"I Would Rather Die Drinking than take the Medicine": Role of Alcohol Use Disorder in Loss-to-follow-up of Tuberculosis Treatment in a Rural Area of Ballabgarh, Haryana

Anwita Khaitan, Sanjay K. Rai, Anand Krishnan, Sanjeev K. Gupta, Shashi Kant, Gopi C. Khilnani[1]

Centre for Community Medicine, [1]Department of Pulmonary Medicine and Sleep Disorders, All India Institute of Medical Sciences, New Delhi, India

Abstract

Introduction: Alcohol use disorder (AUD) is a significant risk factor for tuberculosis (TB) treatment loss-to-follow-up (LTFU). This field-based study was undertaken to understand the role of AUD and TB treatment LTFU and the reasons behind this association in a rural area of Ballabgarh, Haryana. **Material and Methods:** TB patients who had completed their treatment and who had been LTFU were included in the study, along with the National TB Elimination Program (NTEP) staff, healthcare providers, family, and community members from Ballabgarh block of the north Indian state of Haryana. In-depth interviews (IDIs) and focused group discussions (FGDs) were conducted to gauge the perceptions of stakeholders regarding reasons for LTFU, especially in the context of alcohol use. Inductive analysis of the transcripts was done in keeping with the grounded theory, and themes with their sub-themes were identified. A conceptual framework of TB-AUD was constructed, and potential areas for intervention were determined. **Results:** Fifty-eight IDIs and four FGDs were conducted in mid-2018. Almost all key informants and many patient participants believed that alcohol use makes TB patients highly susceptible to treatment LTFU. Key themes identified were shared personality traits and attitudes, combined side effects of anti-tubercular drugs and alcohol use, lack of family support, and an adverse financial situation. **Conclusion:** These findings call for a change in NTEP's approach to AUD-TB. Interventions may include collecting alcohol use information at patient enrolment and closure, integrating brief interventions for alcohol cessation in NTEP, and linking patients to deaddiction centers with the provision of appropriate dietary and financial support.

Keywords: Alcohol use disorder, qualitative, treatment loss-to-follow-up, tuberculosis

INTRODUCTION

India bears the largest burden of the global burden of tuberculosis (TB)—around one-fourth of the 10.6 million incident TB cases, one-fifth of the 410,000 incident multidrug-resistant TB (MDR-TB) cases, and one-third of the 1.13 million TB-related deaths occur in India.[1]

A major obstacle to "freeing" India of TB by 2025 is the phenomenon of treatment discontinuation or loss-to-follow-up (LTFU). Various studies in India have reported treatment LTFU rates ranging between 15–25%.[2-6]

Anti-tubercular treatment (ATT) adherence is compromised by the concomitant presence of alcohol use disorder (AUD) in many TB patients. AUD is defined as a problematic pattern of alcohol use leading to clinically significant impairment or distress. This includes craving or a strong urge to use alcohol, an inability to fulfill major familial and societal roles and obligations due to recurrent alcohol use, development of tolerance, symptoms of withdrawal on cessation/interruption of alcohol use, etc.[7]

Many quantitative studies from India[8] and abroad[9,10] have shown that AUD is more common among TB patients who are LTFU. However, there is sparse qualitative literature that attempts to explain the reason behind this recurring association.

Address for correspondence: Dr. Anwita Khaitan,
Junior Resident, Centre for Community Medicine, All India Institute
of Medical Sciences, Ansari Nagar, New Delhi - 110 029, India.
E-mail: anwitakhaitan@gmail.com

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Therefore, we planned a qualitative study in a north Indian rural community to understand the role of AUD in LTFU, and the reasons behind this oft-observed association.

METHODOLOGY

Methodological details have been published elsewhere.[11] A brief summary is provided below.

Background and study setting

The National TB Elimination Programme (NTEP) is implemented through a five-tier system, starting at the top with the national and state levels.[12] Then comes the district TB center (DTC), which is the pivotal tier for TB control activities and is managed and headed by a district TB officer (DTO). Next, the TB unit (TU) is the nodal tier at the subdistrict level. It caters to a population of 200,000 and is managed by a medical officer–TB control (MO-TC) and the senior treatment supervisor (STS). The most peripheral level where treatment can be initiated is the peripheral health institution (PHI), which has one TB health visitor (TB-HV) and serves 100,000 people. PHIs are essentially medical institutes with a certified physician viz. dispensaries, primary health centers (PHCs), community health centers (CHCs), referral hospitals, TB hospitals, and medical colleges within the respective district. A Directly Observed Treatment (DOT) provider is assigned to every TB patient to supervise adherence.[12]

On the laboratory side, there is one senior TB laboratory supervisor (STLS) for every 500,000 population and one designated microscopy center (DMC) with a lab technologist (LT) for 100,000 population.[12]

We conducted our study in block Ballabgarh, district Faridabad in Haryana, India. In this area, the TB treatment LTFU has previously been found to be between 11% and 14%,[3,6] and the current alcohol consumption among men has been reported to be 30% (in stark contrast to current alcohol use among women—0.2%).[13,14] Two out of nine TUs of district Faridabad viz. TUs Ballabgarh and Mohna were purposively selected. TU Ballabgarh's offices are at the subdistrict hospital Ballabgarh, and it serves mainly an urban population. TU Mohna, co-located at PHC Mohna, serves a rural population. Five PHIs and three DMCs serve the population covered by these two TUs.

Study population

We purposively selected two categories of adult TB patients from the TU records, that is, those who were LTFU and had completed treatment.

We also purposively selected NTEP functionaries, healthcare providers in the national healthcare system, family members of TB patients, community members, and local community leaders as key informants. NTEP functionaries included the DTO at the DTC, MOs-TC, and STS at the TUs, TB-HVs at the PHIs, DOT providers in the villages, as well as the STLS in the block, and the DMC LTs. The other providers included were health supervisors at PHCs which had DMCs, multipurpose health workers (MPHWs) at the PHCs, which were co-located

with the PHIs, and DOTS providers. They were also directly involved in the care of TB patients.

Data collection

In-depth interviews (IDIs) and focused group discussions (FGDs) were conducted to study the perceptions of various stakeholders regarding the reason for treatment of LTFU, especially in the context of alcohol use. IDIs and Key informant interviews (KIIs) were conducted by the first author (AK) in Hindi. A moderator, a pair of note-takers, and a person for preparing the sociogram ensured the smooth conduct of the FGDs. A digital recorder was used for audio recording.

The tools used to collect data were as follows:
1. IDI schedules – Semistructured IDI schedules for patients and key informants were developed based on a literature review on health-seeking behavior. Probes for some previously recognized themes, such as side effects, were included in the IDI schedule. The interview schedules were pre-tested on patients and healthcare providers (who were not included as the study participants) and modified to ensure that the data collected was of high quality.
2. FGD guide – The FGD guide was prepared with a focus on the likely causes of treatment LTFU, including harmful alcohol use and possible solutions to tackle these causes.

Each IDI and FGD were conducted after conversing with the participant(s) to establish a good rapport and create an atmosphere of trust. Only when the participant(s) felt confident that there would be no judgment on sharing sensitive information, did the interviewer proceed with the actual interview. Successive interviews and FGDs were conducted till the data in hand was rich and nuanced, no new insights and no new themes were emerging, and repetitious data was being collected. Hence, data collection was carried out till data saturation was reached.

Data analysis

The data analysis was carried out parallelly with data collection. It was initiated without any a-priori domains in mind and was inductive in nature. Analysis was done in the language of the interviews and FGDs, that is, Hindi. Free-listing of pertinent items was done in all the transcripts. They were then analyzed using the open-coding technique to discover themes and identify subthemes. With each transcript, the coding system was modified as it evolved. The transcripts were then re-coded with the successive coding systems, and domains and subdomains were inductively identified using the grounded theory approach. The coding system was finalized using this iterative technique. Data were triangulated from interviews with different stakeholders to achieve a more holistic understanding of all domains. A conceptual model of the relationship between TB and AUD was constructed. Based on the identified themes, the potential areas for intervention were determined.

Ethical approval

Clearance from the Institute Ethics Committee was obtained (Ref. No. IECPG-460/29.11.2017). Written informed consent was obtained from each participant.

RESULTS

Fifty-eight IDIs—30 TB patients, 25 healthcare providers directly involved with the NTEP, and three community leaders—were conducted in May and June 2018. Of these, 20 IDIs (with a median duration of 65 minutes) were with LTFU TB patient participants, 16 of whom were men. The remaining 10 IDIs (with a median duration of 39 minutes) were conducted with treatment completers, 5 of whom were men. Twenty-eight KIIs (with a median duration of 47 minutes) were conducted with various healthcare providers and community members.

Four FGDs were held with different stakeholders, with a median duration of 45 minutes per FGD. Two of these FGDs were held with members of the community—the first at PHC Dayalpur with 11 female community members, and the second at PHC Chhainsa with eight male community members. The remaining two FGDs were conducted with DOTS providers, with 10 participants in each. Notably, there was no refusal from any of the individuals approached to participate in the study.

All stakeholders opined that alcohol use was one of the most critical determinants of LTFU. However, it was stated to be relevant only for male TB patients. Female TB patients rarely, if at all, suffered from AUD. Some key informants declared that a patient with a history of harmful alcohol use was a "lost cause" and would almost invariably abandon the treatment.

Almost all key informants and many patient participants felt that alcohol adversely affected treatment adherence in different ways. They believed that alcohol makes a TB patient highly susceptible to LTFU. The reasons cited were the patient's inherent personality traits and attitudes, level of motivation, as well as perception of the benefits of and barriers to treatment. The crucial barriers that emerged were the side effects of drugs, lack of family support, health system support, and an adverse financial situation.

AUD and TB treatment LTFU—Two sides of the same coin?

Some patients display an intrinsic discipline that facilitates adherence to each day's dose. Many key informants attributed the ability to complete the ATT course to the patient's intrinsic discipline and determination. Such traits are impaired in AUD-TB patients (and are possibly also responsible for their AUD), leading to treatment LTFU. Among AUD-TB patients, treatment of LTFU was preceded by several instances of sporadically missing doses due to a state of inebriation. Hence, the phenomena of AUD development and TB treatment LTFU could be considered as a "shared personality disorder," or two sides of the same coin.

Further, interviews with patients suffering from AUD revealed that they often harbored a fatalistic attitude toward death. A few even stated that "they would rather die drinking than take the medicines."

AUD-TB patients were also found to perceive the consequences of discontinuing TB treatment (death, spreading the disease to their loved ones, and a longer repeat course) in a more fatalistic and inevitable manner. Key informants reported that AUD-TB patients wanted to complete the treatment so that they could resume alcohol use.

Side effects of ATT and alcohol use—A double whammy

Side effects of ATT drugs are well recognized as a major determinant of treatment LTFU by most healthcare providers; and as the primary reason for discontinuing the treatment by the majority of LTFU patients.

Most stakeholders stated that the concomitant alcohol consumption aggravates the side effects of ATT, especially gastric side effects. If unbearable to the patient, they prefer alcohol over medicines.

Further, some patients were quite convinced that taking medicines and alcohol together would cause a "reaction" in their bodies. Fearful, they felt compelled to "choose" one over the other, and that choice was inevitably alcohol. Further, healthcare providers' advice to quit alcohol also pitted TB treatment against alcohol use. Hence, the AUD-TB patient was presented with a Hobson's choice between alcohol and treatment—this almost inevitably led to the former being chosen.

Familial support—"Nothing more to give"

Lack of family support was found to be a crucial determinant of treatment LTFU among AUD-TB patients. Family support ensures that TB patients take their meals on time, get regular reminders to take medicines (particularly through family DOTS), and take medicines in spite of side effects. Arguably, the emotional and moral support provided by family members is their most significant contribution.

The impact of AUD on the family is very well documented. The family members of AUD patients have usually exhausted their social capital on addressing alcohol use. So, by the time TB occurs, their families have either already "given up" on such patients and/or ousted them from the household.

Health system issues—Pushing AUD-TB patients away

All stakeholders agreed that the healthcare providers' behavior, especially the behavior of DOTS providers, was a critical determinant of the treatment outcome. An AUD-TB LTFU reported that his DOTS provider had talked "very rudely." The "condescending attitude" of the DOTS provider was what had pushed him to abandon the treatment altogether.

Further, as mentioned before, the health system presents AUD-TB patients with a Hobson's choice. AUD-TB patients were unable to comply with the doctor's instructions to abstain from alcohol. Instead of discussing this problem with their DOTS provider, they decided to abandon TB treatment and resume alcohol consumption on their own.

Financial issues—TB is a new adversity in existent scarcity/"No more left to spend"

The financial burden of TB was a recurring theme. Under the national program, ATT drugs and routine laboratory

investigations are provided free of cost. However, there were other direct costs and indirect costs viz. transport, medicines for side effects, dietary supplements, and certain additional investigations. The indirect costs included wage loss. Half of the KIIs revealed that the treatment outcome was influenced by the patient's income. All these factors were especially true for AUD patients, whose addiction led to downward socioeconomic mobility, because of their inability to retain a job or get a new one, increasing the risk of LTFU. Dietary support was a recurring topic of discussion in the IDIs, particularly the Direct Benefit Transfer scheme for nutritional support (*Nikshay Poshan Abhiyan*). Some key informants opined that the money provided for dietary support would be misused, especially for purchasing alcohol. Free rations, instead of money, would be better.

DISCUSSION

Alcohol use is seen in one in six Indians with a heavy male preponderance,[15] something that is also seen in ATT LTFU. AUD is seen to affect one out of every three TB patients.[16] In 2021, the estimated number of new TB cases attributable to alcohol was 0.72 million, that is, 7% of all incident TB cases.[1] The link between TB and AUD is well-recognized.[17-20] Both are considered diseases of poverty, with several overlaps in social risk factors and consequences.[16] AUD patients are more susceptible to TB infection and disease, and poorer treatment outcomes such as treatment failure and/or death.[16,17,21] AUD is also one of the major factors associated with higher ATT LTFU rates.[21]

Any individual who suffers from AUD is vulnerable to high-risk behavior. This has been seen in the case of persons living with HIV-AIDS (PLHA),[22] and can also be seen in TB patients. Treatment LTFU is a manifestation of such high-risk behavior. Our study found that AUD-TB patients face a difficult road right from the stage of TB diagnosis. At first contact with the healthcare system, they are forewarned about the harms of consuming ATT and alcohol together and are counseled to cease

alcohol consumption for successful treatment.[22] However, for many, this proves to be an unachievable goal. Psychological and/or physiological dependence on alcohol ensures that its cessation, without any external help or family support, is an almost insurmountable challenge. The lack of alleviation of ATT-related side effects (further aggravated by alcohol consumption) with symptomatic treatment or an adequate diet makes AUD-TB patients vulnerable to abandoning treatment. Further, AUD-TB patients are unable to bear the costs of treatment, whether they be direct or indirect, due to job loss and/or loss of financial support from their household. In the lack of family support, AUD-TB patients have essentially no one to counsel them against abandoning TB treatment. Their only source of support is the DOTS provider, who is generally not trained for this. Motivators, such as the desire for cure, and the fear of death, are very weak. This is further compounded by a fatalistic acceptance of premature death.

In our study, we ensured the participation of every relevant group of stakeholders. There was also no refusal to participate. Further, not only was data saturation achieved, but all the treatment LTFU patients in the two TUs were successfully included in the study. A single investigator conducted all interviews in the local language, that is, Hindi. Additionally, the final results were based on the triangulation of data from the IDIs, KIIs, and FGDs conducted with various stakeholder groups, which led to increased dependability and confirmability of the findings. Since the study was conducted in north India, the findings may not be transferable to other areas with a different socioeconomic context.

Hence, based on the findings of our study as well as an extensive literature review, we developed a conceptual framework for the relationship between AUD and TB [Figure 1]. We surmize that the causes as well as the consequences of AUD affect the natural history of TB in a patient at every level. AUD leading to TB treatment LTFU is one of the key paths that we can target to decrease the adverse outcomes of TB.
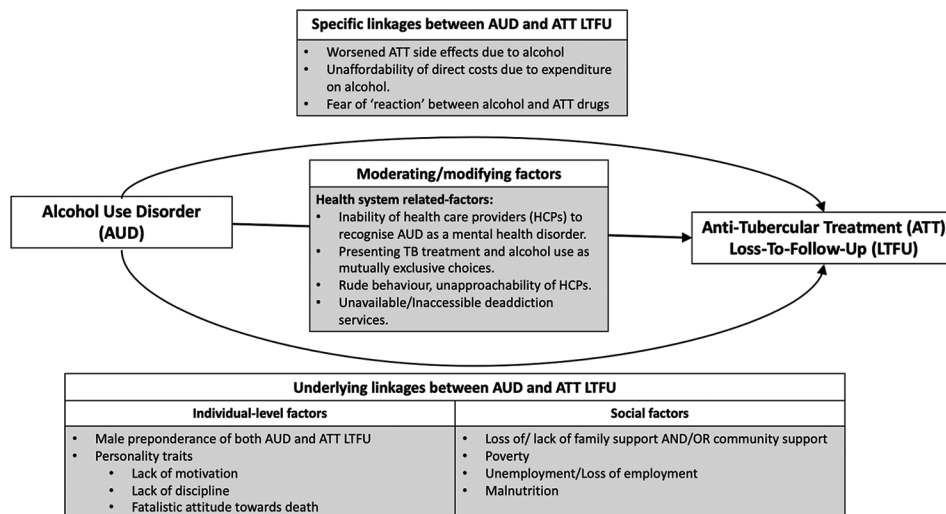

Figure 1: Conceptual framework of the relationship between alcohol use disorder (AUD) and anti-tubercular treatment (ATT) loss-to-follow-up (LTFU)

These findings call for a change in our approach to AUD-TB patients under NTEP. The approach of NTEP for tobacco and diabetes provides a good template on which to build. The lack of a national program or policy on AUD is a significant barrier in this regard. We recommend that information on alcohol use be collected separately at the time of enrolment and closure of a TB patient. We must sensitize and reorient the health system to address alcohol use with more empathy. Even though it is desirable, providers must understand that it is not always possible for an AUD-TB patient to cease alcohol use during treatment. However, if we integrate brief interventions for alcohol cessation in NTEP and possibly link such patients to deaddiction centers, there is hope for the cessation of alcohol use.[23] Dietary support should also be provided but only as food supplements to prevent the misuse of the funds. Energy-dense nutritional supplements may have a role as it has already been proven feasible.[24] Finally, it is critical to monitor and report outcomes separately for AUD-TB patients. With adequate awareness generation, IEC activities, and programmatic improvements, we can hope to achieve the targets of a "TB-Free" India.

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Conflicts of interest

There are no conflicts of interest.

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