

‘I didn’t know so many people cared about me’: support for patients who interrupt drug-resistant TB treatment

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SUMMARY

SETTING: Early interventions for patients who interrupt their treatment for drug-resistant tuberculosis (DR-TB) are rarely reported and assessed. A novel, patient-centred intervention for patients at risk of loss to follow-up (LTFU) from DR-TB treatment was implemented in Khayelitsha, South Africa, in September 2013.

OBJECTIVE: To explore the experiences and perceptions of patients, key support persons, health care workers (HCWs) and programme managers of a patient-centred model.

DESIGN: This was a qualitative study consisting of 18 in-depth interviews with patients, key support persons, HCWs, key informants and one focus group discussion with HCWs, between July and September 2017. Data were coded and thematically analysed.

RESULTS: The model was well perceived and viewed

positively by patients, care providers and programme managers. ‘Normalisation’ and tolerance of occasional treatment interruptions, tracing, tailored management plans and peer support were perceived to be beneficial for retaining patients in care. Although the model was resource-demanding, health workers were convinced that it ‘needs to be sustained,’ and proposed solutions for its standardisation.

CONCLUSION: An intervention based on early tracing of patients who interrupt treatment, peer-delivered counselling and individualised management plans by a multidisciplinary team was considered a beneficial and acceptable model to support patients at risk of LTFU from DR-TB treatment.

KEY WORDS: adherence; patient-centred; patient support

IT IS WELL DOCUMENTED that adherence to drug-resistant tuberculosis (DR-TB) treatment is complicated; people diagnosed with any form of DR-TB find themselves plagued by a number of obstacles throughout their treatment journey.^{1–3} A systematic review examining loss to follow-up (LTFU) among patients on DR-TB treatment in 31 countries showed that LTFU rates ranged from 0.5% to 56%.⁴ Globally, more than one in five patients who started treatment in 2013 were documented as LTFU—a testimony to the struggle of patients to adhere to and stay on treatment.⁵

Known for a high dual human immunodeficiency virus (HIV) and TB/DR-TB burden,^{6–8} Khayelitsha, a peri-urban township in South Africa, has reported a high rate of LTFU (30%) among patients on DR-TB treatment over the years.⁶ In September 2013, Médécins Sans Frontières (MSF) implemented a novel enhanced adherence support intervention in nine clinics providing decentralised DR-TB treatment and care for DR-TB patients at risk of LTFU in Khayelitsha. The intervention allows for early iden-

tification, tracing and management of treatment interruption among DR-TB patients.

There have been a plethora of studies, mostly quantitative, looking at the factors associated with LTFU among patients on DR-TB treatment. However, considerably fewer studies have reported on interventions that address adherence and retention in care.⁴ Patients’ and care providers’ views on such interventions are rarely described or investigated. However, the literature highlights the urgent need for patient-centred interventions, including the provision of individualised, sufficient and timely assistance to patients, optimised care for treatment side effects and cultivation of patient-provider relationships.⁹ As resources for DR-TB programmes are often limited, a thorough critical assessment of the benefits, feasibility and acceptability of interventions that address LTFU is essential.

The aim of the present qualitative study was to explore the experiences and perceptions of patients, key support persons, health care workers (HCWs) and programme managers of this patient-centred intervention for DR-TB.

METHODS

Design

This qualitative study made use of in-depth interviews (IDIs) and one focus group discussion (FGD). The study was conducted between July and September 2017 in Khayelitsha.

Study setting

Khayelitsha is home to about 450 000 people,¹⁰ 50% of whom reside in informal settlements where crime, substance use, unemployment and poverty are rife.^{11,12} Approximately 200 people are diagnosed with DR-TB annually, 70% of whom are also co-infected with HIV.⁸

Treatment interruption intervention

In Khayelitsha, DR-TB treatment is offered under either directly observed therapy (DOT) or self-administration of treatment (SAT); the majority of patients on SAT are supported by community care workers (CCWs), as described previously.^{13,14} HCWs identify patients based on either a previous history of treatment interruption beyond 2 months, i.e., LTFU, treatment interruption that exceeds 2 weeks or chronic interruption (several short-term interruptions for less than a week at a time). Patients are referred to a mobile MSF intervention counsellor who begins tracing the patient using telephone messages and a home visit.

During home visits, the intervention counsellor carries out a standardised session plan that includes an understanding of the patient's reasons for treatment interruption, with screening for alcohol/substance use and mental illness. Individualised management plans are devised by the multidisciplinary team, including the management of clinical complaints, counselling support and referral to social workers, substance use treatment centres or short-term in-patient care if required, and discussing motivational factors for completing DR-TB. Extended support and additional interventions, such as family meetings, mobile support forums, monthly follow-up visits or telephone calls, are provided for patients who struggle to remain in care.

Figure 1 depicts the flow of activities of the intervention, and Table 1 provides a comparison between the standard-of-care management of treatment interruption and the treatment interruption intervention.

Study population selection and recruitment

Patients were purposively selected from the programme database on the basis of duration of enrolment (whether enrolled for less than or longer than 2 months), age and sex. The selection of patient-identified, key support persons was dependent on consent from the patient and his/her availability.

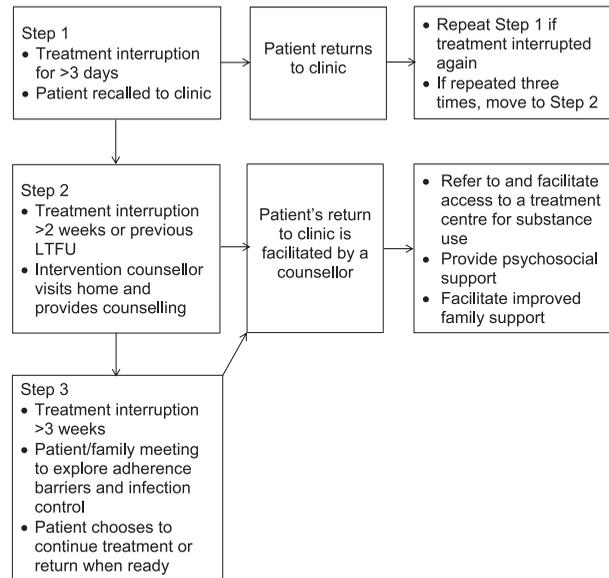


Figure 1 DR-TB treatment interruption intervention, Khayelitsha, South Africa, 2013–2017. LTFU = lost to follow-up; DR-TB = drug-resistant tuberculosis.

Convenience sampling was used to select HCWs. Key informants were selected based on their professional profile. Recruitment was done by telephone, mobile messaging (WhatsApp™), e-mail, home visits and clinic visits by the principal investigator and research interviewers.

Data collection

Data were collected by the principal investigator, who was trained in qualitative research methods and data collection, with support from three Xhosa-speaking interviewers who could transcribe from Xhosa to English.

Seven DR-TB patients enrolled in the intervention were interviewed irrespective of the type of treatment received (DOT or SAT). Additional interviews were completed with five of their key support persons (Table 2). The FGD was held with nine physicians and two nurses. Two additional nurses were recruited for IDIs using the FGD questionnaire to broaden the nurse's perspective. Three key informant interviews were conducted with programme managers/coordinators responsible for the TB/DR-TB programmes of their institutions.

In-depth interviews

The majority of the interviews were conducted in Xhosa. All interviews were audio-recorded. Interviews were conducted in participant homes or clinic and were conducive to privacy, confidentiality and infection control when appropriate. Interview guides consisting of open-ended questions were used to guide the interviews. Interviews lasted between 15 and 25 min.

Interviews with nurses and key informants took

Table 1 Comparison between components of standard of care and treatment interruption intervention, Khayelitsha, South Africa, 2013–2017

Component	Standard of care	Treatment interruption intervention
Early identification	Not consistent	Yes
Tracing		
Home visit	Not always possible	Yes
Phone call/SMS/WhatsApp™	Not always possible	Yes
Structured counselling session	No	Yes
Leave a message to return to care	Yes	No
Counsellor facilitates return to clinic	No	Yes
Counselling		
Reasons for interruption discussed?	Yes	Yes
Normalising of interruption	No	Yes
Screening for mental illness and substance use	Not performed consistently	Yes
Multidisciplinary management plan		
Family meeting/ discussion	No	Yes
Clinical management of side effects	Yes	Yes
Individual plan	Not always done	Yes
Facilitated referral to substance/alcohol use treatment centre	No	Yes

SMS = short messaging service.

place at their workplaces, lasted between 25–40 min and were conducted in English.

Focus group discussion

The FGD was conducted in English by the researcher, and lasted 40 min. Seven doctors and two nurses consented to be part of the FGD, which took place after a DR-TB patient clinical meeting. HCWs were aged 28–59 years, with different years of experience among them.

Data analysis

Most of the transcription took place in a one-step process to English. The interviews and the FGD were translated verbatim. A selection of interviews was discussed immediately after data collection and was later verified against the final transcripts. Data coding was completed by two investigators and codes and themes were grouped in tables, discussed and

compared. Data were analysed manually, and a thematic network approach was utilised. Primary themes that emerged from the data were grouped into organising themes and then into an overarching global theme, as described by Attride-Stirling.¹⁵

Ethics

The study protocol was approved by the MSF Ethics Review Board, Geneva, Switzerland (1654), the University of Cape Town Human Research Ethics Committee (HREC 123/2017), the City of Cape Town City Health, Cape Town, and the Western Cape Health Research Committee, Cape Town, South Africa. Before enrolment, all participants provided written consent to participate.

RESULTS

Three main themes emerged from the study, along with various subthemes.

Patient reasons for treatment interruption

The majority of the patients said that their DR-TB treatment left them with side effects, substantial pill burdens, limited understanding on the part of family members and economic difficulties. Reasons for interrupting treatment included improved health, substance use, forgetfulness, life events, fear of being reprimanded and guilt, and in half of cases, SAT (Figure 2). One patient related multiple reasons for treatment interruption.

I was shocked ... not happy... [It] is a lot of treatment that we have... [If] you are unemployed, sometimes you will get a job and you will stop [treatment] again... [T]here is no understanding here at home ... I didn't take my supply... I am not going

Table 2 Patients and key support persons interviewed under the treatment interruption intervention, Khayelitsha, South Africa, 2013–2017

Interviewee no.	Sex	Age years	Time under the intervention
Patient			
1	Male	31	4 months
2	Female	34	3 weeks
3	Female	34	4 months
4	Female	28	2 months
5	Female	28	2 weeks
6	Male	30	15 months
7	Male	48	3 weeks
Key support person			
1	Female	61	Mother
2	Female	60	Mother
3	Female	64	Aunt
4	Female	54	Mother
5	Female	42	Girlfriend

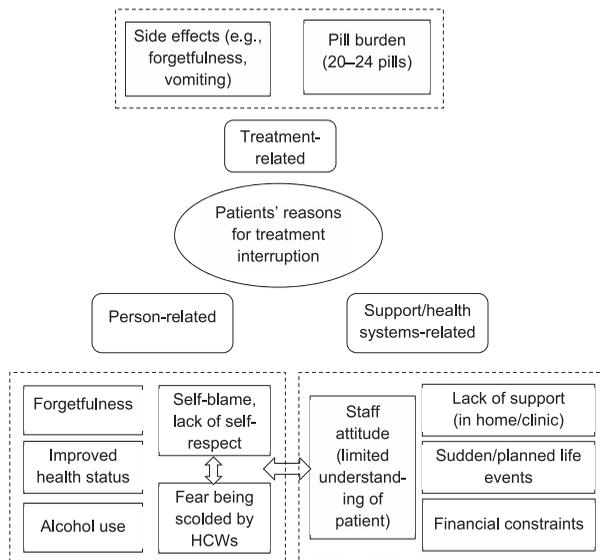


Figure 2 Reasons for treatment interruption. HCW = health care worker.

to make excuses for that. I was arrested but I was already interrupting. (P6, 30-year-old male)

A woman described the overwhelming effect of the pill burden.

I was annoyed even looking at the pills. Sometimes I would take four of them in the morning and the others in the afternoon, I would not finish all of them. I think there were 24 or 21 pills... They asked what the problem was and I told them I am tired of these pills. (P3, 34-year-old female)

One patient shared her struggle to adhere to treatment on her own, and explained how she was given the option of stopping or continuing treatment.

I started struggling after I was discharged [clinic] because in there they would give you your pills and they made sure you take them. There was a time when I didn't go to collect the treatment for about a month. She [counsellor] asked if I wanted to stop or to continue and I said I want to continue. We agreed on me waking up in the morning and taking the treatment at the clinic. (P3, 34-year-old female)

Another patient also told us she received treatment at the clinic.

Because I had this problem of forgetting...we came up with the solution that I would take the treatment at the clinic every day. (P5, 28-year-old female)

One patient reflected on an unfounded fear about being reprimanded by the staff stopping him from returning to care.

I was scared that they would shout. But I never saw them shout at anyone but you know a person think about that stuff although they haven't seen it before. (P1, 31-year-old male)

The burden of the treatment journey is shared by key supporters

Key supporters described the impact of treatment on themselves and patients. One key support person described the effect of DR-TB on her family:

[When] he was given a weekly supply, he started interrupting and missed some days of treatment. He started smoking and drinking heavily and not taking his medication. When we came to the clinic, he was told that his sputum results were back to positive... I was afraid if I was discharged [from MDR-TB treatment] while he was still [culture] positive I might be infected again... I would end up saying, 'it's better you leave me and stay with your family' ... (girlfriend, 42 years)

The elderly, sick mother of a patient reflected on the complexity of supporting someone who is 'dodging' or avoiding taking treatment.

She was dodging treatment because sometimes she would run away to her sister... She used to hide the medicine under the mattress or flush them in the toilet [...] I wanted to see her taking medication, so I wake up, give her porridge and after, give her medication. She used to vomit the medication, so I was crushing it for her. (mother, 60 years)

Patients describe their experiences of the intervention

All patients and their key support persons spoke positively about the support provided to them as part of the intervention. Most participants described this as 'encouraging' and 'motivating', while others alluded to counsellors stating that patients take their life 'seriously' and take treatment or deal with the consequences of not taking treatment (Figure 3). Some patients recounted how the home visit by the counsellor was helpful in getting them to return to the clinic.

She [counsellor] is the one who went to my house, spoke to my mom and told her [my mom] to meet her and speak to me. Then she [intervention counsellor] came to me... I really wanted to come back by that time, but, but... You know... you are guilty of something ... (P1, 31-year-old male)

The majority of key support persons reflected on the support given to them as well as patients:

The nurse helped her a lot, by telling her to stick to her treatment. I used to call [the counsellor] a lot. She was a good supporter and the manager at [in-patient unit] was very supportive. I became relieved after calling them. [They] always included me and I would be there whenever there would be a plan to be done for her [patient]. (mother, 60 years)

The family of a patient receiving their treatment supply to take at home received phone-call reminders to collect her treatment from the clinic:

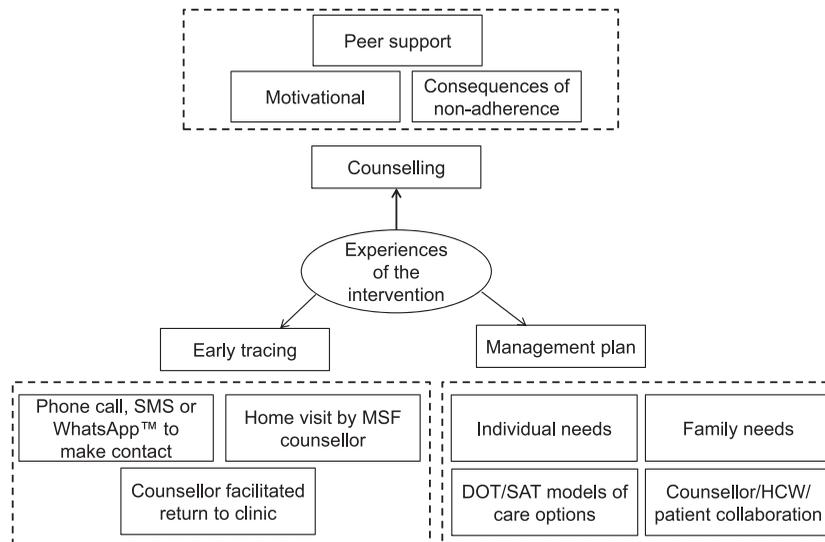


Figure 3 Experiences of patients and key support persons during treatment interruption intervention. SMS = short messaging service; MSF = Médecins Sans Frontières; DOT = directly observed therapy; SAT = self-administered therapy; HCW = health care worker.

A nurse at the clinic who called in a day before to remind her to collect the treatment... It had a good impact because she collects her medicines on time now...we are all involved as a family. (aunt, 64 years)

The girlfriend of a patient explained how she had requested that her partner take his treatment daily at the clinic, under supervision.

I asked if they can let him take the treatment at the clinic every day because sometimes I am not at home so I cannot be sure he has taken his medication. They did not refuse... (girlfriend, 42 years)

I will not blame them because they were helping me so I did not have to come to the clinic every day [SAT]. The problem was with me being tempted [to drink]. So I was brought back to daily DOT. (P7, 48-year-old male)

For one patient, having the counsellor tell her to take her treatment and take her life seriously, along with her fear of dying, became a motivation to receive treatment:

She would know when I did not take collect my medication, she would tell me I need to take my life seriously and take my pills...I do not want to die. (P2, 34-year-old female)

Another patient recalled how HCWs explained to him that the 'sickness' would grow if treatment was not taken:

The nurse...used to talk to me... They don't shout and they tell that if you don't take your treatment the sickness is growing. (P6, 30-year-old male)

Health care worker perceptions

Most HCWs described the intervention as giving

'hope', 'relieving stress' and being 'helpful'. All HCWs stated that the intervention counsellors were more successful at finding patients who interrupted treatment than the CCWs who are bound to specific geographic areas.

When we send CCWs to find client[s], they do not come. But when we send the [counsellor]...it's just a day, tomorrow morning they are here. (42-year-old female HCW)

The [intervention counsellors] do not focus on a specific [geographical] area. Unlike the CCWs. The CCWs, they can only recall patients that are around certain addresses. (34-year-old male HCW)

The HCWs described what they appreciated most.

The feedback you get... The home visit and investigating, they give you the feedback on the reasons the patient could be interrupting. I appreciate that. (40-year-old female HCW)

The staff also felt relieved that responsibility could be shared.

You don't feel like you have to carry all the responsibility by yourself... it gives [you] better understanding. Especially if there is a family interview. (40-year-old female HCW)

However, half of the HCWs expressed their frustration and helplessness, as the model was limited in its ability to make an impact on patients repeatedly interrupting their treatment despite HCWs' efforts to support them.

We even reschedule times...trying to assist them. [Saying] 'you can come at such a time. You don't have to wait. They don't wait at all.' So when they

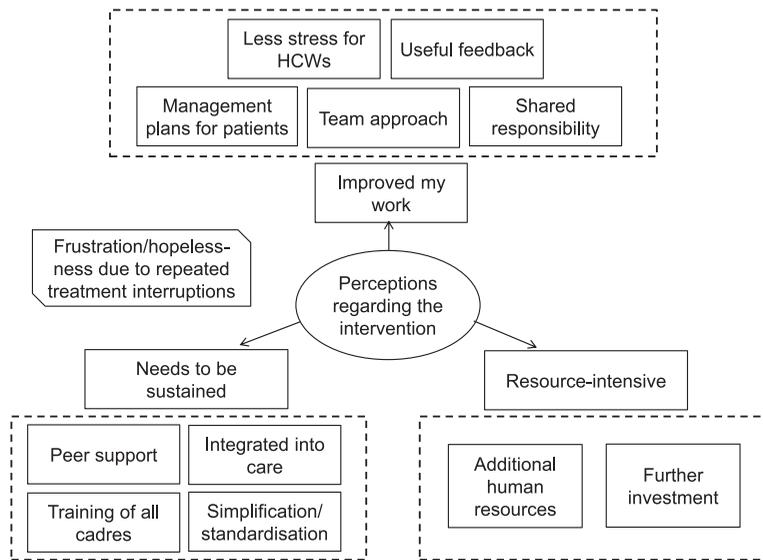


Figure 4 Schematic presentation of HCW perceptions of treatment interruption intervention. HCW = health care worker.

interrupt again, I feel that despite all that I am doing, it is not helping. (42-year-old female HCW)

When they come in [post-interruption], you feel like ‘I am tired of this person because they do the same thing over and over and over.’ (30-year-old female HCW)

Recommendations for the programme from health care workers and key informants

Most HCWs recommended training, peer support and addressing HCW attitudes to ensure the sustainability of the intervention (Figure 4). Training was highlighted as a way forward by several participants:

I think there should be a process of knowledge transfer [from intervention counsellors]. (34-year-old female HCW)

The CCWs can take over [if they get] more training. (42-year-old female HCW)

One HCW raised the issue of peer support:

The current [intervention] counsellors are ex-patients themselves. And they have got that understanding. It’s part of their personality. That personality, it’s part of what gets the patient back. (46-year-old female HCW)

Several HCWs reflected that HCW attitudes that lead to reluctance to return to care among patients after treatment interruption should be addressed.

I have many patients who come from different areas and you ask them ‘why don’t you go back?’ And they say ‘I am scared of being shouted at’. Obviously, that’s happened before so they are fearful to go back to that clinic because they don’t want to face the consequences. (28-year-old male HCW)

Knowledge is maybe important but it’s more attitude; and how do you [intervention counsellors] pass that on? In particular, when staff is always changing. That’s why I am saying there must be a social worker who oversees ... (59-year-old female HCW)

Key informants’ views

Key informants echoed recommendations made by HCWs—the buy-in and sustainability of a new intervention depended on how well it could be integrated into current standard of care activities and resources. A female key informant reflected that an integrated care package (HIV-TB clinical and psychosocial care package) would be more sustainable:

We find an integrated package of care is much more sustainable actually... Cause everyone can keep each other responsible for their role in this scenario...the training needs to happen.

Training models for all cadres of staff that encourage the engagement of patients in understanding why they are interrupting treatment were also suggested by another female key informant:

...doctors to nurses to counsellors. I think all need to be trained in models of engaging with patients... because I don’t think we understand the social and other issues in patients’ lives which have led them to default.

DISCUSSION

This qualitative study of a novel, patient-centred, early intervention for patients interrupting DR-TB treatment showed that the model was well perceived and viewed positively by patients, key support

persons, HCWs and key informants who manage the programme. Barriers to adherence and challenges in adhering to DR-TB care, as evidenced by quantitative and qualitative studies,^{1–3} were confirmed in our study by patients who interrupted their treatment but had not been declared LTFU.

Two main themes stood out as patients described the barriers to treatment adherence: fear of being ‘scolded’ by HCWs and self-blame for interrupting their treatment. They described being fearful that they will be shouted at by staff for missing a few doses or interrupting their treatment. The apprehension and fear of reproach became a barrier to remaining in care, and this fear has been reported before.^{16,17} The sense of self-blame described in the literature among patients with diabetes mellitus struggling to achieve treatment goals¹⁸ is expected in an environment where patients are blamed by others, HCWs and families for their poor adherence.^{17,19,20} This remains an area that requires further study, particularly in HIV and TB patients. Patients also described how HCWs included the health consequences of non-adherence in counselling approaches, giving patients a choice between taking their treatment or not. Patients described trying to avoid these health consequences as a reason for remaining in care; this supports one theory present in the literature that patients make ‘informed decisions’ about treatment adherence.^{19,21}

‘Supportive HCWs’ (the idea that HCWs could be supportive) also emerged from the data. The majority of the patients felt that intervention HCWs were supportive once they were back in care—this has not been documented in the literature to our knowledge. Frustration targeted only towards patients who repeatedly interrupt treatment leads to the assumption that occasional treatment interruption is to be expected and considered ‘normal’ among patients with prolonged and difficult treatment journeys. The focus was on ensuring that patients returned to and remained in care through the provision of individualised management plans, as such strategies are lacking, according to a recent literature review.¹⁶

The counsellors were peers (successfully treated for TB in the past), and this element of support was perceived to be beneficial by patients and HCWs. A relatively recent systematic review reported that patients had better outcomes under programmes in which patient-care provider relationships were good and if CCWs were engaged.⁴

Proof of the efficacy of DOT in DR-TB is controversial, and several recent studies have favoured models such as SAT, in which patients are empowered to take their medications at home.^{13,22} In Khayelitsha and elsewhere, researchers have advocated for and piloted alternative models to DOT, challenging the ‘one size fits all’ approach.^{13,23} The intervention described in the current study allowed

for management plans to be tailored to patient needs, and both DOT and SAT were offered as options.

However, despite the benefits, the model did not seem able to address patients with repeated interruptions. This resulted in frustration among some HCWs. Research into a more intensive, structured, comprehensive screening method is needed to identify this high-risk group and to provide targeted interventions that address barriers to adherence, which could include even more support.

Our study was subject to several limitations. Overall, the qualitative nature of the study potentially affected the generalisability of the data presented. HCWs seemed overly concerned and preoccupied with the probability that the programme might end. This might have influenced their assessment of the programme; the focus of the discussion was thus diverted towards sustainability and scalability before a comprehensive appraisal was made.

Nevertheless, our study was strengthened by the triangulation of the data between patients, key support persons, HCWs and programme managers. We have explored a novel intervention which, although pragmatic, field-based and patient-centred, contains very little literature. We followed the consolidated criteria for reporting qualitative research (COREQ)²⁴ checklists to report our study findings.

On the basis of these results, we recommend a model for bringing DR-TB patients who have temporarily interrupted treatment back into care, with the long-term aim of preventing LTFU. Key elements of the model should contain an early warning system that allows for early tracing of patients interrupting treatment, a motivational counselling approach that ‘normalises’ temporary, occasional treatment interruptions that is ideally delivered by peers, an individualised, patient-centred management plan and tools which involve the patients themselves, their key support persons and a multidisciplinary team of HCWs.

CONCLUSION

A structured intervention based on early tracing, peer counselling and an individualised integrated management plan by a multidisciplinary team was considered beneficial and acceptable to address treatment interruption among DR-TB patients at risk of LTFU. In the future, resources should be invested in similar interventions to address the challenges faced by patients and health care systems and to reduce LTFU rates.

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R É S U M É

CONTEXTE : Les interventions destinées aux patients qui interrompent leur traitement de tuberculose pharmacorésistante (TB-DR) sont rarement rapportées et évaluées. Une nouvelle intervention, centrée sur le patient, destinée aux patients à risque de perte de vue (LTFU) au cours d'un traitement de TB-DR, a été mise en œuvre à Khayelitsha, Afrique du Sud, depuis septembre 2013.

OBJECTIF : Explorer les expériences et les perceptions des patients, des principales personnes de soutien, des travailleurs de santé (HCW) et des gestionnaires de programmes dans un modèle centré sur le patient.

SCHEMA : Cette étude qualitative a consisté en 18 entretiens approfondis avec des patients, des personnes de soutien, des HCW et des informateurs majeurs ainsi qu'une discussion en groupe focal avec les HCW, entre juillet et septembre 2017. Les données ont été codées et analysées par thème.

RÉSULTATS : Ce modèle a été bien perçu et vu positivement par les patients, les prestataires de soins et les gestionnaires de programme. La « normalisation » et la tolérance d'interruptions sporadiques du traitement, la recherche des patients, des plans de prise en charge individualisée et le soutien par les pairs ont été perçus comme bénéfiques à la rétention des patients en traitement. Bien que ce modèle ait été exigeant en termes de ressources, les HCW ont été convaincus qu'il « devait être pérennisé » et ont proposé des solutions en vue de sa standardisation.

CONCLUSION : Une intervention basée sur la recherche précoce des patients qui interrompent leur traitement, les conseils délivrés par les pairs et des plans de prise en charge individualisée par une équipe multidisciplinaire ont été considérés comme un modèle bénéfique et acceptable pour soutenir les patients à risque de LTFU au cours d'un traitement de TB-DR.

R E S U M E N

MARCO DE REFERENCIA: Son escasos los informes y las evaluaciones de las intervenciones realizadas poco después de que los pacientes interrumpen su tratamiento por tuberculosis farmacorresistente (TB-DR). Desde septiembre del 2013 se puso en práctica una nueva intervención centrada en los pacientes y dirigida a las personas con riesgo de pérdida durante el seguimiento (LTFU) en Khayelitsha, Suráfrica.

OBJETIVO: Explorar las experiencias y las percepciones de los pacientes, las personas que prestan un apoyo importante, los profesionales de salud (HCW) y de los gestores de programas del modelo centrado en el paciente.

MÉTODO: Fue este un estudio cualitativo que comportó 18 entrevistas exhaustivas a los pacientes, las personas que prestan un apoyo importante, los HCW y los informantes clave y un grupo de opinión con HCW y se llevó a cabo de julio a septiembre del 2017. Los datos se codificaron y se realizó un análisis temático.

RESULTADOS: Se observó una buena comprensión y una apreciación positiva del modelo por parte de los pacientes, los HCW y los gestores de programas. Los aspectos percibidos como favorables a la retención de los pacientes en la atención fueron la 'normalización' y la tolerancia de las interrupciones esporádicas del tratamiento, la localización de los pacientes, los planes de manejo personalizados y el apoyo por pares. Aunque el modelo es exigente en recursos, los profesionales están convencidos de que 'es necesario mantenerlo' y proponen soluciones encaminadas a lograr su armonización.

CONCLUSIÓN: Una intervención basada en la localización temprana de los pacientes que interrumpen el tratamiento, el asesoramiento prestado por pares y planes de manejo individualizado y ejecutada por un equipo multidisciplinario se considera como un modelo útil y aceptable de apoyo a los pacientes expuestos a LTFU de la TB-DR.
