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Hear us! Accounts of people treated with injectables for drug-resistant TB

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BACKGROUND: WHO drug-resistant TB (DR-TB) treatment recommendations now emphasize all-oral regimens, recommending against certain injectable agents and deprioritizing others due to inferior safety and efficacy. Despite increasing focus on patient-centered care, we are not aware of systematic attempts to qualitatively document patients' perspectives on injectable agents. This may inform implementation of WHO guidelines, emphasizing the importance of consultation with affected communities.

METHODS: Testimonies were provided by TB survivors who experienced hearing loss from treatment with injectable agents. Testimonies were submitted in writing in response to minimal, standardized, open-ended prompts. Participants provided a signed consent form (with options to participate anonymously or as a named co-author), and later gave input into the overall shape and recommendations of the article.

RESULTS: Fourteen TB survivors in 12 countries contributed testimonies. The following common themes emerged: lack of access to appropriate testing, information, treatment, or a collaborative treatment environment; the power of supportive care and social environments; stigma and isolation from TB treatment itself and resultant disability; and inaccessibility of cochlear implants.

CONCLUSIONS: Survivor testimonies indicate strong preferences for avoidance of injectable agents, supporting rapid implementation of revised WHO guidelines, as well as for quality and supportive care for both TB and disabilities.

Until recently, injectable agents (amikacin [AMK], streptomycin [SM], kanamycin [KM], capreomycin [CPM]) were the backbone of the globally recommended treatment for drug-resistant TB (DR-TB), despite a lack of quality evidence of efficacy and extensive clinical documentation of their toxicity and limited patient tolerance and adherence.[1–3] Hearing loss, or ototoxicity, is one of the most debilitating side effects of injectable drugs and occurs in up to 61% of patients treated for DR-TB.[2]

Injectable agents used to treat multidrug-resistant TB (MDR-TB) are antibiotics classified as aminoglycosides (AMK, SM, KM) or a polypeptide (CPM). The first of these drugs emerged in 1944 with the discovery of SM in the beginning of the antibiotic era, followed by KM in 1957, CPM in 1960, and AMK in 1976.[4,5] These drugs require intravenous or intramuscular administration, as they are poorly absorbed in the gastrointestinal tract and are therefore ineffective when taken orally.[6] Injectable TB drugs induce ototoxicity by destroying the hair cells in the cochlea, leading to irreparable hearing loss in most cases, since cochlear hair cells do not regenerate.[7] Although aminoglycosides and polypeptides have short half-lives, they accumulate in the fluid of the inner ear and can persistently destroy hair cells even a year after discontinued use.[8] Aminoglycoside and polypeptide antibiotics also have many other serious side effects, including renal damage, gastrointestinal disturbances, and psychiatric disorders,[9] and injections over the series of months previously recommended are painful.[10] Ototoxicity is consistently noted as one of the most impactful side effects and is often met with significant stigma and discrimination from family members, health providers, and local communities, contributing to experiences of social isolation and poverty.[11,12]

In 2019, in recognition of mounting evidence—most notably from South Africa, which removed all injectables from its standard DR-TB treatment in 2018[13]—and of the availability of safer, more effective alternatives, the WHO released updated guidelines for the treatment of multidrug/rifampicin-resistant TB (MDR/RR-TB). The 2019 guidelines follow the WHO's rapid communication in August 2018, when injectables were first deprioritized in favor of all-oral regimens.[14] The revised guidelines feature fluoroquinolones, bedaquiline (BDQ), and linezolid as the treatment backbone, relegating some injectables (AMK, or SM in cases of resistance or unavailability of the former) to a last resort option and only if audiometric monitoring and drug susceptibility testing (DST) are available; and others are not to be included in longer regimens entirely (KM and CPM, as they are associated with poorer health outcomes and the risk of ototoxicity outweighs their benefit).[1] The WHO further strengthened these recommendations at the end of 2019 with a rapid communication noting that "All patients with MDR/RR-TB, including those with additional resistance to fluoroquinolones, stand to benefit from effective all-oral treatment regimens, either shorter or longer, implemented under programmatic conditions".[15]

To capture a diversity of patient perspectives regarding treatment choice and the impact of hearing loss due to injectables, we present here the testimonies and recommendations of 13 patients and survivors of DR-TB—and one survivor of drug-susceptible TB—treated with injectables in 12 countries. These

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KEY WORDS
DR-TB; deafness; hearing loss; ototoxicity

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testimonies demonstrate that despite the heterogeneity of environment or circumstance, common motifs arise in each testimonial that unify the message of resounding harm caused by injectable drugs when presented together. These testimonies were documented before the shift in WHO guidelines recommendations to deprioritize use of injectables, and not only provide support for the 2019 recommendations but can also inform current decision-making, as many countries have not yet adopted or fully implemented these guidelines at the national level.

STUDY POPULATION, DESIGN AND METHODS

Testimonials were contributed by the former patient co-authors in 2017 who had experienced hearing loss after injectable treatment and expressed interest in co-authoring this article. Testimonials were solicited by non-survivor co-authors (EL, JS) by contacting known TB survivor advocates, DR-TB clinicians working in a range of countries who relayed the opportunity to their patients, and leading global institutions engaged in clinical research or treatment of DR-TB (Burnet Institute, Melbourne, VIC, Australia; FHI 360, Durham, NC, USA; KNCV, The Hague, The Netherlands; and Médecins Sans Frontières, Paris, France; Partners In Health, Boston, MA, USA; and the International Union Against Tuberculosis and Lung Disease, Paris, France). Anyone who wished to be a part of this project was included as long as they agreed to contribute their testimony and share authorship of the article. The testimonies are written by the co-authors with only minimal standardized prompts asking them to discuss their treatment experiences and hearing loss. All co-authors have signed a written consent form indicating their willingness to be co-authors and to have their real names (or pseudonyms, as preferred) published. Co-authors who wished to have their photo included have also signed a written photo release consent form. In August 2017, the co-authors wrote their testimonials in English, Spanish, and Romanian. Testimonials in the latter two languages were then translated into English. All testimonials were edited for length and clarity before being returned to co-authors for approval. While the project focused on providing testimonies rather than formal qualitative research, themes were coded according to standard qualitative analysis methods. Co-authors were actively involved in the revision and verification of the updated versions of their testimonials, as well as providing general recommendations and direction for the article prior to submission. No additional ethical clearances were necessary.

RESULTS

Testimonials

Alhassan Musah (Accra, Ghana)

In 2012, I fell ill with symptoms normally attributed to malaria. After ineffective self-medication, then malaria treatment, I developed a cough. It took over a year and a half—including sputum microscopy with inconclusive results, and a pneumonia diagnosis and treatment, before I was finally diagnosed with TB and started treatment. As my physical condition worsened, I could not continue working, and missed some medication refills. Nevertheless, my TB was declared cured after 6 months. When the cough returned, I received different medication for 3 months, and was again declared cured.

A month later, the cough returned. The hospital said there was nothing they could do. My family thought I was possessed. They eventually kicked me out. I was living on the streets, vomiting blood. I prepared to kill myself. However, I heard a voice telling me to visit a certain hospital. There, I was told my case was too complex. But as I was leaving, a man told me about a DR-TB program, which he contacted. Within 3 days, I was referred to a teaching hospital. I was filled with hope, but was told there was no treatment. I returned home again to die.

Two weeks later, the doctor called and said I was eligible for treatment involving daily injections for 2 years. A friend who was a nurse agreed to administer the injections. I had to arrange to get the medicine from the hospital to the nurse's clinic. My nurse was my only support.

Although I was told about the side effects, they were never monitored**.** After 3 months, I realized I was losing my hearing. I alerted the medical staff. My treatment was switched, but the deterioration continued. Today, I have lost about 80% of my hearing and 60% of my sight. I am unable to continue DJing or return to my job as an electrician. Despite the challenges, I am grateful to God to be alive.

Carlos Hernán Sánchez Ríos (Iquitos and Lima, Peru)

My history with TB began in April 2015. I was working as a motor taxi driver in Iquitos (Peru), when I started to lose weight rapidly and coughing. I was diagnosed with and started treatment for drug-susceptible TB. After 2 months, my health was not improving and because of my family history of DR-TB, my doctors believed that I also had contracted DR-TB.

In June 2015, I began the DR-TB treatment regimen, which I took until 2016, when I began feeling better. The treatment was very strong and I couldn't bear to continue with the injections. A few months later, I once again didn't feel well and returned to the Iquitos regional hospital. I was placed on an individualized regimen that included AMK, but I was still testing positive for TB. My doctors recommended that I travel to Lima (Peru) to receive additional treatment.

In February 2017, I was admitted to a hospital in Lima. I received a hearing test when I arrived and discovered I was suffering from light deafness. I was given a treatment regimen that once again included AMK, but I decided to stop the medicine after a month when I realized my hearing loss had become severe.

I was never told that hearing loss could be a consequence of the treatment and I was never monitored for hearing loss back when I was treated in Iquitos. I was never offered substitutes for the injectables, like delamanid (DLM) or BDQ.

I now have a great deal of trouble communicating with people and can only keep up conversation when people write what they want to say to me. I am worried about my hearing, but I want to focus on curing myself of the TB first. I hope that I will be able to receive treatment in the future to help reverse my hearing loss. Without my hearing, I will not be able to work.

The medication for TB should not cause us harm. I put up with my medication because I want to be cured. I wish someone would have just explained to me what the problem was and the drugs that they were giving me. I am now waiting to begin my 24-month treatment regimen here in Lima, but I am worried about not having a place to stay outside of the hospital and how I will get to the hospital if I cannot hear.

Enrique Delgado (Venezuela and Panama)

I was diagnosed with TB in 2009 after some intense months of travel for my job, in the field of telecommunications and electronics. My promising professional career was truncated by this illness. I had no idea that the cure for this illness would come after almost 7 years of treatment, traveling to four countries, a lo-

FIGURE Images of TB survivors and co-authors: **A)** Alhassan Musah; **B)** Carlos Hernán Sánchez Ríos; **C)** José; **D)** Ko Soe Soe; **E)** Mildred Fernando-Pancho; **F)** Morina Gasane; **G)** Nandita Venkatesan; **H)** Veronica V Villegas; **I)** Worknesh Bushura.

bectomy (removing one third of my right lung), and three relapses before finally, being cured of DR-TB.

Aside from the physical and psychological effects of the illness, I suffered from the adverse effects of the medication I took: suicidal thoughts, peripheral neuropathy, changing of skin color, and irreversible deafness. Fortunately, I only lost about 30% of hearing in my left ear and possibly less than 10% in the right. The medications that primarily affected my hearing were AMK (taken for 3 months) and CPM (taken for 4 years).

The doctors told me that there was a possibility of my hearing being affected by the injections, but I decided that the risk was worth it in the face of death. I wish at the time that I had access to other medicines, like DLM or BDQ, which wouldn't have affected my hearing and that I had constant monitoring for hearing loss.

Dealing with a partial loss of hearing sometimes makes day-to-day life uncomfortable, like having to ask people to repeat something they said or changing which ear to use when listening on a phone. I have been fortunate nevertheless, because some people I've met have completely lost their hearing.

José (Lima, Peru)*

At the end of 2013, I was 18 years old and had just started studying computing here in Lima (Peru). I developed a cough and began to lose weight. I went to a health center and was diagnosed with TB. I started treatment, but I did not take the pills every day and would often throw them away. I did not know how important it was to stick to the treatment.

My condition did not improve and I was diagnosed with DR-TB in August 2014, which required 8 months of CPM. I became very nauseous and even had difficulty walking. I was in a lot of pain and was still secretly throwing out my medication. My condition worsened. My mom pleaded with the health center to have a nurse come by the house. Despite this, I did not get better and by April 2015, I was evicted from the treatment program.

My mom got me admitted into a hospital in Lima and I was diagnosed with pre-XDR-TB. I was put on 18-month treatment, including 10 months of KM. I was never told that I could lose my hearing from the injectable, and my hearing was never monitored. My parents pressured the doctors to evaluate my hearing, but they never did. I was never offered DLM or BDQ; I didn't know they existed.

In June 2015, I realized I was losing my hearing when it became more and more difficult to hear people on the phone. The doctors ignored my pleas for a treatment that would not affect my hearing and insisted that I finish the prescribed regimen. I was cured of TB in 2016 and, thankfully, my sputum samples since have all been negative.

I am now focused at getting my hearing back. Specialists tell me the only solution is cochlear implants, but I can't afford them. I have gone on TV and radio shows to ask for help, but have not gotten any positive responses yet. I just want to go back to school and study and continue on with my life. I feel socially isolated and embarrassed to go out because I can no longer hear. I wish I had known about the side effects and been given other options.

Ko Soe Soe (Yangon, Myanmar)

I used to work at the Yangon City Development Committee (Yangon, Myanmar), collecting waste that was often full of syringes and other medical waste. I suspect that it was while I was working there that I contracted HIV from contaminated blood samples. I don't lead a risky life, I never smoke, I don't drink, or do anything else bad.

In 2015, I got TB and received treatment. After 2 months, I decided to stop taking the drugs because I felt healthy. But I was still sick, and was hospitalized four times at Aung San TB Hospital. My wife and I sent our two children to live with other relatives for fear of transmitting TB to them. I realized I would die if I didn't take the proper treatment. In March 2016, my status changed to DR-TB. I started the 20-month long TB treatment, including 6 months of injections. During the first 2 months, I received AMK injections six times a week. However, I was losing my hearing and became very weak. The doctor reduced the number of injections from six to three times a week.

I can now only hear a little with my right ear and have totally lost my hearing in my left ear. I rely on lip reading and body language to communicate.

In September 2016, I started pre-XDR-TB treatment with one of the new drugs, DLM. This oral drug treatment is better for me as I have not felt any side effects thus far. I prefer the oral drugs to injections, because the oral medication has not had an effect on my hearing. But if I have to choose between deafness and death, I prefer to live.

Maria Virgina Ianoşi (Dolj County, Romania)

Before I became sick with TB, I had a normal life, a happy family with a husband and two wonderful children, and a job as a dressmaker that I loved. When I got the diagnosis, it felt as though something broke inside me. I was admitted to a hospital where I stayed for about 6 months.

After a couple months of treatment, I noticed that I was not hearing well. I did not think it was serious, I just thought there might be something in my ear. Then a friend told me it was from the injections of KM and if I continue to receive the shots, I would lose my hearing completely. I was never told that this would be a side effect of the medication. Just 2 weeks later, I couldn't hear anything anymore. It was a terrible moment when I realized I was no longer hearing my children when they called me, I could not understand what they were asking. I did not want to see anyone anymore. A hearing specialist told me that the only solution to hear again is a very expensive implant.

This disease leads to loss of hearing, family breakdown, loss of friends, and loss of work. In my job, communication is very important. I wonder how I will raise my children if I can no longer work. How can I take them to the sea? I can barely go shopping or to the park in this state. At this moment, my husband and I do not know each other, we are like two strangers.

I am not able to take any new or repurposed drugs here in Romania. My wish is that no one else has to face the challenges that have begotten me. I wish I had access to treatment that could have prevented my hearing loss.

Mariam (Rostov, Russia and Yerevan, Armenia)*

I was diagnosed with TB 2 years ago. I was happy with my life in Rostov (Russia). My husband and I are originally from Armenia and were looking to apply for Russian citizenship. I was diagnosed with TB during the last medical screening required for citizenship. I was told to return to Armenia for treatment, which I started 3 days later.

I am glad I started treatment quickly, even though I really did not want to. I was supported by the medical staff. There were even times when I was ready to stop treatment, but my medical

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*Pseudonym used to preserve the author's anonymity at their request.

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team explained the importance of adherence. I chose to continue my treatment and am grateful for their encouragement.

Before starting treatment, my medical team explained the disease, the drugs that I would receive, and possible adverse effects. This was hard for me to accept because I already had difficulty hearing from when I was younger. When I learned that TB drugs could further affect my hearing, I was really worried.

I began treatment with the injections, but I was constantly monitored. My hearing began to deteriorate in both ears about a month into treatment. The team changed my treatment regimen and I began receiving treatment with new drugs, including DLM, in August 2016. I felt my hearing continued to worsen and it was confirmed with audiometry. However, I continued to take the medication on schedule.

I am a social and cheerful person, but I feel alone anytime I miss a question that was asked of me. It is a difficult time and I often think "why has all of this happened to me?" But I realize that this is my path to follow and that we all have problems we deal with.

Marius (Giurgiu County, Romania)*

I used to be a very happy and sociable person. I loved life very much. I enjoyed having fun and was the life of the party. I used to do construction work and enjoyed it. Regarding my beautiful family, they have always supported me and I am grateful for them. I used to have a lot of close friends. I was a dreamer.

At the beginning of October, I became deaf. My wife noticed my hearing loss, telling me that I was speaking too loudly, but I didn't want to believe it. I completely lost my hearing in 1 week as a consequence of a very long and difficult treatment lasting 5 years.

With time, I became more introverted. I was left with only a few friends; I can barely count them. Many of my relatives also distanced themselves from me because of my illness. I cannot work properly anymore. I am more reserved because people do not understand me. I am moody and prefer the company of my family and closest friends. Because I have lost my hearing, I avoid social situations because even with my hearing aids, I have to read people's lips.

My family still supports me whenever I encounter a problem I cannot solve on my own. I think it is almost impossible for people to overcome such health problems morally and psychologically by themselves. I am thankful to my family who made me understand that by losing something, I earned my right to live. I am not ashamed of my disability.

I am grateful to my doctor who encouraged me to continue my treatment even though the shots were responsible for my hearing loss. It was my only option to stay alive. I was unlucky. I now understand how important health is and we should enjoy all moments.

Mesrop Adjuntsov (Yerevan, Armenia)

About 4 years ago, I was diagnosed with TB. Soon after, I found out that I had DR-TB. I started treatment, which forced me to adapt to the strict regimen of the hospital and caused me to lose my job. I found out that the treatment was not effective after almost a year of receiving the medication. I was recommended to start treatment with BDQ and an injectable. When I was told about the adverse effects of the medications, I was not concerned, as I knew that all the medications have side effects. I was more scared of the idea of receiving injections for 2 years. But one thing was clear: No matter what happens, I should take the drugs and get cured by all means. I did not think that those adverse effects would be this serious.

The injectable began affecting my hearing, I had constant rattling and various noises in my ears. Sometimes these sounds disturbed me so much I could not hear anything else. At first, I thought: "Well, it's ok as long as I am cured of TB." But the problem worsened. I finally shared my concerns with my doctor, who decided to change the medication. But I could only change from one injectable to another. I continued my treatment as long as required, as there was no other option. Every day I took my medication, knowing day by day, little by little, my hearing was deteriorating.

It has been 2 months since I completed treatment and the adverse effects are gradually improving. The sounds and rattling have lessened but the issue is still there. I got used to it and I am proud that I have defeated my serious disease. I have learned to communicate with my relatives and loved ones freely, even if I do not hear all that is said.

Mildred Fernando-Pancho (Makati City, Metro Manila, the Philippines)

In November 2001, I was a 19-year-old student finishing college when I was first diagnosed with TB through a chest X-ray. I was still testing positive when the 6-month treatment finished. I was next given SM and was continually tested using X-rays for the next 2 years. Three years after my initial diagnosis, a clinic in a bigger hospital in Manila gave me my first drug susceptibility test. I felt optimistic that I was now in good hands and would be cured soon.

But I kept getting hospitalized for massive hemoptysis. When I was introduced to my fourth doctor, I had already been experiencing tinnitus. The ringing in my ears worsened under AMK injections in June 2005; after 9 months, it had become a constant ringing. When I asked my doctor if she could do anything about my tinnitus, she sarcastically answered me: "What do you want me to treat, your TB or your tinnitus?"

By mid-2006, I ran out of new drugs to take and was referred to another hospital. I began a strict 18-month treatment regimen. I did not have a baseline audiometry test. I was declared cured from TB, but I knew that my hearing worsened because I started to lip-read.

Six months later, it was confirmed that I relapsed. I was enrolled in a clinical trial and re-started treatment in 2009. Audiometry tests were used to monitor further hearing loss from CPM. By the time I was cured again in 2011, my hearing loss had worsened from moderate to severe.

Today, I still have tinnitus that never stops, gets louder, and more painful. I now use a hearing aid, which only amplifies sound and does not make it clearer. I struggle to hear everything at a high frequency, from the chirping of birds to fire drill alarms at work. I always get caught off guard by the sound of car horns in the distance when crossing the street. I don't like to tell others about my disability, which makes me feel isolated. I try to protect myself from stigma and discrimination by being alone. I worry that I will one day wake up completely deaf. It never occurred to me that I would have to sacrifice a part of my body just to be freed from TB. No one should have to trade off their hearing in order to survive TB.

Morina Gasane (Delft, South Africa)

I first got TB in 2012. I was travelling far from home to work as a cleaner and when I got sick, I was no longer able to make the

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*Pseudonym used to preserve the author's anonymity at their request.

daily trip. I started receiving treatment and when I had completed it after 6 months, I was told I was cured of TB. I did not feel better, and inevitably became sick again in a few months' time. I was diagnosed with DR-TB at the end of 2013 and admitted to a hospital in downtown Cape Town (South Africa). The treatment put a great strain on my family life, the medication made me nauseous, and I completely lost my appetite. I eventually decided to stop the treatment early and return home.

I eventually came in contact with a clinic nearby my home where I continued my treatment. In January 2015, I returned back to the hospital in downtown Cape Town and thankfully with some new drugs, I began to feel better after almost a year of treatment. I now live at home in Delft (South Africa) with my mother, daughter, and son, and survive on a disability grant. I am very thankful to be TB-free now.

However, I lost my hearing almost immediately 3 months into my DR-TB treatment. I hadn't performed a hearing test previously and I suffered severe hearing loss before I finally got one done. I'm still able to talk to family and friends, but it is very difficult to communicate with strangers. Life with my hearing loss has made me very nervous, especially when I'm alone. One night when I was sleeping, the shack beside my home caught fire and I could not hear my neighbors banging on my door. My son finally woke and we narrowly escaped the house. My son feels very embarrassed about my disability and does not like to bring friends around the house. My daughter no longer respects me since I've become deaf, and I worry about the life choices she makes without my guidance.

I am attending a consultation to look into the possibility of receiving cochlear implants. I really hope they can help me.

I hope that there won't be any more injections in the future, as I still have lasting pain in my buttocks and legs even 3 years after completing treatment.

Nandita Venkatesan (Mumbai, India)

In August 2007, while I was in college for my undergraduate degree, I began experiencing acute stomach pain, fever, and appetite loss. I was diagnosed with intestinal TB 3 months later, and underwent a prolonged treatment course of first-line drugs. I was eventually cured and continued my life. In 2013, the TB returned and I once again began treatment. As my condition sharply declined, I had to undergo six surgeries in my intestine. I was started on KM injections.

In November 2013, I woke up from taking a mere 10-minute afternoon nap to suddenly find I had lost 90% of my hearing. In the drop of a pin, this life-altering permanent disability occurred, which took a lasting financial, emotional, and mental toll on me. I was never warned that the drugs might affect my hearing and I had no idea how to deal with my newly found deafness.

I was plunged into an isolated, soundless world and lost access to things one takes for granted – music, TV, phone calls, proper conversations. Struggling to communicate with loved ones hurt most. I became dependent on others for the smallest of daily activities like hailing public transport, communicating with a shopkeeper, or speaking to a co-worker on a project. The deafness pushed me into a prolonged period of clinical depression and tore apart my self-esteem. I began to lose my speaking ability and had to attend speech therapy to reverse the decline. I isolated myself, going completely against my outgoing and ambitious nature.

I eventually returned to work in 2016 to my job as a journalist at a leading financial daily newspaper. Ironically, I am a communications professional and now have a great deal of trouble communicating with other people. As I pick up the pieces of my life, manage my disability, and move towards self-reliance, I know the road ahead isn't easy.

Veronica V Villegas (Makati City, Metro Manila, the Philippines)

In 1980, I was diagnosed with "minimal TB" at age 33. I was a full-time high school teacher. I went to a doctor because I had a bad cough. He told me to go for a chest X-ray. Immediately he prescribed SM injections, once daily for 30 days. I was never offered oral medication, and I was never told of the side effects that could be caused by the injections.

About 2 weeks into the treatment, I began to sway sideward while walking. Inside my house, I found myself bumping into furniture, wall corners, and door handles. My doctor told me that it was probably due to poor vision, but the ophthalmologist found I had perfect vision. The injections continued, and I became progressively unstable. In public, I had to ask strangers to hold me so I could stay upright and walk straight. At the end of the treatment, I had completely lost my balance and sense of distance. My surroundings seemed to move, with the walls receding and the floor tilting upward and downward. I completely lost my ability for independent navigation.

The condition lasted for several months. A neurologist prescribed medication. Another doctor prescribed intravenous dramamine. I took all those prescriptions but there was minimal alleviation, if any. I stopped taking the medications and decided to just live with the condition. After a year or so, I could walk again and even run a bit without assistance. But I continue having issues walking at night in dim lighting to this day.

About 15 years ago, I was diagnosed with mild deafness and tinnitus. I'm turning 70 this year. I guess age worsens my condition. I detect a gradual creeping return of my loss of balance. My hearing is worsening. The constant ringing in my ears is getting louder. I'm simply taking it all in stride, with forgiveness in my heart for the doctor who perhaps didn't know any better.

Worknesh Bushura (Hawassa, Ethiopia)

In 2008, I developed a cough, fever, severe chest pain, and weight loss. I went to a health facility and was diagnosed with pulmonary TB. I was immediately put on first-line treatment and was declared cured in a matter of months. Later in the year, I developed similar symptoms again and was soon diagnosed with rifampicin-resistant TB. I was allotted a DR-TB regimen and was told about the importance to treatment adherence. Around the third month of treatment, I developed tinnitus and hearing impairment in the span of 4 weeks.

I was never given a hearing test when I started treatment or told about the dangers of the treatment to my hearing. It affected my day-to-day activities and I eventually went for audiometric evaluation, where I was found to have severe hearing impairment. My doctor discontinued CPM from my regimen after 7 weeks of ototoxic symptoms and included DLM in my new regimen.

Once my treatment changed, my hearing began to improve and eventually I got my hearing capacity back, and my tinnitus was resolved. I thank God that I feel better now and am able to communicate with friends since I started the new medication. I am also thankful for the on-site rapid audiometric screening ShoeBox (Ottawa, ON, Canada) from Challenge TB. I think early detection of hearing impairment and appropriate changing of the offending drug with a new drug will help MDR-TB patients to survive TB without complications.

THEMES AND RECOMMENDATIONS

Despite the diversity of the co-authors' backgrounds and nationalities, our stories share several tragic and unjust aspects of struggles with DR-TB diagnosis and treatment more generally, and in particular with injectables and the side effects they cause. While our voices represented in this paper are diverse, our stories share several common themes. We present below both the problems and recommend possible solutions:

1 Poor access to upfront DST to guide appropriate therapy and avoid unnecessary exposure to injectables and other therapy: many of us were not diagnosed with DR-TB upfront and underwent unnecessary treatment, lengthening our journey, and weakening us by the time we made our way to appropriate therapy.

Recommendation: Access to rapid DST for all people with TB and second-line DST as a requirement before starting any injectable-containing regimen. Without DST results, it is not possible for us to make an informed decision based on the potential risks and benefits of injectable drugs. The risks are great, and there may be no benefit if the TB is resistant to them.

2 Lack of informed consent to treatment: very few of us giving testimony through this paper were informed of the potential for hearing loss when we were given an injectable.

Recommendation: Increased information and education about side effects before treatment. We demand the opportunity to make an informed choice about medication before starting any treatment, and especially before starting an injectable, if it is deemed clinically warranted.

3 Lack of appropriate monitoring: again, few of us received audiometry, although hearing loss was an extremely well-known side effect and now simple to monitor using mobile audiometry devices. Even when we specifically asked for hearing tests, we were at times ignored or denied.

Recommendation: If an injectable must be used, baseline audiometry at the beginning of treatment and regular tests throughout treatment, with immediate appropriate changes if hearing loss is detected. José explains, "I hope that doctors will evaluate patients more often for audiometry and to listen when we ask for our hearing to be continually monitored."

4 Inappropriate treatment selection by clinicians: readers familiar with global standards of care will note that many of us received treatment regimens explicitly in violation of them, e.g., adding a single drug to a failing regimen, retreatment without DST, and treatment of inappropriate duration, as seen in Veronica's testimony of a 30-day short course of SM.

Recommendation: Updating national guidelines to reflect patient perspectives and the latest global standard of care, which now does not include injectables, and training clinicians accordingly.

5 Lack of collaboration with clinicians: in addition to providing us with substandard care and denying our right to informed consent, many of the clinicians we encountered on our long journeys to cure minimized the impact of hearing loss, shrugging it off or even belittling us for daring to ask about treatment for it while also being treated for TB.

Recommendation: Patient-centered care as the standard for all interactions between clinicians and patients. Supportive treatment, including counseling about the importance of adherence for patients. The need for consent, respect, dignity, and autonomy should be elevated in all health settings. This in turn may require better training and treatment for clinicians themselves, who are often stressed, under-resourced, and disempowered to provide the best care for their patients.

6 Importance of a supportive clinical team: on the other hand, many of us were literally saved by kind, encouraging treatment teams who helped us persevere on our difficult paths, and who offered us alternatives to injectables. Positive, supportive attitudes along with quality care can make all the difference.

Recommendation: Ensure compassion and empathy, as well as knowledge transfer and involvement, in all clinician-patient interactions.

7 Loss of occupation: isolation from treatment generally, and hearing loss specifically, led many of us to lose our livelihoods, sense of purpose, and income. Several of us are unable to return to our profession and passions, or can only do so with great difficulty, which makes us feel depressed, and concerned about our ability to provide for ourselves and our loved ones.

Recommendation: Supportive services for all people who have lost hearing due to injectables (or have other TB treatment-related disabilities), including free job retraining, sign language and lip-reading classes, and counseling to help overcome the stigma of not only being a person who survived TB, but also someone with, what is in many settings, a highly stigmatized disability.

8 Stigma and isolation: many of us have experienced embarrassment, confusion, and disorientation, suddenly finding ourselves unable to hear at all or as well as we could, which makes us turn inwards and limit our social interactions. Many of us also live in communities where disability carries great stigma, which worsens the feelings of isolation. Several of our relationships with friends and family have been strained, including one of us losing a spouse during treatment and others having either physical or emotional distance from our children as a result.

Recommendation: National and local-level campaigns to mitigate the culture of stigma against people with hearing impairments, TB survivors, and all people with disabilities. This requires more funding support for advocates and community groups representing people with disabilities.

9 Impact of supportive friends and family: conversely, those of us who have been blessed with supportive friends and family know this has contributed to our ability to stick with the treatment and cope with its aftermath. We are very grateful.

Recommendation: Foster a climate of support and belonging within households and advocate for family members to take a more active role in the treatment of those suffering from TB.

10 Inaccessibility of cochlear implants: although we would have preferred to avoid hearing loss in the first place, we would like to be able to address it once the damage is done. However, cochlear implants have remained out of reach for all of us sharing our stories here, largely due to cost.

Recommendation: Immediate treatment for hearing loss, including subsidized hearing aids/cochlear implants to address hearing loss, including donor and national funding to make that possible.

11 Importance of early intervention and newer drugs: those of us who had clinical teams that detected our hearing loss before it was too late (or listened to us when we told them about it), and switched us to a newer drug, are extremely relieved and grateful to have gotten it, but frustrated we did not have the

choice earlier and that many of peers were not given the choice at all.

Recommendation: Widespread access to existing all-oral regimens, as well as the continued development of new options with fewer side effects—as Morina puts it, "my hopes for the future of TB treatment are for new drugs, like the ones I got once I lost my hearing."

CONCLUSION

Of specific note, the narratives of children with MDR-TB are missing from these testimonials and constitute a major limitation in representing all voices of TB survivors, especially those who are most vulnerable. The particular needs of children with TB are noted in the 2019 WHO guidelines, including a call for the avoidance of any injectable drugs in children and an emphasis on providing access to audiometric testing when they are used as a last resort.[1]

The 2019 updates to the WHO DR-TB guidelines are a crucial step towards prevention of harm experienced from injectable antibiotic drugs. However, even with activist campaigns urging an end to routine injectable use, and a joint statement from the WHO Director-General and the Civil Society Task Force on TB calling to make the switch to all-oral regimens by World TB Day 2020, many countries have not yet adopted or implemented the revised guidelines.[16] In fact, the situation on the ground, as reflected in our testimonials, was that many of us received diagnosis, treatment, and care that did not meet the guidelines that were in effect at the time of treatment. Much has remained the same in the present day as TB patients continue to receive inappropriate injectable treatment, even 2 years after the WHO's 2018 rapid communication first deprioritizing injectable agents over safety profile concerns.[14] While these testimonials were collected at a time when global guidance had not yet shifted to recommending all-oral treatments for all, yet even then, treatment alternatives were recommended for patients experiencing side effects, such as hearing loss, from injectable agents. Nevertheless, in many cases, TB survivors seeking treatment were faced with the false choice: "Would you rather be deaf or dead?"

We urge all members of the TB community—including donors, national policymakers, individual clinicians, and civil society—to work towards the full implementation of the new guidelines, and to continue to advocate for further improvements in all national health policies.

More broadly, as TB guidelines from norm-setting bodies continue to evolve over time, these testimonials serve as a reminder of why consent, access, and autonomy demand centrality in all patient decision-making of treatment and care globally. Patients are seldom given a meaningful choice in the decision process behind their treatment plans, which contributes to lowered adherence to medication and diminished dignity and respect in patients.[17]

As Mildred writes, "To those who have the authority to push for the changes in TB treatment: Do not be like my hearing aid. Don't just amplify our voices. Please make things clearer for us."

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CONTEXTE : Les recommandations de l'OMS pour le traitement de la TB pharmacorésistante (DR-TB) mettent désormais l'accent sur les schémas thérapeutiques entièrement par voie orale, préconisant de ne pas utiliser certains agents injectables et de ne plus donner la priorité à d'autres en raison d'une innocuité et d'une efficacité inférieures. Malgré l'attention accrue portée aux soins centrés sur le patient, nous ne connaissons aucune étude systématique ayant cherché à documenter de manière qualitative le point de vue des patients sur les agents injectables. Ce travail pourrait guider la mise en place des directives de l'OMS, en mettant l'accent sur l'importance de consulter les communautés concernées.

MÉTHODES : Des personnes ayant survécu à une TB et ayant connu une perte d'audition due à un traitement par agents injectables ont apporté leurs témoignages. Les témoignages ont été soumis par écrit en réponse à des questions courtes, ouvertes et standardisées. Les participants ont signé un formulaire de consentement (avec possibilité de participer de manière anonyme ou en tant que co-auteur nommé) et ont ensuite contribué au format général et aux recommandations de l'article.

RÉSULTATS : Quatorze personnes ayant survécu à une TB provenant de 12 pays ont apporté leur témoignage. Les thématiques suivantes ont été fréquemment mentionnées : manque d'accès aux tests, informations et traitements appropriés ou à un environnement thérapeutique collaboratif ; importance des soins de soutien et de l'environnement social ; stigmatisation et isolement dus au traitement antituberculeux et handicaps qui en résultent ; et inaccessibilité aux implants cochléaires.

CONCLUSIONS : Le témoignage des personnes ayant survécu à une TB indique qu'elles préfèrent nettement éviter les agents injectables, allant ainsi dans le sens d'une mise en place rapide des directives révisées de l'OMS, et qu'elles préfèrent des soins de qualité et de soutien pour la TB mais aussi pour les handicaps qui en résultent.