



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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SHORT VERSION

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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Miranda Brouwer

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CONTENTS

| | |
|------------------------|---|
| ACKNOWLEDGEMENTS | 2 |
| ACRONYMS..... | 4 |
| EXECUTIVE SUMMARY..... | 5 |

ACRONYMS

| | |
|-------|--|
| 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 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.

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