



Médecins sans Frontières Khayelitsha

**PATIENT SUPPORT INTERVENTIONS TO IMPROVE
ADHERENCE TO DRUG RESISTANT TUBERCULOSIS TREATMENT
COUNSELLING TOOLKIT**



BACKGROUND

In 2007, MSF partnered with Cape Town City Health and the Western Cape Health Department to pilot a decentralized model of care for drug resistant TB (DR-TB) in Khayelitsha. This community-based, patient-centred model of care was established in all 10 primary care clinics across the sub-district. In 2011, a decentralised plan for DR-TB was drafted for the wider Cape Town Metro, which led to adoption and implementation of many components of the decentralised model across other sub-districts in Cape Town. Patient support is a major component of the model and is integral to retention in care for DR-TB patients throughout the arduous two year treatment course. Dedicated DR-TB counsellors were employed in each sub-district across Cape Metro to offer individual and group counselling and psychosocial support for DR-TB patients and their families.

The South African National Drug Resistant TB Management Guidelines (2011) recommend specific DR-TB counselling to encourage optimal adherence to the difficult treatment regimen and to increase the likelihood of a successful outcome for individual patients. It further stipulates that relevant information and educational materials, which are culturally sensitive and appropriate to the literacy levels of the population, should be made available for patients diagnosed with DR-TB.

1. WHY PROVIDE STRUCTURED COUNSELLING SUPPORT FOR PATIENTS RECEIVING DRUG RESISTANT TB TREATMENT?

People diagnosed with any form of DR-TB (rifampicin mono-resistant, multi-drug resistant [MDR] and extensively drug resistant [XDR and pre-XDR] tuberculosis) embark on a two year treatment journey. The DR-TB patient's journey is complicated by a number of obstacles including multiple and potentially severe side effects, high number of pills to swallow, the necessity to attend clinic daily for DOT (Directly Observed Therapy), and a very long duration of treatment which impacts their ability to maintain their usual daily activities (work, school, caring for family, among others). Treatment consists of a multi-drug regimen and patients are required to swallow an average of 10-15 tablets everyday for a minimum of twenty months, sometimes longer depending on their response to treatment. In

addition, an intramuscular injection is administered by a healthcare worker at least five days week for the first six to eight months of treatment. South Africa's DR-TB guidelines require all patients to take their DR-TB treatment under DOT by a healthcare worker for the entire two year treatment duration.

A diagnosis of DR-TB can be traumatic. Patients often experience drug side effects which may severely impact their daily functioning. Intolerance or omission of specific drugs may result in sub-optimal treatment regimens which could lead to the development of further drug resistance and subsequent treatment failure due to potentially sub-optimal treatment regimens. There is a clear need for comprehensive counselling and support in order to ensure that patients adhere to the full treatment regimen. Given that DR-TB is an infectious airborne disease, it affects not only the patient's wellbeing, but also that of their families, close contacts and local communities in which they live. Therefore the provision of information and education for the patient and their family should be comprehensive, culturally appropriate, and easy to understand.

This toolkit describes a structured, standardized, patient-centred counselling approach which may be used by lay counsellors and healthcare workers to support DR-TB patients. It includes counselling sessions that provide necessary information, deal with a variety of adherence issues, and address other potential challenges that patients may face during their treatment journey.



2. WHAT ARE THE BENEFITS OF USING THIS STRUCTURED COUNSELLING MODEL?

2.1 FOR THE PATIENTS

- DR-TB information is standardized to ensure all patients receive the same messages.
- The information provided is simplified and limited to the essential key points to allow for clear understanding, prevent information overload and confusion, and reduce unnecessary repetition.
- The model follows a patient-centred approach: it allows each patient to identify their own individual challenges and therefore take ownership of their own treatment journey.
- Patients are encouraged to identify the three reasons that motivate them to stay healthy and alive. They are assisted to complete an individual adherence plan that addresses various potential barriers to treatment adherence and allows the patient to develop their own strategies in order to overcome these barriers.
- The sessions build upon the original messages, which are reinforced when addressing further challenges such as interruption of treatment or substance abuse.

2.2 FOR THE DR-TB PROGRAMME

- The counselling manual and tools ensure standardization of counselling and information provided.
- The skill and competency of each individual counsellor can be assessed using these sessions as a quality assurance tool.
- Multiple counselling sessions divide treatment literacy over time to allow patients to process information and ask questions as necessary.
- The additional counselling sessions identify and address new challenges or obstacles at different stages throughout the patient's treatment journey.

3. WHAT DO THE COUNSELLING SESSIONS ENTAIL?

3.1 TREATMENT INITIATION COUNSELLING SESSIONS

The counselling model consists of three initial individual counselling sessions that focus on treatment literacy and adherence planning.

One of the initial counselling sessions includes a home visit to focus on:

- identification and screening of contacts
- provision of information and education to the family to encourage support for the patient
- an infection control assessment of the home

The counselling manual guides the counsellor to engage the patient in a two-way conversation. The patient is encouraged to take ownership of their disease and their treatment journey. It is a relational approach rather than an information-relaying approach.

There are 13 simple specific adherence steps to address. The objective of these steps is to support patients to identify and address potential barriers to starting and remaining adherent to treatment.

3.2 COMPLETION OF INTENSIVE PHASE COUNSELLING SESSION

Treatment fatigue may gradually set in over the course of the two years of treatment. Therefore a fourth counselling session at the end of the intensive phase is seen as a milestone to provide additional encouragement and support as well as an opportunity to review the adherence plan for the remainder of treatment. The aim is to acknowledge the achievement of finishing injections, to remind patients that they still have to take the tablets every day for eighteen months, and to motivate them to persevere with treatment.

3.3 TREATMENT INTERRUPTION COUNSELLING SESSION AND FOLLOW UP SUPPORT

100% adherence to any treatment is desirable but not easily achievable, thus occasional treatment interruption will be part of any patient's treatment journey. Treatment interruption may lead to eventual loss from treatment if new or existing challenges are not identified and addressed. In the 'treatment interruption' counselling session, the counsellor discusses potential reasons for treatment interruption specific to the individual and they work together on a condensed version of the adherence plan. The counsellor helps patients to set themselves personal short-term goals which are easily achievable. Follow-up sessions are carried out by the nursing staff in the clinic to ensure these goals are met. The aim of involving nursing staff is also to strengthen the nurse-patient relationship. Clinic staff members are encouraged to observe the language used to address the patient's challenges in order to be more supportive and motivating.



3.4 XDR - TB COUNSELLING SESSION

Another potential complication that patients face is the risk of more extensive drug resistance (pre-XDR and XDR) which is usually only detected 4-6 weeks after the start of MDR treatment. This requires additional counselling to inform patients of the change of their diagnosis (which can be confusing) and the need to modify their treatment. In addition, diagnosis of additional drug resistance can be devastating news, since there is a much lower chance of cure with the current treatment available for extensively drug resistant TB. Therefore the XDR counselling session also touches on some aspects of palliative care to encourage patients to consider the reality of potential treatment failure and the threat to their life. This session includes a clinical component that briefly explains the various treatment options available to them at that stage (to be expanded upon by the clinician).

3.5 PALLIATIVE CARE COUNSELLING SESSION

Not all patients who start DR-TB treatment win the battle against DR-TB: treatment may fail to be effective in some patients despite optimal adherence to treatment. The current treatment outcomes for XDR-TB in South Africa are very poor, with less than 20% treatment success and a high mortality rate. There is a lot of uncertainty regarding the optimal management of these patients and their families, given the infectious nature of the disease.

The palliative care counselling session aims to inform patients and their families about their condition and their prognosis. This session provides practical information on the clinical management of the patient (whether or not treatment has been withdrawn) and guidance on how to access palliative support services.

4. WHAT RESOURCES DO YOU NEED TO IMPLEMENT THE COUNSELLING MODEL?

1. **Session guides for the counsellor and counsellor supervisor**
2. **Adherence plans for the patient (a copy should be kept in the patient's medical file)**
3. **DR-TB flipchart as a supportive educational tool for the counsellor to use during counselling sessions**
4. **Training**
 - Training on all of the sessions can be completed in five days.
 - Three initial days of training include DR-TB theory and practical guidance on how to complete the first four counselling sessions.
 - The fourth training day can be arranged at a later stage when the facility or specific health district feels ready to include the XDR-TB counselling and/or treatment interruption counselling as part of the DR-TB patient support package. It is recommended that the counsellors are competent with implementation of the core four counselling sessions prior to training on additional counselling sessions.
 - The fifth day of the training package covers an introduction to the theory of palliative care and a session on dealing with death and dying.
 - A training package containing guidelines, tools and exercises will be available via the MSF SAMU website www.samumsf.org
5. **Supervision**
 - The patient support component of DR-TB treatment requires ongoing support from managers to ensure that it is prioritized along with the clinical care of the patient.
 - The key role players in the DR-TB programme in your district need to be identified. The role and responsibility of each player should be well defined, and a network of communication established to ensure successful supervision of the counselling model after training and implementation.
 - In the Cape Metro resources include a DR-TB professional nurse, who coordinates the DR-TB programme at district level. This professional nurse completes the post training competency assessments for each counsellor in her district. H/she also records and reports on the number of counselling sessions completed by each counsellor every month. She is responsible for ensuring that each DR TB patient receives all four core counselling sessions.
 - Each DR-TB programme has to work with the resources available and appoint a supervisor that has basic supervision skills to oversee DR-TB counselling support.

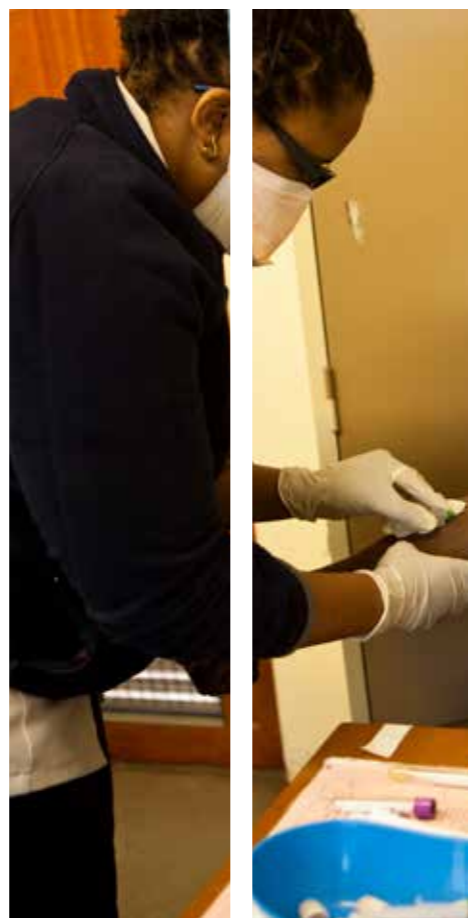


5. WHAT IS THE OVERVIEW OF ALL OF THE COUNSELLING SESSIONS?

SESSION	TARGET	RATIONALE	TIMING AND LOCATION	SESSION CONTENT	RESOURCE MATERIALS
SESSION 1	Newly diagnosed DR-TB patients	Provide patient with information regarding DR-TB to promote insight about their disease, adherence to treatment, and ownership of their treatment journey Plan with the counsellor how to overcome possible barriers to treatment adherence	First day of treatment initiation Clinic	Treatment literacy Basic TB and DR- TB information including definitions, when and where to take treatment and clinic visits; basic awareness of side effects and other treatment related challenges: basic Infection control Adherence steps Step 1 - Getting to appointments Step 2 - Dealing with side-effects Step 3 - Getting support at home Step 4 - Getting support at the clinic Step 5 - Audiometry screening Identify 3 reasons to stay healthy and alive	Session plan- Session 1 Flip chart Adherence Plan Stickers
SESSION 2 (may be combined with Session 3)	DR-TB patients having received counselling session 1	To provide patient with information regarding DR-TB to promote insight about their disease, adherence to treatment and allow patients to take ownership of the treatment journey as they plan with the counsellor how to overcome possible barriers to adherence to treatment	Within one week of treatment initiation Home or clinic	Treatment literacy Basic information regarding adherence and what to expect if adherence is poor; discussing the importance of identifying drugs and dosages; definitions of sputum and culture conversion Adherence steps Step 6 - Preventing future mistakes and completing your treatment journey Step 7 - Identify a treatment partner Step 8 - Communicating with the treatment team Step 9 - How to manage weekend doses Step 10 - Reminder strategies	Session plan- Session 2 Flip Chart Adherence Plan Stickers
SESSION 3 (may be combined with Session 2)	DR-TB patients having received counselling Session 2	Provide DR-TB information to the family and patient; encouraging the family to support the patients; DR-TB contact identification, screening and infection control advice	Within the first month of treatment initiation Home (if the patient refuses a home visit this session can be done in the clinic with a family member joining the patient)	Treatment literacy Basic TB and DR-TB information: TB infection control and how TB is spread; time off work and school; patient journey; details of those at risk for DR-TB and contacts in the home; TB and pregnancy; traditional medication and alcohol use with treatment Adherence steps Step 11 - How to protect my family Step 12 - How to deal with substance use Step 13 - Managing unplanned trips	Session plan- Session 3 Flip Chart Adherence Plan
SESSION 4	DR-TB patient who has completed the intensive phase	Congratulate the patient and revise treatment literacy messages and adherence steps to ensure ongoing adherence (also to inform patient of potential for self-administered treatment[SAT] in some settings)	Completion of intensive phase Clinic	Revision of treatment literacy messages See session 1-3 Revisit adherence steps See session 1-3	Session plan- Session 4 Flip Chart Adherence Plan that was completed post treatment initiation
TREATMENT INTERRUPTION SESSION	Patient who has interrupted DR-TB treatment for two or more consecutive weeks or who frequently interrupts treatment for short time periods	Promote adherence to treatment and prevent default from treatment	As soon as the patient has interrupted DR-TB treatment for two consecutive weeks or more or is a patient who frequently interrupts treatment for short time periods Clinic or home	Treatment literacy What is adherence, what happens if you take your treatment, and what happens if you stop taking your treatment, Adherence steps Step 1- Reminder Strategies Step 2- Getting to the clinic Step 3- Getting support at home Step 4- DR-TB support at the clinic Step 5 -Dealing with side effects Step 6- Dealing with substance use Step 7- Completing your treatment journey	Session plan- Treatment Interruption Session Flip Chart Adherence Plan
TREATMENT INTERRUPTION FOLLOW-UP SESSIONS	Patient who received the treatment interruption session	Monitor adherence on a frequent basis and improve the patient- health care worker relationship	One week post the treatment interruption counselling session Clinic	Follow-up session Monitor goals achieved, set new goals	Adherence plan Nurse monitoring document
XDR-TB SESSION	Patient with a pre-XDR or XDR diagnosis	Educate the patient on pre-XDR and XDR diagnosis, discuss potential future treatment options and limitations (the clinician will continue this discussion), create an awareness of palliative care	As soon as possible after second line resistance has been detected Clinic	Treatment Literacy Adherence Assessment Step 1 - Confirming the patient's support system at home Step 2 - Reviewing contacts for screening Step 3 - SOS plan for emergencies	Session plan- XDR-TB Session Adherence assessment
PALLIATIVE CARE SESSION	Patient in whom DR-TB treatment has failed and identified as such by a clinician	Understanding their diagnosis and prognosis, future treatment and psychosocial support options	As soon as patient is identified by a clinician as a patient in whom DR-TB treatment has failed. Home or clinic	Explanation about current diagnosis; what happens with treatment of other chronic diseases or conditions; how to travel safely if patient intends to migrate	Session Plan- Palliative care session Relevant Facility contact details Referral letter from clinician

SUMMARY

- This DR-TB counselling toolkit aims to standardize DR-TB counselling messages, ensure counselling quality and promote improved outcomes for patients diagnosed with DR-TB.
- The standardized patient support model provides appropriate counselling support for patients across the entire spectrum of their treatment journey: treatment initiation, transition from intensive phase to continuation phase, treatment interruption, extensive drug resistance diagnosis and DR-TB treatment failure.
- The patient centred approach offers individual support for patients to identify strategies to overcome their own barriers to adherence.
- Clinicians gain confidence in the patient support component of DR-TB treatment through standardized counseling messages and appropriate counselling supervision.
- Counsellors undergo professional development through training on the counselling model.
- Supportive supervision of counsellors as they implement the counselling support package promotes quality assurance and counsellor confidence.
- It is essential that all DR-TB clinicians, nurses and counsellors work together to ensure productive and successful support for patients with drug resistant tuberculosis; this support is as essential as the pills they take every day, and must continue throughout the long treatment journey.



PATIENT AND COMMUNITY EDUCATION AND MOBILIZATION

- Patient support interventions to improve adherence to DR-TB treatment require collaboration from various sectors in the community. Civil society groups, community mobilization organizations, community based health services, social workers, and palliative care organizations should all be included in providing DR-TB patients a strong foundation of community support.
- Stigma and fear related to DR-TB impacts on the quality of support patients with DR-TB receive from the community, their families, and health care workers. Educational materials should be available for patients diagnosed with DR-TB, both in their local clinic and in their community. Flyers, pamphlets, posters, and stickers can all be used to convey essential messages related to the signs and symptoms of DR-TB, presenting to care early, DR-TB treatment, and proper infection control. Community education and mobilization are essential to create awareness about DR-TB and to encourage the community to raise their voices on behalf of those infected and affected by DR-TB.

