

'I cry every day': experiences of patients co-infected with HIV and multidrug-resistant tuberculosis

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Abstract

OBJECTIVES To understand patients' challenges in adhering to treatment for MDR-TB/HIV co-infection within the context of their life circumstances and access to care and support.

METHODS Qualitative study using in-depth interviews with 12 HIV/MDR-TB co-infected patients followed in a Médecins Sans Frontières (MSF) clinic in Mumbai, India, five lay caregivers and ten health professionals. The data were thematically analysed along three dimensions of patients' experience of being and staying on treatment: physiological, psycho-social and structural.

RESULTS By the time patients and their families initiate treatment for co-infection, their financial and emotional resources were often depleted. Side effects of the drugs were reported to be severe and debilitating, and patients expressed the burden of care and stigma on the social and financial viability of the household. Family caregivers were crucial to maintaining the mental and physical health of patients, but reported high levels of fatigue and stress. Médecins Sans Frontières providers recognised that the barriers to patient adherence were fundamentally social, rather than medical, yet were limited in their ability to support patients and their families.

CONCLUSIONS The treatment of MDR-TB among HIV-infected patients on antiretroviral therapy is hugely demanding for patients, caregivers and families. Current treatment regimens and case-holding strategies are resource intensive and require high levels of support from family and lay caregivers to encourage patient adherence and retention in care.

keywords HIV, multidrug-resistant tuberculosis, co-infection, adherence, qualitative, India

Introduction

World Health Organization (WHO) (2010) estimates the number of multidrug-resistant tuberculosis (MDR-TB) cases in 2009 in India at 99 000 (79 000–120 000), which represents approximately 25% of the global burden of MDR-TB. The Indian Revised National TB Control Programme (RNTCP) has been scaling up diagnostic and treatment services for MDR-TB (DOTS Plus) in a phased manner across the country since 2009 (RNTCP Annual Status Report 2012). However, because of limited availability of accredited laboratories for culture and drug susceptibility testing (DST), access to timely diagnosis and treatment remains poor. Infection with human immunodeficiency virus (HIV) further complicates management of MDR-TB and poses an extremely demanding treatment schedule for patients (World Health Organization 2011). Both diseases remain highly stigmatised in the Indian context and patients struggle to access

affordable treatment and remain adherent (Kumarasamy *et al.* 2005; Babu & Laxminarayan 2012).

Treatment adverse events, pill burden, rigidity of DOT, psychosocial support and interaction with health personnel pose major challenges to adherence for concomitant anti-TB and antiretroviral treatments (Munro *et al.* 2007; Shargie & Lindtjorn 2007; Ingersoll & Cohen 2008; Sagbakken *et al.* 2008; Gebremariam *et al.* 2010; Toczek *et al.* 2013). However, there are disappointingly few studies that describe MDR-TB treatment experiences from high HIV prevalence settings or among co-infected patients (Mills *et al.* 2006; Munro *et al.* 2007; Johnston *et al.* 2009; Orenstein *et al.* 2009; Gonzalez *et al.* 2011). Understanding the challenges faced by HIV-infected patients being treated for MDR-TB, their families and their caregivers is essential for improving the quality of care provided and the likelihood of retaining patients in care. We report here from a qualitative study conducted between April and October 2012 among HIV/MDR-TB

co-infected patients registered with a clinic supported by Médecins Sans Frontières (MSF) in Mumbai, India. MSF began treating MDR-TB among HIV-infected patients in May 2007, and by April 2012, the cohort included 120 patients. Patients receive therapy through an ambulatory, community-based programme that has been described earlier (Isaakidis *et al.* 2011, 2012). Treatment regimens are individualised, based on the first- and second-line drug susceptibility testing (DST) results and on the patient's treatment history. Patients are treated for at least 20 months, based on WHO guidelines updated in 2011 and put on antiretroviral treatment (ART) for life following the national ART protocol and WHO guidelines (WHO 2010). Clinical and psychosocial needs of patients are met by separate teams that function in consultation with each other. All treatment, including investigations, consultations, medications and counselling, as well as hospitalisation if needed, is provided free of cost. Additional resources are used to trace a relatively small cohort of defaulting patients, yet many patients are unable to stay in care (Errol *et al.* 2012). The study draws on the perspectives of patients, family and lay caregivers as well as formal providers to explore the factors influencing treatment adherence to ART and second-line TB treatment.

Methods

Twelve patients were purposively selected from the a cohort of 33 patients who were receiving treatment for

MDR-TB and HIV from the MSF clinic in Mumbai, India at the time of the study. The selection of patients was made to adequately represent the influence of gender, socio-economic characteristics and treatment phases on the experience of being on treatment (Table 1).

Ten MSF healthcare providers working at the clinic and in the community with co-infected patients were selected to include all categories of staff; these included doctor ($n = 1$), clinic nurses ($n = 2$), outreach nurses ($n = 2$), nurse pharmacist ($n = 1$), social worker ($n = 1$), counsellor ($n = 1$), peer educator ($n = 1$) and receptionist ($n = 1$). Five lay (usually family) care providers (LCP), identified by the researchers as providing substantial care and support for the index patient, were purposively selected.

Data collection

Data collection took place between May and September 2012. Informed consent was obtained from all participants. In-depth interviews were conducted with patients and care providers using flexible topic guides to allow for open-ended answers and probing on emerging themes.

Patient interviews were conducted in Hindi or Marathi and covered their experiences of help-seeking prior to enrolment at the MSF clinic, care received from MSF providers and their expectations regarding improved care and support while on treatment. Interviews with lay providers elicited views on their roles and challenges in caring for co-infected individuals on treatment. Interviews

Table 1 Profile of the sample patients

Patient ID†	Sex	Age	Marital status	Family support‡	Treatment buddy	Treatment status (MDR-TB)
P1	Male	52	Married	Lives with extended family	Wife	Completed
P2	Male	40	Married	Lives with extended family	Wife	CP
P3	Male	50	Married	Lives with extended family	Wife (LCP2)	CP
P4	Male	42	Married	Lives with spouse; migrated to Mumbai for treatment	Wife (LCP2)	IP
P5	Female	37	Married	Lives with extended family	Husband (LCP3)	IP
P6	Male	40	Married	Lives with extended family	Wife (LCP1)	IP
P7	Male	39	Married	Lives with extended family	Wife (LCP4)	IP
P8	Male	35	Married	Lives with spouse; alienated from wider family	Wife	CP
P9	TG	25	Unmarried	Lives alone	Grandmother	CP
P10	Female	35	Married	Lives with spouse; alienated from wider family	Husband (LCP5)	IP
P11	Male	47	Married	Lives with extended family	Wife	IP
P12	Female	34	Deserted	Lives in institute for destitutes	MSF staff member	CP
P13	Male	38	Widowed	Lives with extended family	Brother	IP

†The interview with P4 was not used in this article because the patient withdrew participation after partial interview.

‡In this population, the majority of households are extended or joint. It is unusual for a married couple to live separately from the husband's family.

CP, continuation phase; IP, intensive phase.

with MSF providers focused on their roles in supporting patients on treatment, and the challenges faced in patient retention. The majority of interviews were recorded using a digital recorder, transcribed and translated into English. Notes were taken in cases where the respondents did not wish to be recorded and expanded immediately afterwards.

Data analysis

Data transcripts were reviewed on an ongoing basis, and emerging themes that related both to our original questions as well as unanticipated areas were noted. At mid-point through the study, the researchers began to develop a set of codes relating to three broad dimensions of patients' experience of being on long-term treatment: individual experience (physiological and psychological); the impact on social relations including those within the patients' household; and patients' engagement with the health system and providers over the course of treatment (structural). Once saturation was reached, the data were indexed and manually analysed by two of the researchers. Competing interpretations were resolved through ongoing discussion.

Ethics

The study was approved by the Institutional Review Board of The Maharashtra Association of Anthropological Sciences – Centre for Health Research and Development (MAAS-CHRD), Pune, India. The MSF Ethics Review Board, Geneva, Switzerland reviewed the protocol and advised on the study. Patients were given information about the purpose of the study and their role within it, and informed consent was obtained from them if they were available and willing to participate.

Results

Treatment experiences of patients co-infected with MDR-TB and HIV were marked by numerous problems that reflected a complex interplay of physiological, psychosocial and structural challenges. We examined these dimensions through close attention to the trajectory of patients as they accessed, initiated and struggled to stay on treatment with the support of family and organisational care providers.

Accessing treatment: 'the last chance'

Fragmented, non-integrated care and delays in initiation of effective treatment for co-infection meant that patients'

resources were often depleted by the time they reached MSF. Patients were often in critical condition, and their families financially and emotionally exhausted from the long help-seeking journey. For most patients, this journey had included two rounds of treatment, for new and recurrent TB. Relating the case of a patient who died while on treatment, an MSF peer educator highlighted the impact of the high burden of care on her brother and mother, who were '*sapped of energy*' by the time they came to MSF, '*already very tired from years of taking care*'.

While initiation on to treatment for MDR-TB and ART at MSF represented an important turning point in the trajectory of co-infected patients, it was also seen as the last possible resort when all other options had failed: 'There is no other treatment and no way out. This is the end. There are no treatments after this, this is the last chance' (P6, male, 40 years).

Being on treatment

'Worse than the illness itself': *side effects*.

Once initiated on treatment, patients had to adjust to daily doses of up to 21 tablets and intramuscular injections for 9–12 months, an extreme regimen associated with severe and painful side effects:

'I have to take them [medicines and injections] daily. And I cry every day. Every day I cry for an hour ... the place where they give the injection becomes stone hard. When I take the injection, I can't lift my legs, my legs hurt a lot and I am unable to walk. If you give me pills, I will eat them. As many as you want me to [eat]. I have no problems with that. The injections are very painful. (P5, female, 37 years)'.

Side effects of MDR-TB drugs – nausea, vomiting, giddiness, lethargy, tinnitus, blurring of vision, depression, suicidal tendencies – were described to be '*as bad as or worse than the illness itself*'. The wife of P6 described drastic changes in her husband's temperament after he started treatment:

'He used to take the pills and that caused him to be very uncomfortable and he would get short tempered because of that. He would always say that he is going to leave the house and go away. He was not able to sleep night and day (...) He would lie down in the loft upstairs after taking the pills and would not want even a draft of air or a ray of light in front of his eyes. He would stay there all day till his dizziness passed away (LCP1, female, 35 years)'.

P2, male, 40 years simply said: '*I thought I was going to die because of the medicines...it was that bad*'.

'Stay separately or stay far away': *stigma and loss of support*.

Apart from the physical challenges, many patients and their families expressed the emotional strains of coming to terms with what P1 described as '*the worst of the worst illnesses*'. While both TB and HIV are considered shameful diseases, patients considered HIV to be more stigmatising than MDR-TB. Most patients had disclosed their HIV status only to their spouses and parents, but not to friends or the extended family. This limited patients' and their families' chances of seeking social and emotional support to cope:

'I was dealing with it all by myself. I used to cry quietly. My mother in law was also very sad when she found out. (...) I only told her [my sister] and no one else. She also said she would not tell anyone as it was not something one can tell easily. She did not even tell her husband. I did not even tell my brother as his wife may just blurt it out in front of other people. (LCP1, female, 35 years)'.

Several patients spoke about the embarrassment and loss of self-respect in taking DOT at the doctor's clinic:

'I go to the doctor, there might be 4–5 patients over there, and if I take medicines in front of them, then they will ask 'what is this medicine for?' The doctor will tell them that this man has HIV, then the way other persons look at you changes, people try to keep away from you. And sometimes I vomit, or bring out sputum then they pinch their noses. (P8, male, 35 years)'.

Some patients lost all support when diagnosed with co-infection. In her 5th month of pregnancy, P12, 34 years, was diagnosed as HIV positive. Her husband forced her to terminate the pregnancy, but later abandoned her '*as he could not afford my treatment*'. She sought shelter at a church-run centre for PLHIV after her natal family asked her to move out. P9, a male to female transgender, 25 years old, was asked to leave her transgender¹ group home when she was diagnosed with MDR-TB. Before she became sick, she cooked for the group but once she was diagnosed, the group members refused to eat what she cooked and looked down upon her:

'They say [you should] 'be separate, eat separately, keep your water separate, and stay separately or

stay far away'. I am very sad in my heart, my heart aches because of this.... What can I do?'

'I stopped going to work and stayed home': *the burden of care*.

Patients' households were seriously socially and financially affected by the burden of disease. Half of the patients who were employed before they got sick ($n = 5/10$) had not resumed work even after being on treatment for a year or more and were consumed by worry and guilt for not being able to contribute to the household. Often the family members who cared for the patient needed to organise their lives around the patient's treatment schedule. Spouses and family members attended to the patient's physical and emotional needs and took on their social responsibilities as well. The husband of P10 (LCP5) had to take leave from work in order to accompany her to the clinic. He commented: 'Ever since my wife has come into my life all I have been doing is going to this hospital or that one. I don't think there is a hospital left where we have not gone'. P6 lamented that his wife had to do housework in other people's houses due to his inability to work, and his wife (LCP1, 35 years) confirmed her husband's complete dependency on her: 'I take care of him all day and I even stopped going to work and stayed home for 3 months'.

Staying on treatment

'They helped me find courage': *the role of organisational and family support*.

Médecins Sans Frontières and family providers played a key role in supporting patients to cope with the physical and mental hardships associated with co-infection and its treatment. Patients appreciated the empathy shown by MSF care providers and the non-discriminatory environment of the clinic. P1, (male, 52 years old), for example, suggested that the staff at MSF were very different from '*other places [in which] even doctors are not nice to HIV/ TB patients*'. P7 (male, 39 years old) felt that '*the way guidance is given here [at MSF] has itself made half my illnesses go away*'. P12 (female, 34 years old) detailed the level of emotional and practical support that was provided:

'They [MSF staff] stood by me. They gave me emotional support, helped me find courage. R [nurse] said if ever I did not feel well, or felt that I needed to talk, I was to give her a missed call [on her mobile phone] and then she would call back. (...) It was like she was with me all the time, to help me whenever I needed help. (...) They have cared for me – more than my blood relatives.'

¹This patient was a member of the 'hijra' community where biological men identify themselves as women, adopt feminine names, wear women's clothing and may opt for ritual castration.

Identifying and counselling a treatment ‘buddy’ to help the patient complete treatment was one of the major activities provided by the MSF patient support team. The MSF social worker described their importance:

‘They [patients] are very disturbed psychologically... they are very irritable and the family members or buddies are fed up of all this. We try to explain to them what kind of problems can come up if they do not have the support of family members or buddies and how to maintain that support (MSF social worker, male, 35 years)’.

In the case of a patient who died, the clinic nurse suggested it was the fact that ‘*he had nobody*’ which led him to be ‘*careless about treatment*’. The nurse pharmacist, on the other hand, highlighted the responsibility of relatives to make sure patients took their medicines correctly and on time. Some family members, she said ‘*do this diligently*’ citing the example of a patient’s wife who took out his daily medicines before she left for work. Lay care providers’ accounts confirmed the extent of time and energy expended in supporting patients on treatment:

‘Throughout the day I had to keep offering him something to eat (...) If I was not there he would not eat anything and would not bother with his diet (...) He was not even able to walk. He would hold on to me to walk. He could not even go to the bathroom. We live in small rooms and the toilets are outside but he used to sit for toilet in the house itself as he was not able to walk till the toilets. I used to help him with all of that (LCP1, female, 35 years)’.

This was not limited to spouses. P9, the transgender staying in a pseudo-familial group, for example, talked about her ‘*grandmother*’ (elderly leader of the group) who would ‘*keep a tab on whether I had my medicines or not*’ and tell her not to worry, as well as supporting her with money for her transport.

‘When someone gets MDR [TB], why doesn’t anyone come?’: *the challenges of retention in care*. MSF care providers were often frustrated by the challenges of supporting patients and their families through the arduous treatment especially when patients were lost to follow up or their families failed to provide emotional support. The MSF physician (female, 42 years), for example, expressed some resentment that despite trying so hard –‘*we give 100% for the treatment of the patients*’, some patients were non-adherent. The non-medical support staff, who helped patients keep their appointments, described the effort needed to ensure patients were regular:

‘There is one patient who has a hearing problem. We always talk to her daughter. I have to make reminder calls to her very often as her daughter forgets very often. It has happened many times. (...) So now that I know she forgets, I make sure I remind her even if I do not call anyone else. Once she did not turn up for her 10 am appointment. I waited for her till 10.30 and then when I called her she said ‘oh was there an appointment today? I did not know’. (MSF receptionist, female, 33 years)’.

However, others recognised that adherence to medications was not just a medical issue. The MSF peer educator (male, 34 years) suggested that although MSF was fully equipped to deal with the clinical aspects of adherence, social aspects were more complex to address: ‘MSF, they do 100–110% medically. Socially, we try our best, but I feel maybe we [only] tackle about 80%. In our society, if someone gets malaria, ten people will help him, take him to hospital. When someone gets MDR [TB], why doesn’t anyone come? Does anyone care for him? (...). This is the reality’.

Discussion

To our knowledge, this is the first qualitative study of patients with HIV and MDR-TB in India. While other studies have looked at treatment adherence among people on ART and among patients on second-line TB treatment, this study is unique in triangulating the perspectives of 12 HIV/MDR-TB co-infected patients and a number of their lay and formal care providers in facing the challenges of adhering to treatment. Our findings reflect diversity in experiences and views. It is important to note, however, that patients were drawn from a specific organisational cohort receiving free treatment and care services that go far beyond the services offered in public sector clinics; therefore, their experiences are not representative of the wider affected community. Despite the extent of support received from the MSF clinic, patients found it extremely difficult to remain adherent; the situation for patients who do not benefit from this organisational support can be envisaged to be far worse. This was indicated in part through our sampled patients’ accounts of their experiences of seeking treatment in the private and public sector prior to reaching MSF, confirming the limited access that HIV/MDR-TB co-infected patients in a large city like Mumbai continue to have.

Our sample of patients described side effects of the drugs as being worse than the disease itself and detailed the heavy social and financial burden of prolonged treatment for two highly stigmatised diseases.

Indeed, stigma emerged as an important barrier to treatment seeking and adherence. Patients were embarrassed to follow DOT in facilities located in their neighbourhoods. Stigma also led to non-disclosure of illness resulting in further isolation of patients and lack of mobilisation of additional support resources from family and friends. Studies have shown that HIV-related stigma may have a negative effect on TB treatment in co-infected patients. Studies from Africa and South East Asia showed that although both TB and HIV were stigmatised, more stigma was attached to HIV, similar to our findings, and that reasons for default in TB patients with HIV were mostly to HIV-related stigma and discrimination (Ngamvithayapong *et al.* 2000; Daniel & Alausa 2006).

In the absence of patient- and provider-friendly treatment regimens, interventions to ensure patients' long-term adherence to current treatment regimens are resource-demanding – placing a high burden of care and support on family and lay caregivers. Scale-up of diagnosis and treatment for MDR-TB and ART will, for the near future, remain extremely challenging.

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