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Care of the patient with XDR-TB who has failed treatment

Karen Blake Jacobson, Matthew Tate, Francois Eksteen, Anthony Moll, Nesri Padayatchi, Gerald Friedland, and Sheela Shenoi

Icahn School of Medicine at Mount Sinai, New York, NY 10029, USA (KBJ); Church of Scotland Hospital, Tugela Ferry, KwaZulu-Natal, South Africa (MT, FE, AM); Centre for the AIDS Programme of Research in South Africa (CAPRISA), TB-HIV MRC Extramural Unit, University of KwaZulu-Natal, Durban, South Africa (NP); and AIDS Care Program, Yale School of Medicine, New Haven, CT, USA (GF, SS)

Karen Blake Jacobson: karen.jacobson402@gmail.com

Abstract

In early 2014, a man aged 46 years with HIV and a distant history of tuberculosis treatment was admitted to the communal medical ward of a district hospital in rural KwaZulu-Natal, South Africa, in respiratory distress. He was initially treated empirically for bacterial pneumonia. Sputum taken on day 5 of his hospital stay was positive for acid-fast bacilli with rifampicin resistance on line probe assay. After 11 days in hospital, his doctors learned that he had previously failed treatment for extensively drug-resistant (XDR) tuberculosis and had been discharged without being given further treatment options. He had been living at home with his wife, elderly mother, and five young children, sharing a bedroom with several other family members. The patient and his family believed he had successfully completed treatment; they did not understand his prognosis or the transmissibility of his disease.

This case portrays the confluence of problems that characterise the growing epidemic of XDR tuberculosis in sub-Saharan Africa and worldwide.^{1,2} Although XDR tuberculosis (defined as resistance to isoniazid, rifampicin, a fluoroquinolone, and a second-line injectable drug) can be acquired as a result of unsuccessful treatment of drug-sensitive tuberculosis, a high proportion of cases result from direct transmission, in both health-care and community settings.^{3,4} In South Africa, treatment of XDR tuberculosis is provided exclusively at centralised referral centres in each province. Bed shortages at these facilities result in patients who fail treatment of XDR tuberculosis (defined as absence of culture conversion after 12 months of treatment) being discharged home to make room for newly diagnosed patients.¹ Treatment outcomes for XDR tuberculosis are very poor; only 20% of

Correspondence to: Karen Blake Jacobson, karen.jacobson402@gmail.com.

See **Online** for appendix

After our patient's diagnosis was made known, the local DOTS team brought him to the district's specialist MDR tuberculosis facility in a neighbouring town, where he was admitted to hospital under standard infection control practices. He improved with symptomatic treatment and was discharged home. During the subsequent month, the patient presented to the district hospital twice more complaining of dyspnoea, but hospital staff quickly identified him as having XDR tuberculosis via a note placed prominently inside his medical record folder. He was isolated from other patients and treated symptomatically as an outpatient. 4 weeks after his final outpatient visit, he passed away at home.

We declare no competing interests.

patients ever achieve culture conversion.¹ However, findings from one study¹ showed a median time to death of 19·8 months (IQR 4·16–26·04) in South African patients with XDR tuberculosis discharged after treatment failure, resulting in a prolonged period of potential continued transmission to their families, communities, and fellow patients in community health-care settings.

The long-term solution to XDR tuberculosis will be improved treatment options and an increase in the capacity of health facilities to accommodate all identified patients with XDR tuberculosis immediately after diagnosis. However, this will take time and substantial additional resources to achieve, and ongoing transmission of XDR tuberculosis is happening now. Patients with XDR tuberculosis are ethically entitled to appropriate health services, but transmission of drug-resistant tuberculosis to others must be avoided. Fortunately, many simple measures can be enacted immediately, through the full use of health systems already in place in South Africa at the district and community levels, to make the current practice of home care safe and sustainable for the foreseeable future. We need an immediately implementable plan for patients who have failed treatment for XDR tuberculosis and have nowhere to go but home.

Communication between the patient and provincial and local health systems is essential. Both patients and their household members must receive thorough counselling before discharge about the patient's prognosis and continued infectiousness.^{2,5} Clear institutional policies detailing responsibility for patient counselling, proper training for staff, and culturally appropriate educational materials might help overwhelmed staff incorporate proper counselling into routine practice. A robust communication network is needed for facilities specialised in XDR tuberculosis to quickly and efficiently notify district hospitals and primary health clinics of a patient's return to the community. Timely notification allows the district hospital or local health clinic to reach out to the patient through existing tuberculosis control (directly observed treatment, short-course [DOTS]) or home-based care programmes to provide education, assess the patient's continuing health needs (including HIV treatment and palliative care), and facilitate linkage to care. Should a patient seek care at a local facility, they can be identified as having XDR tuberculosis through colour-coded stickers on health records, medical alert bracelets, or simple screening questions such as history of tuberculosis treatment in the city where the provincial centre is located. The identification of patients with XDR tuberculosis obviously raises issues of patient confidentiality, and this matter must be carefully considered in search of the optimum balance between individual privacy and the health of other patients.

Local resources such as DOTS or home-based care programmes can assess infection control needs and help implement infection control strategies in patients' homes and community settings, such as counselling of patients and their families to keep windows open,⁶ sleep in separate rooms, avoid crowded indoor locations, and wear surgical masks (patients)⁷ or N95 respirators (family members) when necessary—and distributing these supplies in abundance (appendix).⁸ These programmes can also undertake regular contact tracing of patients' household members and other potentially exposed people. Ongoing support of patients and their families, including access to social welfare services, can help to decrease opportunities

for transmission. For example, continuation of the disability grant until death would help eliminate the need to seek employment and thus prevent transmission in the workplace.

WHO has declared palliative care a basic right for patients with tuberculosis.^{9,10} Although inpatient hospices (the infamous sanatoria) might become more commonplace once again,¹¹ we know from the era before the introduction of highly active antiretroviral therapy that home-based palliative care can be efficacious and cost-effective in end-of-life care for patients with HIV/AIDS.^{12–14} Through local DOTS and home-based care programmes and NGOs with experience in HIV/AIDS hospice care, nutritional support, relief from nausea and pain, and even spiritual care can be provided at home. More complex complications including respiratory failure can be managed at home and in outpatient facilities, under the supervision of physicians in partnership with community health workers.

Under South African law, forced hospital admission of infectious patients with XDR tuberculosis is permitted as a last resort. However, individual autonomy should be preserved whenever possible; forced hospital admission does not benefit patients who have failed treatment.² Local health workers can monitor these patients living at home, with opportunities for intervention with further education and support in the case of non-compliance with infection control measures. If patients purposefully continue putting others at risk, collaboration with social services, informed legal partners, and the judicial system becomes necessary.¹⁵

Additional research is needed to determine the optimum health systems approaches that will be successful in resource-poor settings. Our goal should be to strengthen the health system so that it can cope with patients who have untreatable yet highly infectious diseases and to decrease the burden on patients and their families as much as possible.

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