Why people die of active tuberculosis in the era of effective chemotherapy in Southern Ethiopia: A qualitative study

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ABSTRACT

Background: High TB mortality is increasingly understood as an indicator of different problems in the health system and community. Limited awareness of TB in the community, restricted accessibility and/or quality of health services can hamper survival. Exploration and analysis of death among TB patients can lead to a clearer and specific understanding of why the deaths happened and where interventions are likely to make a difference in a specific context.

Objective: The study aimed to assess why people die of active tuberculosis in the era of effective chemotherapy.

Methods: The study was conducted from October to December 2020 in Arba Minch Health and Demographic Surveillance System (AM-HDSS) by applying phenomenological study design. A total of 27 family members of people who had died of TB, 9 health extension workers (HEW) and 8 health care professionals working in TB clinics were participated in open in-depth interview. A total of 130 individuals participated in 16 focus group discussion which composed of patient survived from TB, religious leader, health development army (HAD) and HEWs. Adequacy of information (saturation) was considered as an adequate sample size to create the intended qualitative product. All the interviews and FGD were tape recorded and recordings were transcribed immediately. ATLAS TI 9 software was used to analyse and process qualitative data. From data set codes were created then by identifying pattern among them themes were created. Then, generated themes were compared and some of them were split, combined, discarded and new ones created after returning to data set. Finally, themes were defined and a concise and easily understandable name was given for each theme.

Result: Luck of sufficient knowledge about TB was considered to be a reason for cause of death. Most of the time, TB patients underestimate and ignore when the symptoms first emerge and will not relate it with any diseases. The low level of community awareness about the cause, transmission, treatment and prevention highly contributed to increased transmission rate and death due to TB. The study identified misconceptions in the community; they prefer traditional medicine to the scientific way. First, they try different herbal medicine to get relief from their illness. At the end, if the disease is getting worse, they visit health facilities. Participants mentioned high transportation cost, poor health seeking behaviours, inadequate food consumption and lack of TB awareness as reasons for low treatment adherence. The health facilities were inaccessible for the community. Most of them indicated that health facilities were too far to reach. In some health institution, right amount and combination of medication were not delivery on time and Diagnostic facilities for TB were reported to be inadequate.

Conclusion: Poor treatment adherence, lack of TB awareness, stigma, inadequate food consumption, poor health care seeking behaviour and inaccessibility of health facility were identified as major reasons for death. To prevent death of TB patients all sectors such as education, health, and agriculture should work to address health...
1. Introduction

Tuberculosis (TB) is a major killer disease worldwide. It is the ninth leading cause of death worldwide and the leading cause from a single infectious [1]. Mycobacterium tuberculosis infection might be experienced/caught at home, workplace or during travel and the risk of infection depends on exposure frequency to a source case and the duration of the exposure [2]. Tuberculosis has the potential to affect all people, regardless of sex and age; different groups of people have a variable chance to contract the infection and to develop the disease [3].

In the era before effective treatment for TB was developed, the average time to death (self-cure) was three years, and case fatality was approximately 70% for smear-positive and 20% for smear-negative TB [4]. However, in today’s world most deaths among TB patients can be averted, even in cases of HIV co-infection, through timely diagnosis, effective treatment, and proper patient support [5]. High TB mortality is increasingly understood as an indicator of different problems in the health system and community. Limited awareness of TB in the community, restricted accessibility and/or quality of health services can hamper survival. Evidence suggests that co-morbid TB patients (i.e. those with HIV, diabetes, etc.) are particularly vulnerable when the quality and timing of clinical care services are suboptimal and/or diagnosis is delayed [6,7].

Currently, in Ethiopia, tuberculosis is a major public health problem. The country is still among the 22 high TB burden countries with high number of missed and infectious TB cases in the community [9]. In 2016, 48,910 TB deaths reported in Ethiopia. In Arba Minch HDSS the 07 years data showed that tuberculosis is the major cause of death. Insights into the patient’s care-seeking itinerary and the chain of social, economic and clinical events that led to his/her death can help us to decide where to focus our improvement efforts (6). Exploration and analysis of death among TB patients can lead to a clearer and specific understanding of why the deaths happened and where interventions are likely to make a difference in a specific context [8]. Therefore, this study investigated why peoples are died of due to tuberculosis.

2. Methods and materials

2.1. Study setting and design

Phenomenological study design in their natural settings was implemented from October to December 2020 in Arba Minch Health and Demographic Surveillance System (AM-HDSS) which was established in 2009 with the aim of tracking demographic changes like death, birth, migration and marital status change.

2.2. Study population

For an open in-depth interview, we purposely selected 27 individuals from each household where a member died due to TB in the last twenty-four months before 01 Oct 2020 who were family proxies including spouses, parents, adult children, siblings, or relatives and 9 health extension workers from health post and 8 health care professionals working in TB clinics were the study population.

For Focus Group discussion (FGD), a minimum of five FGDs of health professionals in the site and a minimum of one FGD per kebele of patient survived from TB, religious leader, HEW and health development army (HAD) (total 11) and in which sex, age and kebele was considered on individuals’ allocation in to FGD group for patients survived from TB. A total of 16 FGD were conducted and 130 individuals were participated.

2.3. Inclusion and exclusion criteria

AM-HDSS is a surveillance system under college of Medicine and Health Sciences of Arba Minch University, which was established in 2009 as part of national level response to the shortage of reliable population-based information. The center determines the cause of death

![Fig. 1. Themes generated about the reason for death of TB patient in Arba Minch HDSS, 2020.](image-url)
in the site. The key informants at each village notify death to HDSS filed worker. HDSS filed worker collect the data using WHO 2016 verbal autopsy [10]. Using this data, cause of death is determined at the office of the Arba Minch HDSS by physician. Individuals involved in providing care for patients who died due to TB and having better ability to provide the need information were included in in-depth interview. The context was confirmed or judged by data collectors. For focus group discussion, individuals or care providers in TB clinic or medical ward, patient survived from TB treatment, religious leader and HDA were included in this study. However, individuals unable to speak or hear and seriously ill were not included in this study.

2.4. Sampling size determination

Determining an adequate sample size in qualitative research is a matter of judgment and experience in evaluating the quality of the information [8]. However, the issues that should be considered are dependent on the heterogeneous or homogeneous nature of the sample population [9]. People in Arba Minch HDSS are known to be a closely homogeneous group of people, not only ethnically and culturally, but they also share one language, religion, lifestyle (farmer). For such a closely homogeneous people, adequacy of information (saturation) was deemed as an adequate sample size to create the intended qualitative product [9].

2.5. Sampling technique

Thus, in accordance with purposive sampling techniques, participants were selected due to their knowledge on the phenomenon under study.

2.6. Operational definition

A TB death: is any death occurring to a patient who is diagnosed with TB or who has been on treatment for TB and confirmed, or who has interrupted treatment not longer than one month ago and confirmed regardless of the cause of death in the last twenty-four months before 01 Oct 2020.

2.7. Data collection tools and procedures

A set of questions (rather than hypotheses) was used to collect data for this research: What are the personal, cultural, systemic and everyday practical factors contributing to death due to TB? Infection control measures in health services in the study area? (Table 1).

Open in-depth interview was undertaken until the saturated information obtained. The households from the study setting and interviewees from the household were purposely selected. Occurrence of death due to TB with in the last 2 year (before October 2020) and level of education were used as purposes for households and interviewees selection respectively. Also, 9 health extension workers and 8 health care professionals working as caregivers and focal of TB clinics were interviewed. Interviewers extensively probed participants’ responses and used an interview guide. Participants were interviewed both in their own home and under trees based on their preferences and to avoid noise. All the interviews were tape recorded and recordings were transcribed immediately after the interviews.

Around 16 different groups of focus group discussions (FGD) were conducted. The sex, age and kebele were considered for FGD in case of patient survived from TB treatment. A note-taker observed and noted detailed participants’ body language during the discussions. All discussions were recorded using a digital voice recorder. Whenever necessary, questions were used to prompt participants discussed on TB illness, TB stigma and disclosure about TB status to others.

2.8. Data analysis

A progressive approach to qualitative analysis as suggested by Miles and Huberman [11] was applied in the study. By this approach, the data collection and analysis were undertaken concurrently. ATLAS TII 9 software was used to analyze and process qualitative data. The data was initially collected by Amharic and Gamogna languages, then the audio recordings translated verbatim back to English and transcribed verbatim. After data was prepared, a project file was created. Using the software, quotations were selected and codes were assigned. When the identified codes were considered exhaustive, they were compared to isolate distinct and similar ones. Then comments and memos were applied to conceptualize the data after deep review. Further interrelation between code, memos and data was done. This software was used to sort and structure the data, and querying the data with the aim of discovering patterns and relations. Next, we look over the codes we’ve created, identify patterns among them, and start coming up with themes. Then, generated themes were reviewed to ensure usefulness and accurate representativeness of the data where some of them were split, combined, discarded and new ones created after returning to data set and comparing all themes. Finally, themes were defined and a concise and easily understandable name was given for each theme. Following these, three colleagues who are experts in qualitative data coding reviewed the coded data and themes. A discussion was held with all the reviewers for modification and editing.

3. Results

The data for the study was collected through in-depth interview and focus group discussion. A partner, close relative or sibling who lost a family member with TB and health care provider who is working in selected health facilities TB clinic. One FGD for each kebele was conducted in quiet and comfortable places. Participants of each FGD were purposively selected and consists of patient survived from TB, health extension worker (HEW), health development army (HAD), religious leader and community leader. Representativeness of the participants was assured based on age category, sex, kebele and other selection criteria’s. Each FGD has 8–10 individual participants. An average of 45 min and 1 h was spent to conduct in-depth interview and FGD respectively. During data collection, the study participants were adults’ age 18 years of age and above. Majority of the respondents were married and half of them were completed primary education. About 61 % of the participants were farmers living in the rural kebeles (Table 2).

3.1. Community related factors

3.1.1. Community awareness about TB

In-depth interview and FGD were used to analyse awareness about cause, transmission, prevention, sign and symptom of TB. While most participants didn’t know the exact cause of TB, majority correctly
mentioned ways of transmission from one person to the other. “Tuberculosis is an infectious disease caused by drinking raw milk and transmitted by cough. Besides, it can also be transmitted by sharing of ‘Gaya’”. (FGD, Community leader 1).

“The main means of transmission of TB in our village is sharing of drinking utensils. For example, there is a local drink ‘Tela’ we are drinking tela turn by turn with a single drinking material that is why we are very vulnerable to this disease, TB.” (FGD, Religious leader 1).

Individuals who participated in the focus groups also mentioned the cause of TB. They said the main cause of TB is cold weather.

“The main cause is passing nights out door….the cold air is the main cause. Our father was exposed to cold weather and caught TB.” (FGD, HAD 2).

‘...But one thing I know is that TB is contracted from cold air.” (FGD, Religious Leader 2).

Other respondents mentioned the disease is transmitted through sexual intercourse “we get this disease by sexual intercourse when a normal person has sex with a patient having tuberculosis. We also think that it can also be caused by exposure to dust.” (IDI, a 45yrs old sibling 4).

Furthermore, respondents expressed their knowledge regarding sign and symptoms of TB.

“First, I thought it was a common cold, but later the cough is becoming worsening. You know the experience was not easy, when I was sick I had bloody sputum, chest tightness, loss of appetite, and generalized body weakness.” (FGD, 40yrs old TB Survivor 1).

“Patients with TB can have symptoms like chest pain, dry cough, weight loss, sweating, and loss of appetite.” (IDI, 47yrs old close relative 3).

Luck of sufficient knowledge about TB was considered to be a reason for cause of death. Most of the time TB patients underestimate and ignore when the symptoms first emerge and will not relate it with any diseases. A 28 years old male farmer his sister died of tuberculosis said “the main reason for death due to tuberculosis is lack of awareness about the disease...when the people are coughing they claim that it is simple and considered it as common cold...most of the patient died due to the complication before going to health facilities”.

The low level of community awareness about the cause, transmission, treatment and prevention highly contributed to increased transmission rate and death due to TB.

“...There is no adequate information about TB disease in the community. This is the gap I have observed in the community is the reason for many TB patients death” (IDI, TB case team leader).

3.2. Stigma

Some of the participant noted that there is no significant social stigma or discrimination of TB patients in day to day life. Strong social bond in the community make it difficult to isolate TB patients. They believe GOD will save them from the disease so doesn’t worry about close contact they make with TB patient.

One respondent had this to say;

“We didn’t stigmatize them fearing the curse. If we discriminate or isolate them God will punish us. In one or other way the almighty God could punish us so we will continue the social life as usual” (FGD, HAD 3).

“Previously people were considered TB as curse, hereditary and ‘Stama’ local name for chronic cough with no cure. Nowadays, people are aware of the disease and they understand that it is curable.” (FGD, community leader).

Members of the community eat and drink together. One of TB survivor participated in the study said that her neighbors, relatives and family members were close together when she was on TB medication for six months. She further explained that “I drink coffee together with my own cup, go to funeral, take part in community activities and go to market whenever needed” (FGD, TB survivor).

In contrary to the previous study participants, some reported a number of TB patients hide their illnesses while they are sick fearing the social stigma. Many of them lost their loved one fearing to lose people around them. A 28 years old male farmer his sister died of tuberculosis said “people with cough for a long time are afraid of going to health facilities not to be diagnosed as TB patients. They deny going to health facility afraid of the stigma and even most of time they won’t go outside”.

The participants mentioned that people suspect TB patients have HIV/AIDS in their blood, so they will discriminate. The community believes loss of weight and a consistent cough seen in TB patient was due to HIV/AIDS. One respondent alluded to this;

“In our community, a person with a loss of weight and long-term cough is considered an HIV/ AIDS patient. So, they will be isolated from social and day to day activities from the community.” (IDI, a 28yrs old relative).

The stigma towards TB patient was further supported by health care professional working in public health centre TB clinic. One of health professional said the following;

“...When it is known that a person is test positive for TB, there is stigma and discrimination.” (IDI, TB case focal).

3.3. Personal related factors

3.3.1. Health care seeking behavior

There are misconceptions in the community; they prefer traditional medicine to the scientific way. First, they try different herbal medicine to get relief from their illness. At the end, if the disease is getting worse they visit health facilities.

“The experience of our community including myself to go to a modern health facility is very poor. Unless we get seriously ill we didn’t visit a health facility. The other reason is lack of awareness about the disease and lack of money to cover medical bill.” (FGD, 41yrs old HDA 1).

“The community in our village don’t consider cough as a serious problem. They believe that cough can be easily treated by homemade treatment like eating garlic, ginger, and other herbal medicine.
Taking the ill person to a health facility is the last option.” (FGD, 62yrs old Community leader 2).

One of participant mentioned that comparatively people health care seeking behaviour was improved due to strong government efforts. “Previously the experience of visiting health facilities in our community was less likely; we were using “grawa” the local traditional medicine for every disease. Nowadays thanks to the government people are seeking care from public health facilities after the introduction of community-based health insurance. People are visiting health facilities to get relief from their illness including cough.” (FGD, Religious leader 1).

The level of awareness of the people greatly affected their habits of visiting health facilities when a problem arises. “... We are advising them to go health facilities and explaining that the service is given free of charge but they refuse to go. Previously most of the community members were considering tuberculosis as HIV/AIDS and afraid to be diagnosed. But currently, when they see the recovery of tuberculosis patient those who visited health facilities, now they are showing willingness to visit health facilities.” (FGD, HEW 1).

3.3.2. Life style related

These are ways of life that can greatly influence overall health and well-being of TB patients. The type of occupation and way of life of TB patients has a great influence on the treatment outcome. The other mentioned reason for the cause for the death of TB patients is lack of adequate rest.

“As you know most of the community members are farmers, and they are expected to feed their families. Farming by itself needs high energy, TB patients are farming along with taking drugs which is very difficult for them to get relief from it without rest. Lifting heavy load also exacerbate the disease and cause death.” (FGD, HEW).

Smoking and excess alcohol consumption has a strong influence on TB and is a major barrier towards treatment success. Findings indicate that smoking cessations are an effective way to decrease treatment failure and drug resistance.

“One of them had been using substances and refusing to stop smoking and drinking alcohol while taking the anti-TB drug. Then the disease was worsened because of all such problems and finally he passed away.” (FGD, HAD 1).

Participants further mentioned that a habit of smoking a local cigarette called “Gaya” and different kind of alcohols resulted in death of TB patient even if they are in medications.

“I think one of the other main causes of death among TB patients is smoking “Gaya”. Even after they (TB patients) were diagnosed with the disease they didn’t stop smoking it. On the other way round, before the diagnosis of the disease, they claim that the cough is due to “Gaya”, not the disease. They die before they complete the drugs.” (FGD, HAD 2).

“In our kebeles, people are smoking “Gaya” and drinking local drinks like “Cheka” and “areke” Even TB patients themselves smoke “Gaya” and drink “Cheka” and “areke” we always advise them to stop smoking and drinking but they refused to stop...I think it may have some contribution for the death of TB patients.” (IDI, Male health worker in TB clinic).

3.3.3. Co-morbidity

Several medical conditions such as diabetes mellitus, HIV/AIDS are among the major comorbidities of Tuberculosis and reason for poor TB treatment results. One participant noted the following:

“There is one person who has Co-Infection with HIV/AIDS. He takes anti-TB but he refused to take ART. He died because he discontinued ART even if he takes anti-TB. When, we tried to follow him, he changes his address repeatedly. He did also develop the so called Syphilis. Therefore, he died because he discontinued ART.” (FGD, HEW).

“In my opinion, TB by itself didn’t kill the person; the main cause of death of TB patients is having co-morbidity with other diseases like HIV/AIDS.” (IDI, a 29yrs old TB focal)

3.4. Tuberculosis treatment related

3.4.1. Treatment adherence

Participants broadly articulated the treatment adherence of the tuberculosis patients in their community. Some of the patients discontinue the medications when the symptoms subside. Usually they use the medication for the first two to three months effectively but then they stop. “Acute symptoms such as cough, loss of appetite and sweating will be improved most of the time when the patient took the medication for two month by close monitoring of the health professionals. Listening to family members or close relatives advice and sometimes by themselves, they will decide to stop the follow up.” (FGD, HAD 2).

“...They didn’t go to the health facility in the earlier stage of the disease. Most of the time in our kebele, the people are visiting health facility after the disease is complicated and when they are in the serious situation.” (IDI, 28yrs old family member).

“One of the main reasons for death is a delay in reaching the health facility.” (IDI, a 24yrs old sibling).

Another repeatedly mentioned reason for low treatment adherence was high transportation costs to TB treatment and care. To go to health facility they need to pay for transportation (motor bicycle and or car), this was sometimes difficult. Because of the disease the productivity of the family was affected and the income was remarkably decreased.

“My father passed away a few years back and the family defends on his income to survive. So sometimes he will not go to the health facility due to lack of money to pay for transportation.” (IDI, a 21yrs old sibling).

“In my opinion, most of TB patients are died because of lack of transportation cost to reach health facilities they didn’t go to health facilities given worsening of”: (IDI, a 55yrs old wife).

“Even though the drugs are provided free, the transport cost is expensive and was reasons for interruption of my mother treatment follow up.” (IDI, a 35yrs old sibling).

Some of TB patients who had follow up in Hospital travel by foot since they don’t have money to pay for transportation. When they show up in health facility, they were exhausted. “We need to pay 85 birr during each follow up for transportation. We don’t have that money to pay”. (FGD, HAD 3).

Although TB drugs were provided free of charge to clients, it require expense from patient until the disease is known to be TB. Therefore, before the confirmation of the disease, there is payment for a blood test, chest X-ray, and for other diagnostic and confirmatory investigations. The patients have no sufficient money to pay for these medical bills.

Health professionals advise TB patients to take more food and a balanced diet to minimize the side effect of the drugs. TB drugs are toxic if taken without adequate food consumption. Ample of participants explicitly related lack of adequate food to treatment non-adherence. She explained her experience of the disease and medication.

“I don’t have what to eat and what to drink...so I don’t take the medication…” (IDI, a 44yrs old TB survivor).

“He told me that the healthcare providers repeatedly advised to provide the patient with adequate variety and amount of food. But we were unable to give her and sometimes she skips the drug because of absence of food in the house.” (IDI, a 36yrs old sibling).

The other participants added that the food lacks variety of nutrients, insufficient and untimely which enforces the patient not to take the
drug.

The other challenge mentioned for treatment adherence was side effects of the medications. Some patients discontinue fearing of side effects. The side effects include gastritis, nausea, vomiting, headache, and urine discoloration as explained during the FGD. According to participants reflection, fearing the side effects patient don’t take drugs as health professional’s instructions. Instead when they feel discomfort, patients will skip the morning or night dose.

“If the person takes sufficient meals after medication, they will build his body. Otherwise, the drug will burn all his body parts, the 12 organs, and kill the person after being disseminated throughout his body” (IDI, a 41yrs old TB survivor).

3.4.2. Adverse drug effects

Unwanted, uncomfortable, or dangerous effects that a drug may have reflect the adverse drug reaction or effect. They are one of the major reasons for interruption and complete cessation of TB medications. Greater number of adverse drug effects reported by patients includes nausea, vomiting, abdominal pain, headache, urine discoloration and skin rash. Two participant spoken this;

“Fearing the dangerous effects of the medication, I don’t take drugs as health professional’s order. Instead, when I feel discomfort able, I skip subsequent dose in the morning or night.” (FGD, a 44yrs old female TB survivor).

“...some time he took the drug some time discontinues it because he complains that stomach aches and burning sensation due to this reason my husband died of TB”. (IDI, a 55yrs old housewife).

Respondents mentioned adverse effects of the drug might be the cause for death of TB patients. A 24 years old farmer his father died of TB said that his father died after developing some forms adverse drug effect after taking it. He had to say this;

“One thing I do not forget is the drug adverse effect also is the cause of death. The drug causes stomach ache and severe abdominal pain. My father was always complaining of stomach aches. He feels discomfort when he eats food. He becomes weak and then died.”.

3.5. Health service related factors

Health care providers approach, accessibility of health facility, availability of trained human power and availability of diagnostic facilities were considered as the health service related sub-theme.

3.5.1. Health care provider approach

Health care providers approach to tuberculosis patients was generally good. Patients were advised about side effects of the medications and types of food they need to eat. Two of TB survivor verbalized having been received good care and treatment from health care professional in TB clinic.

“The health professionals were very respectful and caring. They give priority for TB patients. In the first 2 months I was visiting the health center every day and after that I was going every 15 days to get my treatment/pills. They always encourage me to finish the treatment.” (FGD, TB survivor 1).

“Health professionals working in TB clinic were always came to health center early in the morning before other professionals. Always they were examined me and followed my progress well. They were teaching us every 15 days for all of us” (FGD, TB survivor 2).

Participants of in-depth interview shared their experience during visit to health facility. According to them, some of health care providers were not respectful to them and not polite. They added that in many times other staff members or personnel in the hospitals not welcomed them and not supportive. Respondents had this to say;

“Some physician insult, disrespect our mother and us when we didn’t act as they told. Sometimes we didn’t return next time fear of the health care providers’ reactions”. (IDI, a 36yrs old sibling).

“When we ask health professional the direction of clinic, laboratory and toilet, they not respond well. We fell shy and neglected. When the time of follow up comes, all family members worries those ups and downs, especially our mother (patient) chooses not to go”. (IDI, a 40yrs old sibling).

A participant talked about the language problem he faced when he went to hospital with his sick aunt. The local community use a local language “Gamogna” with different variant and health care personnel mostly Amharic for way of communication. They didn’t check whether or not the patient or attendant understood and not request translator at a time. One interviewee had said this;

“When my sick aunt present to the physician in TB clinic, there was no one there who could communicate with us in our language. I believe she doesn’t appropriately take treatment for the TB. Even we do not know what the health professional said after providing the drugs and she was not well informed about when to return”. (IDI, a 40yrs old relative).

3.5.2. Accessibility of health facility

The health facilities were inaccessible for the community. Most of them indicated that health facilities were too far to reach. There was no transportation or no road at all connecting kebeles to Woreda center. Participants’ idea was narrated as;

“They (health facility) are located a long way from us. We travel at least three hours in foot to reach a health center. When someone is sick in our village, we care him/her with bed long distant. Because of this sometimes they (patient) died before we arrive to health center”. (FGD, HAD 2).

“The health center is too far on walk. I had finished the whole course of treatment by going the health center on foot which took about 2 h and 30 min. It is not difficult to guess how it was difficult for a patient with TB disease taking drug.” (FGD, TB survivor 2).

The area where inhabitants are living was mountains and difficult to walk by foot. The numerous hills make the journey challenging and laborious. A 34 years old FGD participant said that “sometimes TB patients discontinue the follow up fearing the distant. They were initially weakened by the disease and when this travel is added, it brings another burden”.

The distance of health facility caused the appointments to be missed and to not follow up regularly casing the medical care to be interrupted. A 30 years old previous TB patient indicated she took two month medications since it was unthinkable to return in short time back to health facility for checkup; “the doctor repeatedly asked me to return again within two weeks but I was unable to do that because of the distance”.

During in-depth interview, health care professional mentioned the interruption of TB care in health post was the main reason for lack of accessibility of health facility. Compared to other health care facility, health posts were accessible. The respondent noted;

“The health service is not accessible for some people. Under our cluster, there are kebele where it takes six ours to walk on foot to reach health facility. Previously, it was accessible since TB care service was extended to Health post. But now, it didn’t sustain.” (IDI, health care provider).

A referral system enables a patient’s health needs to be comprehensively managed using resources beyond those available at the location they access care from health facility. Lack or not making use of a well-established standardized referral system greatly affects the treatment outcome of the patient. At one FGD, a 32 years old female health extension worker disclosed that “Some also reach health facilities by
referral from here but because of unsatisfactory management, they discontinue follow up and die afterwards. Hence, a gap in the referral cascade results in death of many people: inability to reaching to health facility and mismanagement in health facility.” (FGD, HEW).

3.5.3. Lack of facility for diagnosis and care

Here, the investigators look for facilities and resources used for diagnosis and care of TB with in health institution of the study area. In some of health institution, right amount and combination of medication were not delivery on time. This problem was further tangled by long process of obtaining legal document to get medications.

“Sometimes we didn’t get adequate anti-TB drugs for our patients. There are also bureaucracies to obtain legal documents necessary to pick up drugs and reagents.” (IDI, TB focal).

Lack of a separate room for TB patient was one of a reason to not provide care.

“We can provide the service at health post level but there is no separate room for TB patients and no personal protective gears. We are afraid of transmission of the disease to others. That’s why we don’t provide the service.” (FGD, HEW).

Tuberculosis is a very contagious disease and can be transmitted from an infected person to an uninfected person, mainly when a person with TB coughs, sneezes, speaks, or even sings. The level of infection prevention measures in health facility will significantly affect transmission rate. In some facility lack of triage increased the possibility of transmission to other person.

“Because of the absence of triage in our health center TB patients are socializing with other patients and rally in queues to obtain patient cards this increases the transmission of the disease to other patients (IDI, Male health worker in TB clinic).

“Tuberculosis Patients and patients with other diseases sit together and talking each other without preventive measures because we don’t have triage” (IDI, TB focal).

TB clinic room setup, ventilation, location in the institution and availability of personal protective equipment’s such as face mask are crucial for infection prevention measures.

“As you have seen here the room we used to provide the service for TB patients is very narrow and has no ventilation. We (health professionals) working in TB room are also highly vulnerable to the disease.” (IDI, TB Case team leader).

Diagnostic facilities for TB were reported to be inadequate. Some of materials requires maintenance, lack of reagents and poor infrastructure were problems. Most of health facilities have difficulty of GeneXpert and diagnosing MDR-TB.

“Sometimes because of the unavailability of adequate laboratory diagnostic facilities we are facing difficulties to diagnose TB cases on different occasions especially we are facing difficulties to diagnose MDR-TB cases because it is difficult to get a gene expert.” (IDI, Male health worker in TB clinic).

3.5.4. Inadequate trained human power

Availability of qualified and adequate human resources who could provide and support TB care and prevention activities greatly improves the quality of care and treatment outcome. Health professionals should take in-service trainings for continuous professional development.

“In our institution there is inadequate trained human power and lack of continuous training and professional development which have great contribution to the death of TB patients.” (IDI, Male health worker in TB clinic).

Introducing delivery of quality TB patient care and services in patient friendly days could further enhance the treatment adherence and coverage.

“In our context most of the patients are from rural kebeles and most of them visit health facilities on the market day (Saturday). But there is no service for TB patients on Saturday because professionals working on the weekend need duty payment, which is not the case here. I believe that we need to make the service available on all days to make the service convenient for the patients. (IDI, Female health care provider in TB clinic).

4. Discussion

This study was aimed to know why people die of active tuberculosis in the era of effective chemotherapy AM-HDSS site in 2020. Low community TB awareness is usually a reason for not visiting health facility for cough, discontinuation of medication and poor practice of infection prevention and control. In the present study, most of the participants didn’t know the exact cause of TB. Lack of sufficient knowledge about TB was considered to be a reason for cause of death. The findings of the study show that TB patients underestimate and ignore when the symptoms first emerge and will not relate it with any diseases. Similarly, a study conducted in eastern Gojam revealed low community awareness about TB and had the wrong perceptions about its cause [12].

In this study health care seeking behaviour of the community was poor due to mainly low TB awareness and uncoordinated interventions. They prefer traditional medicine to the scientific way and this delay in health facility visit increase the severity of the disease. Similar finding was obtained in a community based cross-sectional study conducted in Northwest Ethiopia. TB suspects took some other kind of individual action which included home treatment and traditional medicine rather than visiting modern health care facilities first [13]. Participants of the study broadly articulated that the treatment adherence of the tuberculosis patients was poor mainly due to poor TB awareness, high transportation cost, inadequate food consumption and fearing the adverse drug effects. In agreement with this, a qualitative study conducted in Southern Ethiopia majority of the TB patients were not adhered to the medication due to lack of money, food shortage, belief in traditional healing for curing TB and lack of family and community support [14]. The socioeconomic status of the study area inhabitants was low and has lack of infrastructures such as Hospitals, road, electricity. These caused the patient or suspect of TB to travel long distance on foot to access health facility and low health education campaign.

Because of strong social bonds in the community, there is no significant social stigma or discrimination of TB patients in day-to-day life as participants witnessed. They believe GOD will save them from the disease, so doesn’t worry about close contact they make with TB patients. In contrary to the previous study participants, some reported a number of TB patients hide their illnesses while they are sick fearing the social stigma. Many of them lost their loved one fearing to lose people around them. A nationwide survey of stigma in Ethiopia revealed more than half of the participants would disclose their status, quarter of them fears the community would avoid them, and others would be asked to stay away from the community [15]. The existence of stigma was related with educational status, knowledge and residency. Health care professionals’ relationship with patients and caregivers was frequently cited as important for treatment adherence. Even though some of participants noted health care professionals approach as satisfactory, majority described they are not respectful to them, not welcomed and not supportive during the visit to health facilities. Due to these and language communication problem, some of the patients choose not to go to institutions. In contrary to the present finding, a study conducted in Southwest Ethiopia reported there was a trust in provider-patient relationship which was strengthened by clear, easily accessible two-way communication, demonstrations of confidence, a willingness to adapt and collaborative decision-making [16].

The health facilities were inaccessible for the community. Most of
them indicated that health facilities were too far to reach. Lack of transportation and or road makes walk by foot difficult in mountains route. The distance of health facility caused the appointments to be missed and to not follow up regularly casing the medical care to be interrupted. In line with these findings, a study done in Ethiopia to assess geographic accessibility of health facilities to offer tuberculosis services showed health care institutions very far for those living in less accessible geographic locations [17]. Diagnostic facilities for TB were reported to transportation and or road makes walk by foot difficult in mountains

A study showed that lack of TB diagnostic services and poor infection prevention measure were observed in health facilities [12]. The present study revealed inadequate trained human power and lack of continuous training and professional development for health care professionals which have great contribution to the death of TB patients. Smoking of cigarette and the local product called “Gaya” has a strong influence on TB and is a major barrier towards treatment success. Findings indicate that smoking cessations are an effective way to decrease treatment failure and drug resistance.

5. Conclusion

The present study explored the reason for death of TB patients in the era of effective chemotherapy. Poor treatment adherence, lack of TB awareness, stigma, inadequate food consumption, poor health care seeking behaviour and inaccessibility of health facility were identified as major reasons for death. To prevent death of TB patients all sectors such as education, health, and agriculture should work to address health education, infrastructures, nutritional supplementation needs of TB patients, care givers and the community as a whole.

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Ethical statement

Ethical clearance was obtained from Arba Minch University College of Medicine and Health Science Institutional Review Board. Participation in the research was voluntary. Consent for participation was obtained from each respondent. Confidentiality of information was guarded, and the privacy of all participants was respected. Participants were assured that the Data was used exclusively used for the stated purposes of the research.

CRediT authorship contribution statement

Mulugeta Shegaze: Conceptualization, Methodology, Software, Formal analysis, Investigation, Resources, Data curation, Writing – original draft, Writing – review & editing, Visualization, Supervision.
Belay Boda: Conceptualization, Methodology, Software, Validation, Formal analysis, Investigation, Resources, Data curation, Writing – original draft, Writing – review & editing, Visualization, Supervision.
Gistane Aylele: Conceptualization, Validation, Investigation, Writing – review & editing, Visualization, Supervision.
Befikadu Tariku: Conceptualization, Methodology, Investigation, Data curation, Writing – original draft, Writing – review & editing, Visualization.
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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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