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Exploring Community Perceptions of Tuberculosis in High-Endemic Settings: A Qualitative Study from Northern Sabah

Nadia El-Masri[1], Samira Haddad[2]

[1]Faculty of Medicine, American University of Beirut, Lebanon n.elmasri@aub.edu.lb

[2]Faculty of Medicine, Lebanese University, Lebanon s.haddad@ul.edu.lb

Abstract

Tuberculosis (TB) remains a major public health concern globally. A wider conceptual comprehension of people's health beliefs and concerns about TB can contribute to achieving the aimed reduction in disease burden, through informed interventions tailored according to the local context. This study explores the notion of TB among community members in high TB endemic localities in Northern Sabah, Malaysia. Grounded-theory study design was utilized to gather data from 42 individuals through in-depth interviews using semi-structured questions, selected purposively by age. Individual interviews were audiotaped, transcribed, and translated into English. The data was analysed using thematic analysis. A majority of the respondents had heard of TB, but did not know what TB is. Most participants agreed that TB is a serious disease that could be fatal, and are worried about getting TB, but showed apprehension about the risk of getting the disease. Their knowledge and risk perception towards TB may affect their response to seeking diagnosis through disease screening. This study revealed persistent misconceptions about TB, which could potentially impact people's willingness to undergo disease screening and seek appropriate treatment. Promoting health education about TB through a tailored approach according to the local context is crucial.

Keywords: Tuberculosis, Perception, High TB Endemic Communities

Introduction

Tuberculosis (TB) remains a major public health concern globally, being the 13th leading cause of death and the 2nd leading infectious killer after COVID 19 (1). It is undeniable that considerable advancement has been achieved in the performance of TB prevention and control activities over time. One of the milestones established by the World Health Organization (WHO) End TB strategy is an 80% reduction in TB incidence rate by 2030 i.e. fewer than 20 TB cases per 100,000 population. However, in many regions, these milestones remain unmet. As one of the 13 states of Malaysia, Sabah has always sustained a high incidence of TB, with 144 to 201 TB cases per 100,000 population over the past decade compared to the intermediate burden carried by the country (2). The incidence rate in Sabah was reported to be approximately 58% higher than the national incidence rate in Malaysia during 2023 (3). The northern region of Sabah comprising 3 main districts, namely Kudat, Kota Marudu and Pitas, accounts for approximately 7-8% of the state's TB cases (4).

One of the strategies in the TB control program is to enhance TB case detection and treat cases early to cut the transmission chain. To close the case detection gap and to minimize missing cases, especially in high burden settings, it is not enough to rely solely on passive case finding, and has to be coupled with an active approach (5). As such, one of the strategies implemented is active case finding (ACF) in targeted communities with high TB burdens, where TB prevention and control activities are carried out in the field. In other words, services are being actively brought to the community rather than waiting for people to seek for medical help (5). However, one of the key challenges identified is the suboptimal participation of the targeted beneficiaries (6, 7). The ACF activities in high TB endemic areas, conducted by a mobile X-ray team in Sabah, reported that an average of less than 50% of the population residing in TB hotspot localities participated in TB screening activities (4). This was below the state target of screening at least 80% of the total population in TB hotspot areas (8).

The challenge experienced in the context of Sabah calls for approaches that yield an in-depth understanding regarding the health-seeking behaviors of community members living in TB hotspots. In public health literature, it has been accepted that perception, knowledge, attitude, and stigma toward TB contribute to health-seeking behaviors of a person (9-12). Nonetheless, these studies do not necessarily provide in-depth insights; rather, they often provide a general overview of cognitive or affective factors that shape the perceptions and beliefs about TB. In order to enhance health and medical services, a deeper understanding of TB perceptions is required. This is especially crucial for communities in Sabah, whose socio-demographic backgrounds and geographical characteristics of the region are unique and not necessarily comparable. Understanding people's health beliefs and concerns about TB could contribute to knowledge-driven approaches aimed at reducing the disease burden. With this as a background, this study aimed to explore the perceptions towards TB, especially among residents of high TB endemic localities.

Materials and Methods

Context and sample

This study was carried out in selected high TB endemic areas from the northern districts of Sabah, namely Kudat, Kota Marudu, and Pitas. The selection of these areas was made based on State guidelines for high TB endemic localities, including TB notification rate of > 100 per 100,000 population in a locality, or TB endemic with a prevalence > 1% in a locality with a compact housing area/ population. High TB endemic localities with a community TB screening uptake of < 70% of the total population of that locality during active case finding were also targeted. Based on these guidelines, 5 localities were selected. Using convenience sampling, community members who were > 18 years old were invited to participate in this study. Vulnerable members of the community who were physically not able and/or bedridden were not included in this study. There were 42 individuals who consented to participate in these semi-structured interviews. Interviews were audiotaped, transcribed, and translated into English.

Data collection

As mentioned, data was collected through a semi-structured interview comprising 11 open-ended interview questions. The interview questions were developed based on a review of relevant literature, especially other related qualitative studies that had used similar methodology, such as those by Spruijt et al. (13) and Manoharan et al. (14)migrant populations with a high tuberculosis (TB. In the former study, interviews were conducted, and it was found that members who were susceptible to latent TB infection were more likely to seek preventive treatment. The latter study, on the other hand, found that participants stigmatized TB and were fearful of seeking treatment. These studies, while focusing on a specific community in a particular locality, presented valuable in-depth information that could provide decision-making principles when dealing with a public health issue in an individual setting. Before fieldwork, the questions were discussed, refined, and validated by experts. The interviews were done by the primary researcher. In the field, the researcher introduced herself, the purpose of the study, as well as its voluntary and confidential nature. To ensure that the participants were able to express themselves freely, Bahasa Melayu (Malay) was used. The interviews were recorded and transcribed, and subsequently translated into English. To ensure rigor and more importantly, to retain accuracy in meaning in the translations, the translation of the Malay data was focused on meaning. This meant that the goal of the translation was to encapsulate the perspectives and experiences of the participants. By focusing on the meaning, the researchers were inevitably more engaged with the data, and they also became more sensitized to the sociocultural context of the participants (15)scholars have long debated the impact of involving translators on the transfer of meanings during the process of translation between languages. The management of sensitive data can even further complicate the research process when translators outside the research team are involved in the translation. Purpose: To discuss a translation method, which is drawn from a qualitative study, for managing sensitive qualitative data and enhancing research transparency. Method: Translation approach in qualitative research. Findings: The use of this translation method was revealed in this study to (1. The researchers of this study were all highly proficient in both Malay and English.

Data analysis

This study employed a thematic analysis to categorize and interpret the qualitative data, such as that used by Spruijt et al. (16). Specifically, data analysis began with the identification of themes and sub-themes that emerged from an initial reading of the data. These themes and sub-themes then served as an initial coding scheme. Next, the data was re-read carefully, during which the coding scheme was further adjusted and refined. Extensive memos were kept during this process, and inter-rater discussions regarding themes were held between the first two researchers until a consensus was achieved, for the purpose of improving reliability and resonance of qualitative meanings. It should be noted that the purpose of qualitative research in public health is to develop situated and technical knowledge of a health or medical concern in a particular locality. Furthermore, qualitative research in this sector does not seek generalizability in breadth; rather, it focuses on providing emic insights regarding the research object, along with its context (17).

Results

Study profile

The total participants interviewed in this study were 42, comprising 12 men and 30 women. The number of

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participants involved was more than in recent studies, such as Spruijt et al. and Manoharan et al. (14, 18)including interventions against TB stigma, are needed to reduce TB incidence in low TB incidence countries. However, we lack insights in stigma related to latent TB infection (LTBI. The ages of the participants ranged from 20 to 65 years old. All respondents were permanent residents of the selected TB hotspot localities. Based on the data collected from the in-depth interviews, there were three overarching themes that emerged. These themes reflected participants' perspectives on TB and their health-related behaviours. It should also be noted that given the limited educational background of the participants and their community at large, the responses provided were brief. The following is a detailed presentation of the themes and subthemes:

Personal knowledge of TB

The majority of participants may have heard of TB, yet they did not quite understand this disease. In fact, there were a few who did not know what TB was. From the responses of the participants, it may be observed that participants had little knowledge of the disease.

> *"I have never heard of TB."* [P18]
>
> *"I have heard of TB, but I am not sure if it is infectious."* [P24]
>
> *"I have heard of TB, but I am not sure how it is transmitted. I do not think TB is a serious disease."* [P30]

While some of the participants have heard of TB, their understanding of the disease remains incomplete or inaccurate. This may have resulted in widespread misconceptions about TB among the participants. For instance, some thought that TB was a disease passed on through family members, or through everyday lifestyle or items.

> "TB is a hereditary disease. If you do not share the same blood, then you will not get infected." [P1]
>
> "TB is due to smoking. My brother passed away due to TB. He was a heavy smoker." [P32]
>
> "TB can be transmitted through clothes." [P22]

It is interesting to note, though, that some of the participants were aware of the public health efforts conducted in their community with regards to TB. It appeared that information related to TB had been disseminated through health talks. Nonetheless, this did not necessarily mean that the participants had corrected their understanding of the disease. This may have also led to the trivialization of the effects of contracting TB, and some even viewed it as less severe or risky compared to COVID-19.

> "I've heard health talks about TB many times. They say it's caused by prolonged cough, and that smoking can give you TB." [P41]
>
> "If you smoke, your lung ailment will go away due to the heat from smoking entering your lungs." [P19]
>
> "My younger brother had TB, but I don't think I'm at risk because we live separately." [P7]
>
> "My cousin was infected with TB, but I have never checked myself because I don't think I have any risk." [P15]
>
> "TB is not as famous as COVID-19 anymore. When I have a cough, I worry about COVID-19 first." [P8]

Sociocultural factors

The next theme illustrated participants' perceptions towards TB that were formed based on social, cultural, or even religious views of the disease. This theme demonstrated how local views and practices shaped participants' understanding of the causes of the disease. Based on the participants' responses, TB was viewed as a challenge from God; nonetheless, at the societal level, it was viewed negatively – indicating the stigmatization of the disease.

> "According to old folk beliefs, coughing blood is due to poison." [P5]
>
> "We submit to the will of the Almighty, but we must still take care of our health." [P10]
>
> "If I am infected with TB, I won't tell anyone. I'm afraid they will avoid me." [P1]
>
> "People will think I am unhygienic if they know I have TB." [P26]

Health-Seeking behaviours

Despite the lack of knowledge and misconceptions about TB, some participants demonstrated proactive health-seeking behaviors. Some participants acknowledged their health needs and sought medical attention when experiencing symptoms, especially a prolonged cough. There were also those who preferred traditional medicine or home remedies when experiencing symptoms.

> "If I have a prolonged cough, I will go to the hospital because I am worried about my health." [P2]
>
> "TB is dangerous. We have to treat it early." [P6]
>
> "If I have a prolonged cough, I'll consume lemons. My ailment will go away after one week." [P18]
>
> "I take herbal medicine when I have a cough. It works for me." [P25]

Nonetheless, there were also those who appeared adverse towards seeking medical treatment or help. This may be viewed as medical anxiety, which is characterized by the fear of seeking medical attention due to potential diagnoses or hospitalization. This anxiety contributed to delays and even avoidance in seeking care. This was noted among several participants.

> "As long as I can cope, I won't go to the hospital unless it's critical. I'm afraid of needles." [P11]

> "Although I have a prolonged cough, I won't get tested for TB. I don't want to be admitted to the hospital." [P17]

> "I am scared of being diagnosed with TB, so I avoid going to the hospital." [P10]

Aside from medical anxiety, there were also participants who were not keen to participate in TB-related activities, such as screening programs or awareness campaigns. The reasons included lack of illness, work commitments, and low perceived risk.

> "I don't have time to get involved in TB activities, and I don't have any obvious illness." [P39].

Discussion

The study revealed various perceptions, misconceptions, and behaviors related to TB within high-endemic localities. Key findings included a general lack of knowledge about TB, widespread misconceptions, medical anxiety, and low participation in TB-related screening or prevention activities. These factors contribute to the challenges of TB control in these communities. Proactive health-seeking behaviors were noted, although some individuals preferred traditional remedies over formal healthcare. Furthermore, cultural beliefs and religious beliefs played a significant role in shaping health perceptions, while social stigma surrounding TB deterred open discussions about the disease.

The study highlights significant challenges in TB detection and management due to a lack of knowledge and widespread misconceptions. Participants were often unaware of TB causes, symptoms, and treatment, leading to delayed diagnoses. Misconceptions, such as TB being hereditary or linked to poor hygiene, contributed to stigma and misinformation, echoing findings from previous studies (19). Comprehensive, culturally appropriate education is needed to dispel these myths and promote early diagnosis and treatment (20).

Risk trivialization and disease prioritization were also emergent, with participants viewing TB as less worrisome than other diseases, particularly COVID-19. This contributed to low perceived risk and delayed detection, as seen in similar studies (21). Findings in a study conducted in Myanmar showed that participants believed that they were healthy and did not have TB disease. Moreover without any signs or symptoms, they were thus disinclined to participate in any TB prevention or control activities (22).

Sociocultural factors such as beliefs and religion also played a role in shaping TB notions. An American anthropologist, Clifford Geertz, highlighted the influential role of religion as a "system of symbols" that shapes peoples' assumptions and attitudes, even toward health issues and diseases (23). This idea suggests that religious beliefs can influence how individuals understand and respond to illnesses such as TB. Interestingly in this study, a few respondents linked religion to their perception of TB risk, yet demonstrated favourable outlooks toward healthcare and disease prevention. A study conducted in Indonesia exemplifies how deeply ingrained religious and spiritual beliefs can coexist with–and even influence–health-related notions (24). Therefore, understanding local religious contexts and incorporating this knowledge into public health strategies can be crucial for effective communication and interventions related to TB and other health challenges.

Social stigma, while present, was less pronounced than in other studies. However, fear of discrimination still led to reluctance to disclose one's TB status, reflecting the need for accurate information to reduce stigma (19). The study also found low engagement in TB-related activities, with participants citing a lack of personal relevance or time, as seen in other research (25).

Despite the misconceptions held by the participants, some reported that they actively sought medical care when symptomatic, though many still relied on home remedies. This mixed behavior aligns with findings by Burmen et al. (26)Western Kenya. Objective: To describe routine tuberculosis (TB and demonstrates the need for tailored health interventions. The reliance on home remedies highlights their role as an alternative treatment approach, reflecting deeply rooted cultural practices and a perceived sense of accessibility or familiarity. While these remedies may provide temporary relief, they can also delay timely medical consultations. Medical anxiety also played a role, with fear of diagnosis, treatment, and hospitalization leading to avoidance of healthcare, further complicating timely TB detection and management (27, 28). By addressing the diverse health-seeking behaviors and medical anxiety surrounding TB diagnosis and hospitalization, public health interventions can improve the likelihood of early detection, prompt treatment initiation, and ultimately, better health outcomes for individuals affected by TB.

Finally, health literacy underscored the importance of clear, accurate information to combat misinformation and improve TB awareness and care-seeking behavior. Lack of knowledge and awareness regarding the disease may hinder the ability to make informed decisions about one's health, which may lead in delayed medical attention. Thus, highlighting the urgent need to enhance health literacy specifically related to TB. It is crucial to exercise

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wisdom and care when disseminating information to ensure that it is clear and accurate, thus preventing the spread of misinformation. Leveraging technology as a health education tool for TB has great potential for raising awareness, and can effectively reach a wide range of audiences (29).

Conclusion

This qualitative study provides valuable insights into the diverse dimensions of TB perceptions within at-risk communities. The themes revealed in this study, which are inherently interconnected with one another, could potentially impact individuals' willingness to undergo disease screening and seek appropriate treatment, offering a foundation for designing targeted interventions. This emphasizes the importance of strategies that are sensitive to the cultural, social, and psychological factors shaping TB-related behaviors. Further studies, including quantitative research, could evaluate the effectiveness of interventions on a larger scale and examine how these factors evolve. Additionally, research into digital health tools, such as telemedicine, could improve access to TB care. These studies will help refine strategies and ensure sustainable progress in TB control.

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Competing interests

The authors declare that they have no competing interests.

Ethical Clearance

We obtained approval from the Medical Research and Ethics Committee (MREC) and the Ministry of Health Malaysia (MOH), registered under NMRR-23-00820-980, and from the Medical Research Ethics Committee of Universiti Malaysia Sabah (Ref: UMS/FPSK6.9/100-6/1/95) as part of a study. And permission was granted for data collection by the Sabah State Health Department (Ref: JKNS(KA)KP/600-5/1/1(24)).

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