HEALTHCARE DELIVERY

Patient support interventions to improve adherence to drug-resistant tuberculosis treatment: A counselling toolkit

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In response to the growing burden of drug-resistant tuberculosis (DR-TB) in South Africa (SA), Médecins Sans Frontières (MSF), with local government health departments, piloted a decentralised model of DR-TB care in Khayelitsha, Western Cape Province, in 2007. The model takes a patient-centred approach to DR-TB treatment that is integrated into existing TB and HIV primary care programmes. One essential component of the model is individual and family counselling to support adherence to and completion of treatment. The structured and standardised adherence support sessions have been compiled into a DR-TB counselling toolkit. This is a comprehensive guide that focuses on DR-TB treatment literacy, adherence strategies to encourage retention in care, and provision of support throughout the patient's long treatment journey. Along with other strategies to promote completion of treatment, implementation of a strong patient support component of DR-TB treatment is considered essential to reduce rates of loss from treatment among DR-TB patients. We describe our experience from the implementation of this counselling model in a high DR-TB burden setting in Khayelitsha, Cape Town, SA.

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Drug-resistant tuberculosis (DR-TB), defined as TB with at least rifampicin resistance, is increasing in prevalence and incidence worldwide.[1] South Africa (SA) has reported some of the highest numbers of DR-TB cases globally: in 2012 alone there were 14 161 laboratory-notified cases of multidrug-resistant TB (MDR-TB) and 1 545 cases of extensively drug-resistant TB (XDR-TB).[2] Regimens available for DR-TB are expensive, toxic, and require a minimum treatment duration of 20 months. In addition, currently available medications often cause multiple side-effects that impact on patients' ability to maintain their usual daily activities.[3] The burden of treatment regimens contributes to poor DR-TB programme outcomes, including high rates of loss from treatment (LFT) and stagnant treatment success rates. A study conducted in the Western Cape Province, SA, found an LFT rate of 27%, which is comparable to LFT rates observed in other DR-TB treatment cohorts in SA.[4] National Department of Health (NDoH) data from 2012 reflect a 40% treatment success rate for MDR-TB and less than 20% treatment success for XDR-TB.[2] It is imperative that strategies to provide structured patient support are developed and implemented to promote retention in care.

Setting

Khayelitsha, a township in the Western Cape, is home to approximately 500 000 people and has one of the highest rates of HIV and TB among subdistricts in the country. It was determined that there were 989 cases of DR-TB diagnosed in Khayelitsha from 2003 through 2010, 200 of which were diagnosed in 2010. In response to the growing burden of DR-TB in Khayelitsha, Médecins Sans Frontières (MSF) collaborated with City of Cape Town Department of Health (CCTDoH) and provincial health services in 2007 to pilot a decentralised model of care in which primary healthcare clinicians initiate and manage treatment of patients diagnosed with DR-TB at Khayelitsha-based clinics. The prevailing model of care for DR-TB previously involved centralisation of treatment to 45 specialised hospitals in SA, which hindered the ability to provide longitudinal support to DR-TB patients and their families in their local community. In contrast, decentralisation to primary care enabled patient support to form a major component of the overall model of care.[5] Two dedicated lay DR-TB counsellors were employed to provide education and support to DR-TB patients managed at 11 primary care clinics in the subdistrict. Since 2011 the model has been managed by the CCTDoH, and various aspects of the model have been adopted and implemented across other subdistricts in the Western Cape. In 2012, MSF, together with the CCTDoH, developed a more structured, standardised, patient-centered approach to counselling DR-TB patients, placing equal emphasis on treatment literacy and adherence support.

Objective

A policy of decentralised management of DR-TB in SA was endorsed by the NDoH in 2011. Although welcomed for its prioritisation of decentralisation nationally, it lacks specific information on how to provide structured patient support and counselling despite its recommendation to provide these services to patients. The DR-TB counselling toolkit aims to provide guidance on how to provide patient support to promote adherence to difficult treatment regimens, to encourage retention in care, and to increase the likelihood of successful treatment outcomes.

The intervention

The counselling toolkit is a comprehensive guide that provides patients with support throughout the duration of their treatment. It aims to encourage patients to take ownership of their treatment. Specific counselling session plans have been included in the toolkit that provide structured scripts of simple key points to convey to patients,

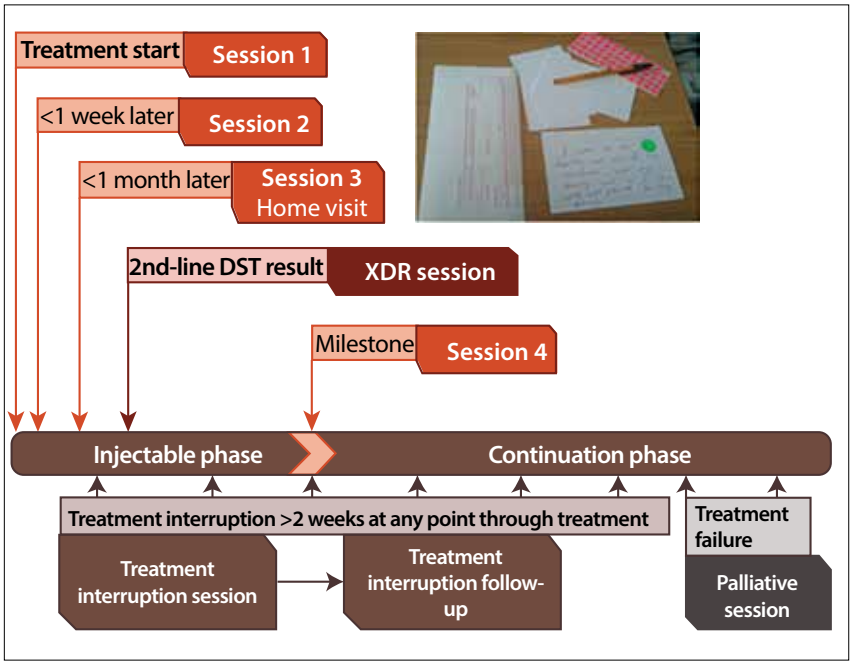


Fig. 1. Overview of the counselling sessions.[6] (DST = drug susceptibility testing.)

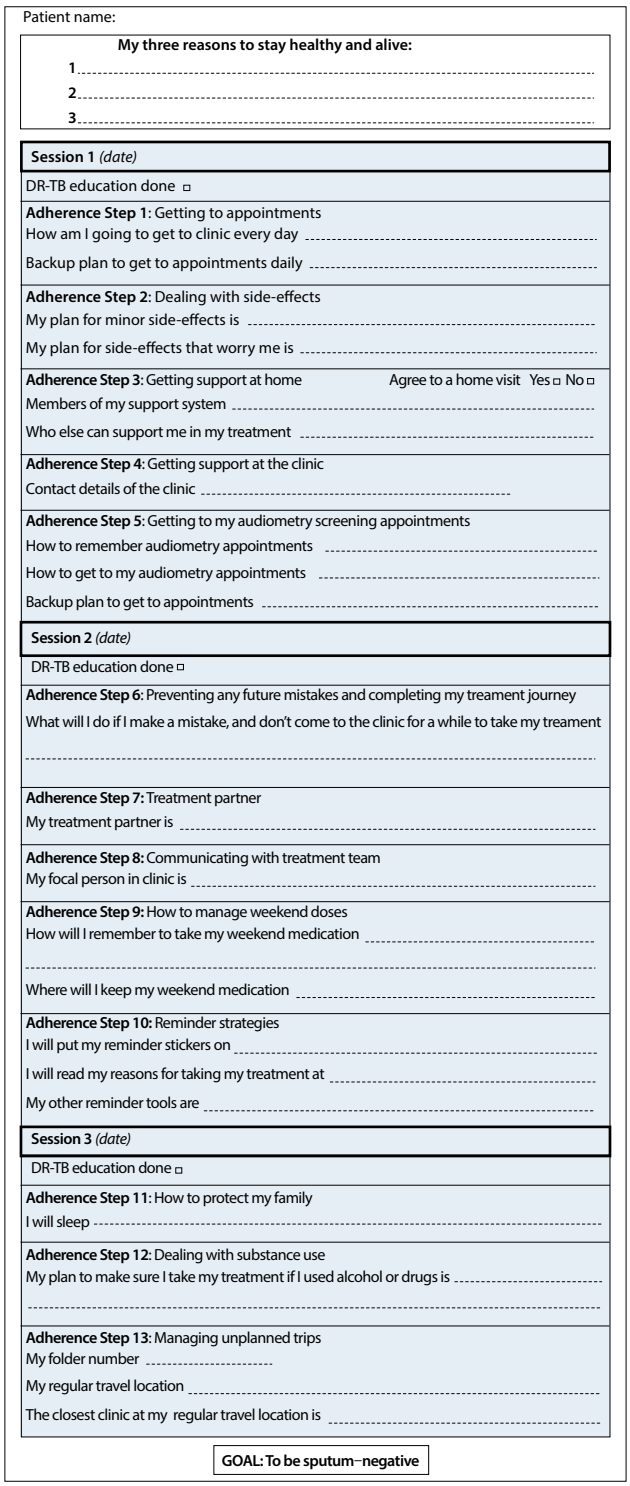
Table 1. Timing of DR-TB counselling sessions[6]

Session	Target	Rationale	Timing and location	Session content	Resource materials
Session 1	Newly diagnosed DR-TB patients	Provide the patient with information regarding DR-TB to promote insight about their disease, adherence to treatment, and ownership of their treatment journey To 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 three 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 who have received counselling session 1	Provide the patient with information regarding DR-TB to promote insight into their disease and adherence to treatment, and allow patient to take ownership of the treatment journey as they plan with the counsellor how to overcome possible barriers to adherence to treatment	Within 1 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 the treatment journey Step 7: Identifying 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

Continued ...

Table 1. (continued) Timing of DR-TB counselling sessions[6]

Session	Target	Rationale	Timing and location	Session content	Resource materials
Session 3 (may be combined with session 2)	DR-TB patients who have received counselling session 2	Provide DR-TB information to the family and the patient, encouraging the family to support the patient; 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 or school; patient journey; details of those at risk of 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 abuse Step 13: Managing unplanned trips	Session plan – session 3 Flip chart Adherence plan
Session 4	DR-TB patients who have completed the intensive phase	Congratulate the patient and revise treatment literacy messages and adherence steps to ensure ongoing adherence (also inform patient of potential for self-administered treatment (SAT) in some settings)	Completion of intensive phase Clinic	*Revision of treatment literacy messages* See sessions 1 - 3 *Revisit adherence steps* See sessions 1 - 3	Session plan – session 4 Flip chart Adherence plan that was completed post treatment initiation
Treatment interruption session	Patients who interrupted DR-TB treatment for ≥2 consecutive weeks or who frequently interrupt treatment for short time periods	Promote adherence to treatment and prevent LFT	As soon as the patient has interrupted DR-TB treatment for 2 consecutive weeks, or if the patient 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	Patients who received the treatment interruption session	Monitor adherence on a frequent basis and improve the patient-healthcare worker relationship	One week after the treatment interruption counselling session Clinic	*Follow-up session* Monitor goals achieved, set new goals	Adherence plan Nurse monitoring document
XDR-TB session	Patients with a pre-XDR or XDR-TB 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	Patients in whom DR-TB treatment has failed, and have been identified as such by a clinician	Understanding their diagnosis and prognosis, future treatment and psychosocial support options	As soon as the 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 the patient intends to migrate	Session plan – palliative care session Relevant facility contact details Referral letter from clinician



Patient name:

My three reasons to stay healthy and alive:

1 .....

2 .....

3 .....

Session 1 *(date)*

DR-TB education done ☐

Adherence Step 1: Getting to appointments

How am I going to get to clinic every day .....

Backup plan to get to appointments daily .....

Adherence Step 2: Dealing with side-effects

My plan for minor side-effects is .....

My plan for side-effects that worry me is .....

Adherence Step 3: Getting support at home Agree to a home visit Yes ☐ No ☐

Members of my support system .....

Who else can support me in my treatment .....

Adherence Step 4: Getting support at the clinic

Contact details of the clinic .....

Adherence Step 5: Getting to my audiometry screening appointments

How to remember audiometry appointments .....

How to get to my audiometry appointments .....

Backup plan to get to appointments .....

Session 2 *(date)*

DR-TB education done ☐

Adherence Step 6: Preventing any future mistakes and completing my treament journey

What will I do if I make a mistake, and don't come to the clinic for a while to take my treament

.....

Adherence Step 7: Treatment partner

My treatment partner is .....

Adherence Step 8: Communicating with treatment team

My focal person in clinic is .....

Adherence Step 9: How to manage weekend doses

How will I remember to take my weekend medication .....

.....

Where will I keep my weekend medication .....

Adherence Step 10: Reminder strategies

I will put my reminder stickers on .....

I will read my reasons for taking my treatment at .....

My other reminder tools are .....

Session 3 *(date)*

DR-TB education done ☐

Adherence Step 11: How to protect my family

I will sleep .....

Adherence Step 12: Dealing with substance use

My plan to make sure I take my treatment if I used alcohol or drugs is .....

.....

Adherence Step 13: Managing unplanned trips

My folder number .....

My regular travel location .....

The closest clinic at my regular travel location is .....

GOAL: To be sputum–negative

Fig. 2. Sessions 1 - 3 adherence plan for patients.[6]

and steps they should follow to overcome commonly experienced barriers to adherence. The initial four sessions are conducted during the intensive phase of treatment (the first three should be conducted within the first 4 weeks of treatment initiation, one of which must be a home visit), with the goals of treatment literacy, stepwise adherence planning, family involvement, contact tracing and infection control advice. In addition to these initial sessions, counselling sessions can occur at any time during treatment to address treatment interruption, the diagnosis of XDR-TB, and treatment failure and palliative care. These additional sessions are particularly important, as they provide detailed scripts for lay counsellors or professional healthcare workers to address very sensitive topics with patients and their families should treatment not yield a successful outcome. Recognising the importance of quality assurance, a counsellor competency assessment for supervisors has also been included in the toolkit.[6] Fig. 1 provides a summary of the timing of the various DR-TB sessions in relation to the patient's journey towards DR-TB treatment completion. Table 1 provides an overview of the contents of the various counselling sessions provided by the DR-TB counsellor to the patient.

While challenges in the implementation of this patient support model can be anticipated, including human resource needs for skilled lay counsellors and their supervision, the structured nature of the approach supports formalised training and monitoring of counsellors and their supervisors. It is further possible to implement counselling sessions in a phased manner to slowly build capacity towards implementing the more specialised XDR-TB and palliative care sessions.

The infrastructure required for the implementation of this toolkit includes four essential components: DR-TB counselling session guides for both the counsellors and their supervisors; adherence plans for patients (Fig. 2); DR-TB flipcharts to use as supportive educational tools during counselling sessions; and a structured training programme for counsellors that contains the tools and exercises necessary to ensure standardised quality of counselling provided to patients.

Conclusions

The counselling toolkit was presented at the 4th Annual South African Tuberculosis Conference held in Durban, SA, on 10 - 13 June 2014. At the conclusion of the conference, the counselling model was recognised for clinical excellence by the organising committee, reinforcing the importance of including a structured patient support component during decentralisation of DR-TB care to primary care level. The DR-TB counsellor is a critical member of the team providing care to patients with DR-TB. It is essential that all DR-TB clinicians, nurses, and counsellors work together to ensure comprehensive support for patients with DR-TB. This support is as essential as the pills patients are required to take every day, and must continue throughout the long DR-TB treatment journey.

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Ethics approval statement. Since this was a retrospective description of the counselling toolkit which involved no data analyses, no ethical approval was needed.

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