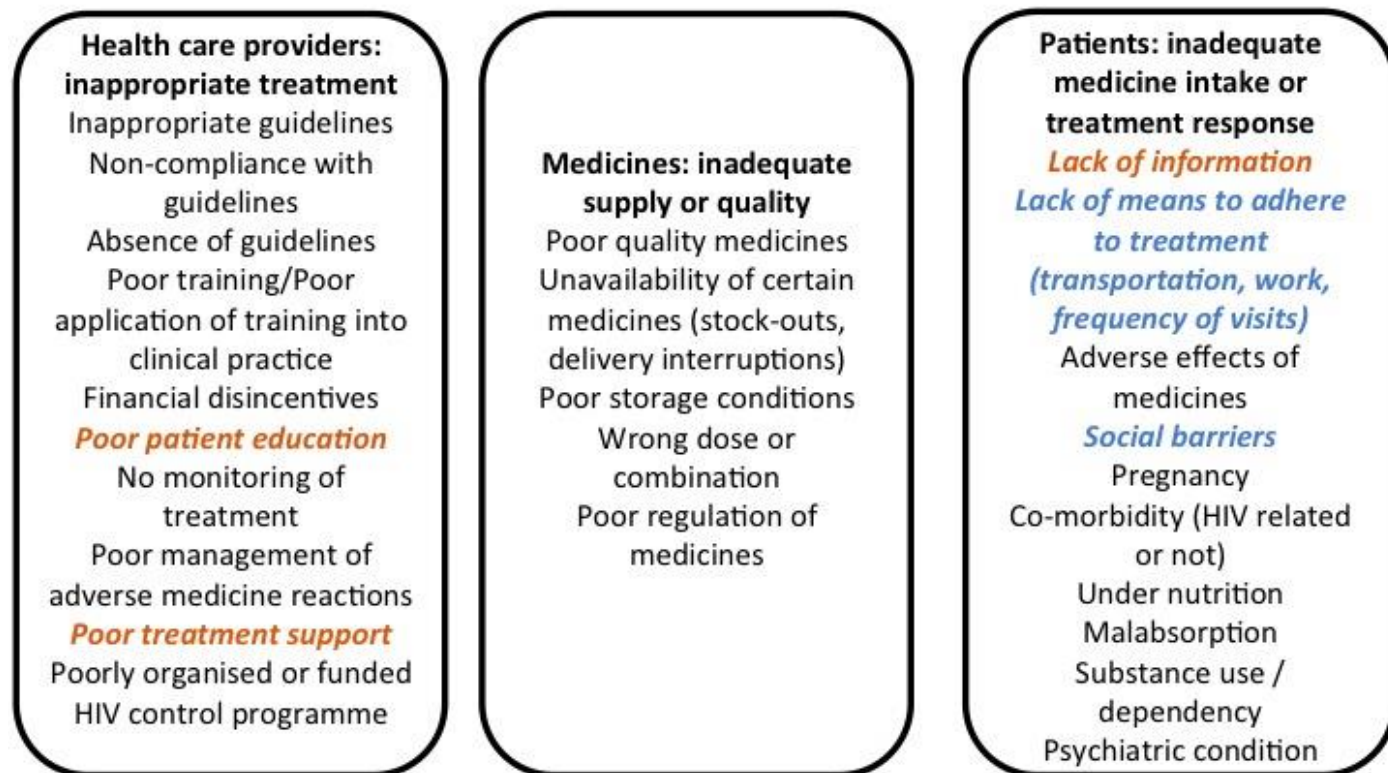


Figure 6 Framework for approach to poor HIV treatment outcomes and treatment failure.

Legend: Orange italic factors: counselling has great influence on these factors. Blue italic factors: counselling has some influence on these factors

The more comprehensive approach could include (but is not limited to):

- Continuous quantitative analysis of available information (age, sex, time on treatment, CAG vs. non-CAG, treatment locality, amongst others), which will become more informative when the numbers increase
- Assess the quality of drugs for active ingredients. Factors that may contribute to suboptimal or low quality of the drugs are: counterfeit drugs, transport from central to provincial to district warehouse, storing conditions at the various levels, and storing conditions at home.
- Address co-morbidities timely and adequately because these may affect absorption of the drugs and result in sub-optimal blood levels.
- Primary resistance may exist. An assessment of resistance before starting ART will provide more information.
- Continuous infection by a resistant partner or a partner with high VL. Though counselling is important in the sense that protected sex needs to be advised, people will not always be able or want (pregnancy wish) to adhere to that advice.
- Treatment adherence is a complex challenge in which counselling is essential, though not the only factor. Additionally, adherence may not work for all patients similarly. Further work into supporting patients on ART such as active promoting and implementing reduced medication collection frequency (4x or 2x/year for patients meeting certain conditions) and promoting the development of social care services (existing in Mozambique but difficult to access) may further improve treatment adherence. Another possibility could be to team up with traditional healers that have such an important role in the community.
- Coordinate with partners to avoid duplication and find synergies. Under Challenge TB, community based DOTS will be implemented. Though MSF in Tete is not engaged into TB work much (apart from screening during community testing), there may be opportunities to integrate approaches.

CONTINUE TO WORK ON FORMAL ACCEPTANCE OF THE LAY COUNSELLOR POSITION.

To increase access to counselling for all patients in HIV care in Mozambique, acceptance that not sufficiently trained social and psychology workers are available is important and that lay counsellors can satisfactorily fill this gap. This needs to have basic conditions met for the lay counsellors performing adequately:

- Recognition of the position by the MoH including an initial training programme
- Continuous mentoring and supervision
- Material support for the tools counsellors use
- Support for the counsellors to do their work: transport and other means.

MSF should continue to advocate for acceptance of the lay counsellors with the MoH.

ANNEXES

ANNEX I: TERMS OF REFERENCE

Context and background

| Subject/Mission | OCB Mozambique: Changara: counselling activities |
|--|--|
| Evaluation Sponsor/ Owner | Marc Biot |
| Evaluation Focal Point (HoM?) | Amaury Gregory Head of Mission |
| Primary Stakeholders/ Evaluation Communication Group | Cell, HoM, Medco, Fieldco, Tete Medco |
| Starting Date | December 2015 |
| Duration | 12 weeks |
| Time period to be evaluated | 2014 & 2015 |

The proposed evaluation falls within the terms of the Direction générale Coopération au développement et Aide humanitaire (DGD) financial contract MSF has signed for its projects in Tete. The objective is to evaluate one of the pillars of its project in Changara: the counselling activities. Convinced since years that the programmatic approach towards HIV in Mozambique requires inclusion of counselling, MSF has piloted an intervention that includes additional cadres specifically dedicated to the counselling task. While outcomes are positive in some aspects (i.e. Retention In Care (RIC) at 12 months > 90% in Community Adherence Groups (CAGs) – to which the majority of the counselling is targeted - vs. ~70% in non-CAGs cohort), it turns out that routine VL results start showing very surprising results. Both populations irrespective of their enrolment in CAGs, show similar patterns of high viral loads. While the mission is looking at this reality from a medical and quantitative point of view (i.e. with genotyping tests), MSF proposes to hold a qualitative evaluation of the counselling activities.

The program is taking place in the district of Changara (province of Tete, Mozambique), where the evaluation will have to take place.

Reason for evaluation / Rationale

MSF has done over the last few months a major advocacy campaign over the need of counsellors (regional reports “how does the job” that looks at 8 sub-Saharan countries) and has engaged in the country in joining efforts with CDC (under the request of Direção Nacional de Assistência Médica – DNAM) to integrate the counselling into the JD of the new cadres. Lessons from Changara including the evaluation would be absolutely valuable to feed into policy making and the review that will follow the implementation of the new cadres.

Overall objective and purpose

Carry out a qualitative evaluation of the counselling activities of the MSF OCB project in Changara District in order to inform future project orientations, thus contributing to a reduction in morbidity and mortality related to HIV/Aids & TB.

Specific objectives / Evaluation questions

- Where the counselling activities carried out as originally planned?
- Have the counselling activities affected the approach to people not enrolled in CAGs (i.e. do these people in fact also receive counselling and how it this done)?

- How does counselling contribute to adequate action taken by patients (for example, does counselling include advice on actions to be taken when people unexpectedly experience shortage of their ART medicines and do they act on this)?
- What is the current VL status of the targeted population??
- What is the perspective of the patients (with high viral load) : perceived adherence problems , reasons for low adherence , barriers to access medications (any stock-out reported)
- Contribution of CAG activities on adherence for patients at the beginning of treatment and during treatment with a focus at the detection of high Viral load
- What are the adherence intervention done by the CAG group for new initiated patients – and how the CAG group support to improve adherence of patients with high viral load)
- What are the limitations/opportunities inherent in the counselling approach?
- How can the counselling approach contribute to achieve lower VL in target population?

Expected results

1. **An inception report** detailing the methodology and approach to be taken
2. **Participatory feedback** to the project teams based on initial findings and observations
3. **Intermediary reporting** to steering group on findings after each field visit
4. **A final evaluation report** (English Max 60) including executive summary;
 - Analysis, findings, conclusions (Based on SEU standard)
 - 5 key recommendations
 - Minimum 1 example of 'best practice'
5. **A final presentation** including Microsoft PowerPoint (English Max 20 slides)

Tools and methodology proposed

- Review and analysis of project documents
- Meeting/discussion/interviews with key-team members at HQ and field levels
- Meeting/discussion/interviews with key-authorities
- Meeting/discussion/interviews with patients/former patients
- Natural group discussions or focus groups
- Observation

Recommended documentation

- Project Documents and Log frames for 2014 & 2015
- DGD (donor) proposal (2014)
- Monitoring Reports for 2014 & 2015
- Trip reports

Practical implementation of the evaluation

| | |
|---|----------------------|
| Number of evaluators | 1 |
| Timing of the evaluation | Dec 2015 -March 2016 |
| Required amount of time (Days); | 25 |
| • For preparation (Days) | 5 |
| • For field visits (Days) – in country | 13 (incl travel) |
| • For interviews (Days) – outside country | 2 |
| • For writing up report (Days) | 5 |
| Total time required (Days) | |

Notes: *Any additional criteria relevant to the selection of evaluation consultants*

Profile/requirements: evaluator

- Extensive HIV/TB experience, including programming
- Language requirements: English and Portuguese (Fluent)
- Evaluation competencies and experience

ANNEX II: LIST OF INTERVIEWEES

The table below shows the people met and talked to and the sites visited. The table does not include patient names. The evaluator did not record patients' names because of confidentiality reasons. The same applies to a lesser extent to some of the health care workers interviewed.

| Date | Description of activity | People met/interviewed |
|--------|--|---|
| 25-Jan | Arrival in Tete | |
| 26-Jan | Meeting and discussions with project team, finalisation programme for visit | Christine Bimansha - medical coordinator, Igor Damiana - deputy project coordinator |
| 27-Jan | Field visit: Changara district hospital - interview patients and staff, observation of clinic routine, limited observation of counselling activities | Interview 12 patients (individual, small groups 2-3 people), interview clinical officer, interview 3 counsellors (in group); medical director absent |
| 28-Jan | Provincial Health Authority | Courtesy meeting with Director of Health Dr. Carla das Dores Mosse, exchange of ideas on the project |
| | Field visit: Misawa Health Centre - interview patients and staff, observation of clinic routine | Interview 5 patients (individual, groups 2 people), interview clinical officer, interview 1 counsellor and the counsellors' supervisor |
| 29-Jan | Provincial Health Authority | Meeting and interview with Dr. Alex Bertil - responsible HIV/AIDS provincial programme |
| | Field visit: Matambo Health Centre - interview patients and staff | Interview 6 patients (groups of 2), interview mother-and child health nurse, interview 1 counsellor |
| | Review and analyse collected data (to date) - work on analysis | |
| 1-Feb | Field visit: community linked to Changara district hospital: attended group counselling session, identification of person not adherent to consultation follow up, person with high VL, initiation of MAC mechanism | Exchange with patients in all encounters; community visit accompanied by counsellors' supervisor and counsellor; |
| 2-Feb | Provincial Health Authority | Sr. Raul José Catete - responsible CAG |
| | Chass - FHI360 | Armindo Vasca - leader community team, Kalika da Silva - responsible psychosocial team |
| | Interactive meeting with counsellors (MSF office) | Counsellors: Narciso Mwaganhar, Alfa João Navaia, Pedro Amaral, Margarida Smith, Bresneve João, Lourenco Elias Gandapanse, Felismina Felix Jonasse, Josefina Saide; Counsellors' supervisors: Raja Reis Simone, Nunes Viola. Note: some counsellors did not make it to the meeting. |
| | MSF | Sergio Dezembro - until recently working for MSF; has had various positions over the years, and working for a long time with the counsellors and the CAGs |
| | MSF | Renata Rodrigues - MSF manager patient support activities (until December 2015) - skype interview |
| 3-Feb | Public holiday - meeting with MSF staff, preparation debrief | Erica Simons - MSF epidemiologist, Jean-Guy Audeoud, MSF GIS specialist |

| | | |
|-------|--------------------------------|---|
| 4-Feb | Morning: debrief with MSF team | Christine Bimansha - medical coordinator, counsellors' supervisors Raja Reis Simone and Nunes Viola |
| | Afternoon: flight to Maputo | |
| 5-Feb | Debrief Maputo | Debrief Ruggero Giuliani - Medco Maputo, Edna Nhampalele - Medco Adjunct Maputo |

ANNEX III: INFORMATION SOURCES

1. Peace Agreement for Mozambique. 1992.
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8. Médecins Sans Frontières. Role of counselling in the provision of quality HIV testing and adherence support to HIV and TB treatment - Johannesburg declaration. 2015.
9. Médecins Sans Frontières. Aconselhamento de melhoria da adesão (AMA). Paciente com suspeita de falência terapêutica. Checklist. 2015.
10. Médecins Sans Frontières. Monitoring narrative and results frame work 2015 quarter 1-4. 2015.
11. Ministério da Saúde, Direcção Nacional de Assistência Médica. Guia de tratamento antiretroviral e infecções oportunistas no adulto, adolescente, grávida e criança. 2014.
12. Nachega JB, Marconi VC, van Zyl GU, Gardner EM, Preiser W, Hong SY, et al. HIV treatment adherence, drug resistance, virologic failure: evolving concepts. *Infect Disord Drug Targets*. 2011 Apr;11(2):167–74.
13. Kitson A, Marshall A, Bassett K, Zeitz K. What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *J Adv Nurs*. 2013 Jan 1;69(1):4–15.
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ANNEX IV: GUIDE FOR INTERVIEWS AND GROUP DISCUSSIONS

Guia^v de entrevistas

Nota: o ênfase das entrevistas é com os doentes e os conselheiros.

Introdução

Bom dia /boa tarde! Me chamo Miranda e sou médica. MSF me pediu de avaliar um projecto. O projecto é sobre o trabalho dos conselheiros no tratamento de HIV. Gosto de gravar a nossa conversação si o senhor/ a senhora concorde. O papel de gravação é de entender melhor o que o pessoal tem dito. Depois finalizar o relatório, vou destruir a gravação. Toda informação que o pessoal me da, fica confidencial. Não vou partilhar com outras pessoas, mesmo da MSF, só numa forma geral.

Guia para os doentes

Informação geral

Sexo : M / F

Idade :

Data (mais e ano) de diagnostico HIV:

Data (mais e ano) de começar TARV:

Data (mais e ano) de entrar no CAAG (grupo de apoio e adesão comunitário) – se aplicável:

Estado civil:

Nível escoliaria:

- Quando receber o diagnostico de HIV, o senhor/ a senhora conversou com o conselheiro^{vi}, não é? Como foi esta conversão? O que o senhor/ a senhora aprendeu nesta conversão? O senhor/ a senhora pensa que conversão esteja importante? Por que é importante (ou por que não?)?
- *[Se não participa num CAAG, qual foi a razão de não participar? Gostaria de entrar num grupo? Como pode acontecer a entrada dum grupo?]* – só para pacientes não em CAAG
- Depois iniciar o tratamento, já encontrou alguns problemas? Se sim, que tipo de problemas? Estive preparado pelos problemas? Se sim, como estive preparado? Alguém ajudou resolver os problemas?
- Ficou algum momento sem medicamentos de TARV? Se sim, o que aconteceu? Se não, sabe o que fazer quando fica sem medicamentos?
- Já esqueceu os medicamentos um dia? Se sim, lembrou o que aconteceu? Se não, pode imaginar que acontecera um dia que esquece os medicamentos? Se sim, por que? Se não, porque não?
- Sabe o que significa aderência/toma de medicamentos correcta? Pode me explicar? Qual é a importância de aderência/toma de medicamentos correcta? Como pode tomar os medicamentos corretamente?
- Depois iniciar o TARV, já encontrou de novo com o conselheiro? Se sim, qual foi a razão? Se não, gostaria/teria gostado de encontrar com o conselheiro? Por que não encontrou com o conselheiro?
- Quais são os desafios mais grandes com o tratamento TARV? Encontra estes desafios frequentemente? Se sim, como ultrapassa estes desafios? O conselheiro ajuda com os desafios?
- Como pode ser ajudado de ficar aderente ao TARV? Quem pode ajudar e como?
- Você já teve uma carga viral? Sabe o que é carga viral? Como foi a sua? Qual é o significativo deste nível de CV?

^v É uma guia, não é necessário de usar todas as perguntas.

^{vi} Pode ser conselheira.

- Tem alguma sugestão como melhorar o trabalho dos conselheiros?

Guia para os conselheiros

Informação geral:

Sexo : M / F

Idade :

Data (mais e ano) de começar como conselheiro:

Interrupção do trabalho de aconselhamento? Se sim, por quanto tempo?

Estado civil:

Nível escoliaria:

Recebeu formação de aconselhamento? Se sim, quando e por quanto tempo?

Recebeu formação de reciclagem? Se sim, quando e por quanto tempo?

Quais são os três pontos mais importantes durante o aconselhamento inicial?:

Quais são os três pontos mais importantes durante o aconselhamento de aderência?

- Recebe suporte no seu trabalho de aconselhamento? Se sim, como? Quantas vezes? De quem?
- Qual foi a razão de começar o trabalho de aconselhamento? O que gosta de seu trabalho? O que não gosta?
- Quanto tempo por semana trabalha como conselheiro? Qual é o seu lugar do trabalho?
- Quanto tempo fica na comunidade por semana? O que são as tarefas no centro de saúde? O que são as tarefas na comunidade?
- Encontra problemas/desafios no trabalho? Se sim, que tipo de problemas? Estive preparado pelos problemas? Se sim, como estive preparado? Alguém ajudou resolver os problemas? Se não, quais são os problemas que pode encontrar no trabalho?
- Conhece doentes que ficaram algum momento sem medicamentos de TARV? Se sim, como aconteceu? Você ajudou o doente com este problema? Se não, sabe o que fazer quando um doente fica sem medicamentos?
- Durante o aconselhamento, como fala de aderência? O que diz ao doente o que o doente deve fazer quando fica (quase) sem medicamentos?
- Sabe o que significa aderência? Pode me explicar? Qual é a importância de aderência? Como os doentes podem ficar aderente?
- Sabe o que é carga viral? Qual é o significativo de CV? Encontrou doentes que tiverem CV? Qual foi o resultado? O que significa deste resultado?
- Como ajuda os doentes com a aderência? Quais são os problemas que encontram? Pode sempre ajudar ultrapassar estes problemas? Se não sabe o que fazer, qual é o próximo passo?
- Como sente se fazer este trabalho? Qual é a importância deste trabalho na sua vida?
- Tem alguma sugestão como melhorar o eu trabalho?

Informação geral

Sexo : M / F

Idade :

Trabalho + local de trabalho:

Posição:

Data (mais e ano) de inicio do trabalho nesta posição:

Tempo depois a formação básica:

- O que sabe sobre o projecto de trabalho de conselheiros (leigos) de MSF? Existe desde quando?
- Quais são as vantagens deste projecto? Quais as desvantagens?
- Quais são os resultados do projecto? Quais provas tem destes resultados?
- Tem alguma sugestão como melhorar o projecto?
- Se não existia limite de recursos, como gostaria de mudar este projecto? Destes, qual é a mudança mais importante? Porque?
- Si você estaria uma pessoa vivenda com HIV, qual tipo de suporte gostaria de receber? Porque?

Stockholm Evaluation Unit
Médecins Sans Frontières