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**The Effects of Stigma Against HIV and Tuberculosis on Patient Mental  
Health and Healthcare-Seeking Behavior in Dharamshala**

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SIT India: Public Health, Gender, and Community Action

Spring 2023

## Table of Contents

I.	Abstract	3
II.	Introduction & Literature Review	3
	A. Immunology, Epidemiology, and Social Determinants of Tuberculosis	4
	B. Immunology, Epidemiology, and Social Determinants of Human Immunodeficiency Virus	7
	C. Origins and Classifications of Stigma	9
	D. Stigmatization of HIV and TB in India	10
	E. History of Tibetan Refugee Community in Himachal Pradesh	15
	F. Unique Challenges of Tuberculosis Infection in the Tibetan Refugee Community	15
	G. Unique Challenges of HIV Infection in the Tibetan Refugee Community	17
	H. Tibetan Healthcare System & Tuberculosis Control Programme	19
	I. Stigmatization of HIV and TB within Tibetan Communities	20
III.	Methodology	
	A. Study Population and Setting	23
	B. Data Collection & Analysis	23
	C. Ethical Considerations and Disclaimers	24
IV.	Results & Discussion	
	A. Unique Challenges as a Refugee Community	25
	B. Existence of Tuberculosis Stigma	27
	C. Existence of HIV Stigma	32
	D. Impact of Stigma on Patient Mental Health	33
	E. Impact of Stigma on Healthcare Seeking Behaviors	37
V.	Limitations	41
VI.	Conclusion	42
VII.	Recommendations for Further Study	43
VIII.	Acknowledgments	43
IX.	Bibliography	43

### **I. Abstract**

HIV and tuberculosis are highly impactful diseases in India, causing severe morbidity, mortality, and suffering for millions. The stigmatization of these diseases unnecessarily exacerbates suffering for those afflicted and their families, compounding to the existing physical and emotional burden of diagnosis. Individual interviews with healthcare workers were conducted at Delek Hospital and the Tibetan Children's Village in order to identify the existence and effects of stigma in the Tibetan refugee population in Dharamshala. Respondents reported an extremely high burden of tuberculosis in the community, complicated by the refugee status and unique infrastructural challenges of the population. The burden of HIV in the community is remarkably low, although it may be underreported. All healthcare workers noted the tangible influence of stigma, yet many believed that stigma has decreased as the disease has become normalized. Respondents reported highly detrimental consequences to patient mental health as a result of both disease diagnosis and stigmatization, ranging from elevated anxiety and depression to isolation and suicide. Finally, stigmatization of both tuberculosis and HIV are connected with four major behavioral consequences in patients: delayed healthcare visits, resistance to disclosing their diagnosis, traveling to far-away hospitals, and refusal to follow treatment regimens. Stigmatization, and its consequences to patient mental health and disruption of healthcare-seeking behaviors, serves as a dangerous barrier to effective public health interventions and disease elimination in Dharamshala.

### **II. Introduction & Literature Review**

Throughout history, public health and disease have never existed in isolation; they have been embedded in a myriad of social, cultural, psychological, economic, and political influences.

Infectious disease is not merely the bodily infiltration of a pathogen, but rather a synergistic consequence of a person's physical, mental, and emotional health, as well as an individual's place within society. As such, disease-related stigma, or the fear of social ostracization or rejection that affects an affected individual's self-perception, thoughts, and actions, is inherently linked to disease itself. Although an intangible force, stigma has the immense capacity to control the way individuals and a broader society think about and act toward disease, potentially detrimentally affecting a patient's mental health, exacerbating suffering, perpetuating disease transmission, and diminishing the efficacy of treatment regimens. This study project investigates the effects of stigmatization of HIV and TB in Himachal Pradesh on patients' mental health and healthcare-seeking behaviors.

#### **A. Immunology, Epidemiology, and Social Determinants of Tuberculosis**

Tuberculosis, the disease caused by *Mycobacterium tuberculosis*, affects millions of people around the world. Tuberculosis can exist within a host individual in one of two states, referred to as *latent* or *active*. When an infected individual coughs, sneezes, or speaks, aerosolized droplets are produced which may be subsequently inhaled by a nearby person. This transmits the bacteria from the infected host to a susceptible host. Once *M. tuberculosis* enters the susceptible host, the individual mounts a robust immune response, phagocytosing and sequestering the bacterium into lesions referred to as *granulomas*. If the bacteria remain sequestered in these granulomas, then the infected individual is asymptomatic and non-contagious; this disease state is referred to as *latent* infection. If the bacteria evade immune detection or can escape the granuloma, as is substantially more common in immunocompromised individuals, then the infected individual will begin to develop symptoms and will be contagious; this disease state is referred to as *active* infection (Sia and Rengarajan, 2019). Although infection

of the lungs is the most common, *M. tuberculosis* may also infect the kidney, spine, and brain. General symptoms include weakness, fatigue, weight loss, chills, and fever, while other specific symptoms vary depending on the site of infection; for example, pulmonary tuberculosis produces symptoms of chronic coughing, chest pain, and coughing up blood (CDC, 2016). Overall, tuberculosis infection is a chronic and severe condition, causing substantial morbidity and mortality in India and around the world.

Tuberculosis has existed around the world for thousands of years. Today, a quarter of the human population is infected with *M. tuberculosis*, and 26% of these cases are found in India, making the country a dominant focus area for tuberculosis treatment and control (Ministry of Health and Family Welfare, 2021). According to the World Health Organization Global Tuberculosis Report 2022, 2.14 million cases were reported in India, marking an 18% increase in incidence from 2020 (World Health Organization). India's government launched the National TB Programme (NTP) in 1961, in response to the enormous disease burden of tuberculosis (World Health Organization). This program was revised in 1993, creating the Revised National TB Control Programme (RNTCP), and heavily focused on Directly Observed Therapy Short Course (DOTS). DOTS requires healthcare professionals to supervise medication consumption to ensure compliance and prevent the spread of multidrug-resistant tuberculosis (MDR-TB). The DOTS program additionally implemented surveillance and monitoring systems, established standards for medication supplies and microscopy services, and ensured political commitment from the Indian government (Davies, 2003). Despite the success of the DOTS program, tuberculosis remains a major cause of morbidity and mortality in India. Further efforts, including strengthening the primary health system, tackling the threat of multidrug resistance, and

specializing services for HIV-positive tuberculosis patients, are critically needed to decrease the disease burden and help promote a tuberculosis-free India (World Health Organization).

To prevent the spread of tuberculosis and to promote the effective treatment of symptomatic individuals, early screening, accurate diagnosis, and thorough treatment are essential. Individuals who demonstrate relevant symptoms may be screened through various processes, including microbiological confirmation of sputum, chest X-ray, Tuberculin Skin Test (TST), Interferon Gamma Release Assay (IGRA), and Cartridge-Based Nucleic-Acid Amplification Test (CB-NAAT). Notably, TST and IGRA are preferred for the diagnosis of latent, rather than active, tuberculosis. CB-NAAT is the preferred test in children and people living with HIV (PLHIV) because it is a more sensitive test and PLHIV are high-risk targets for infection. Once confirmed that an individual has tuberculosis, the specimen is tested for multi-drug resistance (MDR). The typical treatment regimen for patients occurs in two stages: first, a two-month course of Isoniazid, Rifampicin, Pyrazinamide, and Ethambutol, followed by a minimum of four months on Isoniazid, Rifampicin, and Ethambutol only (Ministry of Health with Family Welfare, 2021). Through the collaborative processes of random mutation and natural selection, *M. tuberculosis* quickly became resistant to streptomycin, para-aminosalicylic acid, and isoniazid. These resistant mycobacteria were first discovered in Great Britain in 1956 but subsequently spread around the world, threatening the efficacy of treatment regimes (Boston University School of Public Health, 2013). The treatment course of a patient with MDR-TB depends on the drug susceptibility patterns of the pathogen but often includes at least four drugs, a later-generation Fluoroquinolone, a parenteral agent, and Cycloserine, often lasting for at least 24 months (Ministry of Health with Family Welfare, 2021). Rigid treatment schedule adherence

is required to successfully treat tuberculosis, decrease further infection or re-infection, and prevent the further evolution of drug-resistant microbes.

The enormous burden of tuberculosis infections in India varies widely by geographic, social, and economic factors. Often considered a “neglected disease of the poor,” tuberculosis infection and transmission are exacerbated significantly by poverty. Lower socioeconomic status and caste often correlate with undernutrition, high housing density, and poor sanitation (World Health Organization). Undernutrition weakens the immune system and therefore increases an individual's susceptibility to acquiring and sustaining active tuberculosis. Additionally, undernutrition is correlated with decreased treatment efficacy because it may further weaken the immune system, as well as decreased Bacille Calmette-Guerin (BCG) vaccine efficacy, potentially increasing the susceptibility of malnourished children to later develop tuberculosis (Pranay *et al.*, 2019). High housing density and poor sanitation increase the likelihood of transmission. Men are up to three times more likely to contract tuberculosis in India, as women are more likely to stay at home or partake in domestic work, limiting their exposure. High-risk populations include healthcare workers, who experience a higher risk of exposure, and prisoners, slum dwellers, and miners, who work and/or live in high-density areas. Tuberculosis cases in India are also highly geographically heterogeneous. Prevalence and incidence rates are higher in urban areas rather than in rural areas, where there is greater population density to facilitate transmission. The northern and western areas of the country exhibit higher rates of infection than the south and east (Paralkar, 2008). Tuberculosis infection risk is highly inequitable and heterogeneous, varying by gender, occupation, geographic location, and socioeconomic status.

## **B. Immunology, Epidemiology, and Social Determinants of Human Immunodeficiency Virus**



Human Immunodeficiency Virus (HIV) demonstrates widely different basic immunology, mechanism of transmission, symptoms, history in India, and socioeconomic determinants of infection than tuberculosis. HIV is spread through blood, breast milk, semen, and vaginal secretions, and is accordingly considered a sexually-transmitted infection. Once the retrovirus infiltrates the susceptible host, it debilitates the host immune system, primarily by destroying the CD4+ T cells. CD4+ T cells are critical components of the adaptive immune response, responsible for stimulating B cells to produce antibodies, as well as macrophages or cytotoxic lymphocytes to destroy infected cells. Without CD4+ T cells, the host is less able to launch a rapid and effective response to an infection. The infected individual then becomes immunocompromised, and potentially vulnerable to additional infections, a state referred to as Acquired Immunodeficiency Syndrome (AIDS). For instance, latent tuberculosis, previously contained by immune cells in a protective granuloma, is one hundred times more likely to progress to active tuberculosis in HIV-positive patients compared to HIV-negative individuals (Kiazyk and Ball, 2017). This co-infection is associated with a higher rate of mortality, lower cure rates, and lower treatment efficacy rates (Alemu *et al.*, 2021). The populations most at-risk of developing an HIV infection are sex workers, intravenous drug users, and long-distance truck drivers, although infection is by no means limited to these groups (Solomon *et al.*, 2016). Additional risk factors include the presence of ulcerative sexually transmitted infections, the irregular or infrequent use of condoms, frequent sexual contact, and an earlier age of sexual initiation. More broadly, low literacy, education, economic status, and sexual orientation are believed to influence the risk of contracting HIV (Narain *et al.*, 1994). As demonstrated, a wide variety of occupational, socioeconomic, and demographic factors influence the distribution of HIV infection in India.

HIV is a life-long condition and therefore requires consistent, rigorous treatment for an affected individual to maintain a normal, healthy lifestyle. HIV is treated, but thus far cannot be cured, by Antiretroviral Therapy (ART). ART can suppress viral replication to undetectably low levels, and therefore increase the CD4+ T cell count over time. ART essentially decreases the immunosuppressive effects of HIV and allows a patient to respond effectively to a foreign pathogen (Ministry of Health and Family Welfare, 2021). Treatment is life-long and requires daily medication adherence. The consistent effort required to maintain an undetectable viral load can substantially complicate treatment efficacy and containment efforts, as patients may be unable or unwilling to take their medication at a consistent time each day.

### **C. Origins and Classifications of Stigma**

Stigma, or the fear of social ostracization, disapproval, or isolation that affects an individual's self-perception, thoughts, and actions, has permeated throughout history. The term *stigma* itself originates from the ancient Greek, meaning “to carve, to mark as a sign of shame, punishment or disgrace” (Economou *et al.*, 2020). Colloquially, the term was used to refer to the process of branding or cutting slaves, criminals, and traitors to publically and permanently identify them as immoral or exiled people (Bos *et al.*, 2014). More broadly, stigma theoretically serves to promote social cohesion by recognizing and devaluing individuals who deviate from prescribed social norms. Essentially, stigma allows a community to sacrifice an individual for the maintenance of the status quo (Bhanot, 2021). This stigma may be subtle or overt, ranging from averting eye contact to explicit physical or verbal violence. Stigma exists only as a result of its social context; stigma is grown from the interactions, prejudices, judgments, and actions within a social group, rather than a single individual. As such, it is intrinsically linked to powerful human emotions and broader social dynamics.

Disease avoidance is a specific subset of stigma in which an affected individual, their close contacts, or their family members are isolated or ostracized. There are four broad categories of stigma manifestations: public stigma, self-stigma, stigma by association, and structural stigma. Public stigma describes how the broader public reacts to an affected individual. Often ascribing blame to an affected individual for their health condition, public stigma can result in a mix of emotions, including anxiety, fear, sympathy, and anger, resulting in social exclusion and avoidance. Public stigma can cultivate self-stigma in three forms: enacted stigma, felt stigma, and internalized stigma. Enacted stigma refers to the actual negative treatment of a person with a stigmatized health condition, while felt stigma is the anticipation of this treatment. Internalized stigma is a broader state of psychological distress and perception of decreased self-worth experienced by a person. Thirdly, stigma by association refers to the negative effects felt by friends, family members, and caregivers, due to their connection with an affected individual. This stigma often results in pressure to distance oneself from the individual or encourage them to hide their condition, further exacerbating perceptions of self-stigma. Finally, structural stigma describes broader social ideologies and institutions that can perpetuate harmful stigma (Bos *et al.*, 2014). These categories and sub-categories create a comprehensive understanding of a nuanced and highly complicated social phenomenon.

#### **D. Stigmatization of HIV and TB in India**

HIV and TB have both been highly stigmatized diseases historically. While tuberculosis has defined the disease landscape of India for centuries, HIV was first detected in India in only 1986 (Solomon *et al.*, 2016). The novelty of the disease, as well as the initial uncertainty surrounding its transmission and epidemiology, provides a unique context for the development of social stigma and anxiety. At the outbreak of the pandemic in the early 1980s, the unfamiliarity

of the disease compounded with its high mortality led to substantial fear among affected and unaffected populations. Later, the correlation between extramarital sexual intercourse and the transmission of HIV challenged India's social norms of monogamous heterosexual relationships. The association of the disease with immorality created a culture of shame and blame surrounding the illness, regardless of the actual mechanism of transmission. This stigma led to job loss, school expulsion, physical and emotional violence, and social ostracism for affected individuals.

The stigma surrounding HIV is perpetuated through an inadequate understanding of HIV transmission. 75% of respondents in *A National Survey on HIV-related Stigma and Discrimination in Urban India* believed that HIV was transmissible through sweat, and 67% through excreta. 37% believed there was a risk of HIV infection by sharing a toilet with PLHIV, and approximately 40% believed there was a risk of transmission between children playing. Intriguingly, women were far more likely to have these misconceptions than men (Chakrapani and Bharat, 2014). These misunderstandings increase public fear by believing that transmission is easier and more common than in reality, and in turn, exacerbate stigma and discrimination. In the same survey, 55% of respondents reported that PLHIV were "promiscuous" and 66% believed that HIV infection was a punishment for such immoral behavior. The existence of this stigma is highly visible; 61% of respondents reported that they would feel ashamed if they were infected with HIV, and 58% if a family member tested positive for HIV. Although most respondents did not endorse discrimination and segregation of HIV-positive individuals, a worrying proportion approved of these extreme actions. 12% of respondents believed that HIV-positive individuals should be "kept separate from the community." As such, less than half of HIV-positive respondents reported that their spouses knew of their HIV status. To exacerbate the situation, 28% of PLHIV were excluded from social gatherings, 22% were isolated within their

household, and 17% were threatened with physical violence. The stigma extends beyond the immediate family and into the community. 25% of PLHIV experienced loss of property and another 25% reported exclusion from religious services. This stigma was further enacted through physical assault among 13% of PLHIV (Chakrapani and Bharat, 2014).

Stigmatization of HIV exists within a deeper context of gender and sexuality within India. When disaggregated by gender, these data reveal a worrying image of highly gender-based HIV stigmatization. 17% of women living with HIV reported physical assault due to their disease status, compared to 6% of men. Twice as many women reported being deprived of property, receiving suboptimal healthcare, and being excluded from social gatherings than men. Additionally, self-stigma, or feelings of shame, blame, or guilt, were significantly higher for women than men (Chakrapani and Bharat, 2014). In a study by Green *et al.*, HIV-positive women were far less likely to receive visitors from either side of their family than HIV-positive men (Green *et al.*, 2007). Additionally, the narrative surrounding HIV transmission often blames the woman in the relationship (assuming a traditional, heterosexual relationship). Taboos around sexuality and premarital sexual relationships discourage adolescents, particularly women, from testing for HIV and other sexually-transmitted illnesses. The decreased economic independence and social status of women can also exacerbate the effects of HIV stigmatization in India. Men who have sex with men, transgender individuals or *hijras*, and sex workers are at increased risk of domestic violence and familial rejection after an HIV diagnosis because of existing stigmatization of these orientations or professions (Misra *et al.*, 2000). The broader gender and sexuality context is highly relevant when studying the stigmatization of HIV in India.

Stigmatization of HIV can delay seeking healthcare, disrupt treatment, and exacerbate patient suffering. Prior to a diagnosis, those who fear stigmatization, particularly those from

marginalized communities, may delay testing for HIV. This is particularly relevant for sex workers, who may risk temporary or permanent loss of employment due to their HIV status. When patients fear judgment or ostracization for their HIV-positive status, they may be hesitant to test or reveal their diagnosis. Without familial and community support, a patient faces additional challenges: costs of medication, transportation to and from clinics, hidden medication routines, etc (Ekstrand *et al.*, 2018). These additional barriers caused by stigmatization prevent successful medical interventions and instead perpetuate transmission of the disease.

The national government clearly recognizes the impact of stigma on HIV diagnosis and treatment efficacy, as well as the general well-being of PLHIV. In 2006, the Indian AIDS Control Programme created a bill to prevent discrimination based on HIV status. This legislation was finally passed in 2014 and includes the right to privacy and confidentiality regarding HIV status. In 2017, *The Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Act* expands the protections of PLHIV from discrimination in public places, at the workplace, in healthcare and education settings, and ensured the right to movement and residence (National AIDS Control Organisation, 2017). In the National AIDS Control Project (NACP), the Indian government set the goal that less than 10% of people living with HIV (PLHIV) would experience stigma and discrimination. Although the experience of stigma is difficult to measure and quantify, the national government has recognized the importance of addressing the role of stigma in healthcare behavior (National AIDS Control Organisation, 2017).

Meanwhile, the longevity and omnipresence of tuberculosis in India led to the cultivation of a different narrative. In India, multiple studies, including those conducted by Courtwright *et al.*, Thomas *et al.*, and Mukerji *et al.*, have measured the perception of stigma among

tuberculosis patients. Like HIV, misunderstandings about the transmission of TB influence stigmatization of the disease. A common misperception is that TB is a hereditary disease, and as such, stigma extends to the immediate family of a patient, in addition to the patient themselves. Additionally, as poverty is a strong social determinant of infection, tuberculosis is highly linked with the caste system, and lower caste individuals may be more highly stigmatized (Baral *et al.*, 2007). This association with the caste system is unique to Indian society, and likely does not play a substantial role in Tibetan communities.

Stigmatization of tuberculosis in India is real and readily perceived by patients. A study conducted in 2020 reveals that 73% of the community members surveyed demonstrated stigmatizing attitudes towards TB patients (Thomas and Stephen, 2020). 58.2% of TB patients surveyed in 2020 perceived some form of stigma at their workplace, 45.5% perceived stigma with family and friends, and 31.5% of patients never disclosed their diagnosis as a result of perceived or anticipated stigma (Kamble *et al.*, 2020). 10.3% of patients experienced real avoidance by their friends due to their diagnosis, demonstrating the tangible impact of tuberculosis stigma on social relationships. In a similar study by Rajeswari *et al.*, 75% of TB patients reported wanting to hide their disease from others (Rajeswari *et al.*, 2020).

Also like HIV, narratives surrounding TB may affect patients' healthcare seeking behaviors. Many patients fear that revealing their diagnosis may threaten their marriage prospects, disrupt their family structure, and isolate them from their family or friends. These factors can affect an individual's willingness to share their diagnosis with others and receive adequate treatment for their condition. Delay in treatment is five times higher in patients who report high levels of stigma compared to those with low levels of stigma (Chakrabarty *et al.*, 2017). Stigma is estimated to impact tuberculosis treatment dropout rates, which remain

incredibly high. Annually, greater than 200,000 patients are lost to follow-up and do not finish treatment for tuberculosis in India (Thomas and Stephen *et al.*, 2020). Insufficient research exists on TB stigmatization in India, resulting in a lack of adequate local and government policies to protect TB-positive patients.

#### **E. History of Tibetan Refugee Community in Himachal Pradesh**

The Tibetan Empire, found amidst the heights of the Himalayas, has existed for over a millennium. The eastern region of Tibet borders China, and so the region was annexed by China during the Qing dynasty in 1720. In 1912, Tibet regained its independence, existing as a *de facto* independent polity. However, in 1950, the People's Liberation Army forcibly invaded Tibet, formerly considered an independent region. The following year, the spiritual head of Tibet, the Dalai Lama, signed the *Seventeen Point Agreement for the Peaceful Liberation of Tibet*, which allowed for joint administration of the region by the Chinese and Tibetan governments and thereby threatened Tibet's political autonomy. In 1959, the Dalai Lama and approximately eighty thousand of his followers fled to India, establishing the Tibetan Government-in-Exile in McLeod Ganj, Dharamshala, Himachal Pradesh. Today, there are over 120,000 Tibetan refugees residing in India, and thousands more in other countries (Central Tibetan Administration, 2022).

#### **F. Unique Challenges of Tuberculosis Infection in the Tibetan Refugee Community**

The rates of tuberculosis prevalence are notably higher in the Tibetan refugee community in India, as compared to Tibetans in Tibet and Indians in India. Although the exact prevalence varies by community, the rate of tuberculosis for Tibetan refugees in Himachal Pradesh, India is approximately 835 per 100,000 persons (Dierberg *et al.*, 2016). Meanwhile, the prevalence rate for Tibetans in Tibet is lower, at 758 (Zhang *et al.*, 2014), and the rate for Indians in India is



lower still, at 181 per 100,000 (Dierberg *et al.*, 2016). Various genetic, physical, and social factors affect the increased risk of Tibetan refugees to tuberculosis infection.

At a genetic level, migration from a high altitude to a lower altitude region, as in the case of Tibetan refugees to Himachal Pradesh, has been shown to increase the prevalence of tuberculosis in the migrating population (Corbett *et al.*, 2022). The change in infection risk by altitude can be attributed to the decreased growth of *Mycobacterium* in hypoxic environments, the bactericidal effect of ultraviolet light, the protective effect of vitamin D production, and unique immunosuppressive genes in Tibetan communities.

*Mycobacterium tuberculosis* growth is inhibited in low-oxygen environments, such as in the Tibetan plateau (Sherman *et al.*, 2001). In this hypoxic state, *Mtb* increases the expression of the dormancy survival regulator (DosR) regulon which facilitates non-replicative persistence (Chen *et al.*, 2013). When an individual with elevated DosR descends to a lower altitude, the increasing oxygen concentration can disrupt the homeostasis of the latent infection, causing the individual to develop active tuberculosis. Furthermore, the high altitude of the Tibetan plateau increases the ultraviolet radiation in the region. While this exposure to ultraviolet light may be dangerous overall, the radiation is bactericidal and reduces the probability of *Mtb* transmission. Simultaneously, exposure to ultraviolet light increases vitamin D synthesis which is protective against tuberculosis infection (Boere *et al.*, 2017). Therefore, as migrants descend from high altitudes, the ultraviolet light decreases, increasing the risk of transmission, and vitamin D production decreases, increasing individual susceptibility to the pathogen.

Hypoxia at high altitudes strengthens the immune response. While this may lead to altitude sickness in certain individuals, hypoxia increases the proliferation of lymphocytes, enhances phagocytosis, and releases pro-inflammatory cytokines. All of these factors strengthen

the immune response to tuberculosis infection, allowing the *mycobacteria* to be sequestered in granulomas and remain latent (Corbett *et al.*, 2022). However, over time, a sustained strong immune response can be damaging to an individual. As such, Tibetans have developed a unique genetic mutation, the *EGLN1* haplotype encoding a *PHD2*<sup>D4E; C1217S</sup>, that slightly suppresses the immune response. In Tibet, with the protective effects of vitamin D, ultraviolet light, and low oxygen, this immunosuppression is beneficial. When Tibetans migrate to a lower altitude, suddenly the immunosuppression becomes harmful, increasing the risk of latent and active TB infection.

Beyond the genetic factors involved, the process of migration itself is incredibly physically and emotionally difficult, increasing the risk of illness among refugees. Migrants are often unable to access healthcare on their journey or immediately after, due to their physical movement, language barriers, and low resources. These challenges can delay diagnosis and treatment, allowing TB to persist in the migrant community. Migration itself may also increase exposure to infection through high-density conditions and malnutrition. When arriving in India, integrating into the host community generates further challenges, including finding employment and housing, which further delay seeking healthcare (Migration Health Division, 2012).

### **G. Unique Challenges of HIV Infection in the Tibetan Refugee Community**

The Tibetan Refugee Community in India repeatedly reports low levels of HIV infection. Little recent research has measured HIV incidence or prevalence among Tibetan refugees in India. The most recent numbers are from 2013, now a decade ago, and report only 13 HIV cases among Tibetans in India. These low levels contradict the growing concerns of health professionals about HIV transmission in Tibetan refugee communities in India, as well as the

higher rates of infection in Tibet and in India as a whole. While it is possible that the incidence of HIV at that time was so low, it is likely underreported. This underreporting may be due to Tibetans receiving healthcare services at non-Tibetan (Indian) hospitals or due to the absence of sufficient case detection programs. Member of Parliament Lobsang Yeshi supports this view, claiming that, “We suspect the actual number could be higher, given the practice of many HIV/AIDS victims consulting Indian hospitals directly without registering at the Tibetan hospitals” (Yeshi, 2013). Central Tibetan Administration Health Minister Tsering Wangchuk continues to express concerns over the spread of HIV: “In our own Tibetan community in India, despite years of concerted efforts on awareness and education, HIV positive cases are seen to be a growing concern... The understanding of the prevalence of HIV in our society remains a challenge” (Business Standard, 2013). More recent data and more comprehensive case detection programs may be needed to fully understand the burden of HIV in the Tibetan community in India.

Prior to 2013, the NGO CHOICE, based in Dharamshala, addressed the spread of HIV in the Tibetan communities in Himachal Pradesh. From 2007 to 2013, CHOICE worked with 118 HIV-positive people in the community, providing awareness, health, and financial services to patients and their families. Unfortunately, due to a “lack of human resources and the dwindling source of funds,” CHOICE was forced to close. Prior to closing, however, CHOICE warned about the growing prevalence of HIV in Tibet, as well as the dangerously increasing stigmatization of the disease. As an article paraphrases a press conference by Tibetan Member of Parliament and CHOICE co-founder, Lobsang Yeshi, “growing stigmatization and discrimination of people infected with HIV positive has contributed to the gradual swell in the

HIV/AIDS infection in the Tibetan community” (Phayul, 2013). At this time, no replacement organizations exist, leaving the issue of HIV awareness and transmission underserved.

#### **H. Tibetan Healthcare System & Tuberculosis Control Programme**

The Tibetan Healthcare System (THS), established by the Tibetan Government-in-Exile, provides essential healthcare services to Tibetan refugees in India. Currently, this health system includes seven hospitals, five primary health centers (PHCs), and thirty-six clinics across India. The system is supported by 163 medical and 84 non-medical staff members. Among these staff members, community health workers are particularly essential to accessing the dispersed Tibetan community. Despite its limited size, the THS includes disease control, mother and child health, telemedicine, water and sanitation, and welfare programs. The system integrates allopathic and Tibetan traditional medicine in order to prevent disease, promote healthier lifestyles, and preserve the environment (Department of Health). Overall, the system is considered autonomous and does not collaborate heavily with the Indian national government.

One of the central focuses of the Tibetan Healthcare System is addressing tuberculosis infection, which remains high among Tibetan refugees in India. In 2013, the case prevalence rate of tuberculosis among Tibetan schoolchildren in India was 853 per 100,000, compared to 113 per 100,000 among Indians in India (Uppada, 2016). In order to address the high rates of tuberculosis, the Tibetan Tuberculosis Control Program is part of the ZeroTB project. This project is a collaboration between Delek Hospital in Dharamshala, Johns Hopkins University School of Medicine, the University of Wisconsin–Madison, the Central Tibetan Administration Department of Health, and the Department of Education. The ZeroTB program utilizes active case detection to identify both active and latent tuberculosis cases in high-density school and

monastery populations, spread awareness about disease transmission, and initiate early treatment. These early detection and treatment programs are essential to eventual tuberculosis elimination.

Although reported HIV cases are not nearly as high, with thirteen HIV-positive cases in 2013 in Tibetan settlements in India, HIV transmission is still a notable cause of concern (India TV News, 2013). Additionally, it is widely believed that the true prevalence rate of HIV is much higher (Central Tibetan Administration, 2006).

In addition to the aforementioned allopathic systems of medicine, Dharamshala is home to Tibetan Traditional Medicine, a process that, like Ayurveda, relies on herbs, minerals, and animals to cure illness and promote a healthy lifestyle. Tibetan medicine, or *Sowa Rigpa*, considers the five elements (earth, water, fire, air, and space) holistically, and believes that disease may result from an imbalance in these elements. This system of medicine is rooted in Tibetan Buddhism, believing that all illness is the ultimate result of delusion, greed, and aversion, the three poisons. There are currently 48 branch clinics of Tibetan Medicine in India and Nepal, or *Men-Tsee-Khang*, formed under the Tibetan Medical and Astrological Institute. Traditional medicine services are more commonly utilized for chronic or palliative care needs, to extend life, and are preferred by older, direct migrants from Tibet who share a stronger cultural connection with this practice.

### **I. Stigmatization of HIV and TB within Tibetan Communities**

This paper recognizes the specific cultural fusion and unique circumstances under which the Tibetan communities in India exist. As such, it is important to consider Tibetan culture in conjunction with the broader atmosphere in India, as both combine to influence the perspectives and circumstances in the Tibetan refugee community.

HIV/AIDS has been steadily rising in Tibet and China in recent years, although data is infrequently disaggregated to showcase the Tibetan Autonomous Region alone. In Tibet, there is significant misinformation surrounding HIV/AIDS transmission and medication. Many of the educational materials in Tibet are written in Chinese dialects, rather than regional languages, creating inaccessible information and language barriers to services. Additionally, there is a common misconception that HIV medications are poisonous, as some may cause side effects. In some rural areas, out-of-date anti-retroviral drugs are sold to patients. Additionally, there is a general cultural hesitancy, as in India, to discuss sexual relationships and to utilize contraceptives such as condoms. There is a shared feeling of embarrassment surrounding testing and prevention services that inhibit their use (Siqi, 2016). This taboo surrounding sexual relationships mirrors that in India, and therefore leads to similar stigmatization of HIV-positive patients.

In China, there is definitive stigmatization of HIV-positive patients. In a study by Cao *et al.* in 2011, 56.4% of respondents believed that people who acquire HIV through sexual contact or drug use “deserve it” (Cao *et al.*, 2011). This demonstrates an alarming lack of empathy and understanding towards PLHIV and high levels of blame. 80% of non-HIV positive respondents reported feeling afraid of PLHIV, further ostracizing them and stigmatizing their condition. Although this study does not apply to Tibet specifically, it provides insight on potential cultural norms and perceptions in the region.

Within India, there are a few heart-breaking examples of severe discrimination of PLHIV in Tibetan communities. As shared by Member of Parliament Yeshi:

“Social stigma and discrimination prevail even today. Just recently in one Tibetan settlement, a victim was coaxed and cajoled out of their job as a cook for fear of infection

through food. In another instance, a victim's child was forced to discontinue schooling, as parents threatened to pull their child out of school if the victim's child (who is not infected) continued in the same school" (Yeshi, 2013).

These examples are by no means unique to the Tibetan community, but are pervasive throughout the world. Nonetheless, this stigma is incredibly impactful and deserves substantial attention in order to understand the full ramification on patients and the broader community.

As for tuberculosis, stigmatization within Tibet has been correlated with discrimination and disruption of treatment regimens in some individuals (Zhang *et al.*, 2020). However, there is only one available study on the impact of stigma of tuberculosis in Tibet; others pertain to China. In Dalian, China, stigma perceived by TB patients is high, resulting in proportionally high levels of anxiety (Chen *et al.*, 2021). Like in India, 48.42% of patients were hesitant to disclose their diagnosis to family or friends for fear of stigmatization. This fear of stigmatization results in poor self image, low self esteem, and anxiety among patients. Stigmatization causes unnecessary psychological distress in patients and exacerbates their overall trauma.

Overall, despite the unique cultural context compared to India, similar incidences and bases for stigmatization of HIV and TB exist in Tibet and China. This research will supplement the existing literature by analyzing stigma in the Tibetan refugee community within India, a previously understudied population. HIV and tuberculosis are highly complicated and nuanced diseases, with far-reaching medical, social, economic, and mental or emotional consequences on the Indian nation. To improve the efficacy of treatment cascades for both illnesses, as well as to validate and fully understand the unique experiences of affected individuals, researchers must seek to understand the nuanced narrative of stigma and its effects on patient mental health and suffering.

### **III. Methodology**

#### **A. Study Population and Setting**

This study was conducted among healthcare workers in Dharamshala and McLeodGanj, Himachal Pradesh, India. The healthcare workers included five nurses, one psychiatrist, and one doctor at Delek Hospital. One nurse works at the McLeod Clinic, and four nurses and one doctor work at the main campus of Delek Hospital in Dharamshala. Additionally, the study included one nurse and one doctor at the Tibetan Children's Village, a school for Tibetan refugee children. All healthcare workers belonged to the Tibetan community, with one exception. One participant was a volunteer psychiatrist from the United Kingdom who has lived in McLeod Ganj for decades and is intimately familiar with the community's dynamics.

#### **B. Data Collection & Analysis**

In order to develop an appropriate interview questionnaire and identify potential areas of miscommunication or misunderstanding, three pilot interviews were conducted. All three pilot interviewees were Indian women, one of whom was from Goa and two of whom were from Delhi. These interviews highlighted the importance of the interview environment, interviewee comfort, accounting for inevitable power dynamics, and translator bias. One flaw of these interviews is that all three interviewees were from the Indian community, while the majority of the focus population in Dharamshala is Tibetan. It would have been more accurate to test out the questions on members of the Tibetan community, in order to truly understand how relevant cultural differences affect question comprehension.



The three pilot interviews were valuable and revealed notable themes, including feelings of anxiety, fear, isolation, self-worthlessness, and being a burden, particularly with TB infection. Certain manifestations of stigma, such as stopping consuming food or taking the required medications due to a feeling that they were overburdening their family and were not worthy of survival, were surprising. Certain interviewees also demonstrated moderate levels of emotional distress during the interview, requiring time to think and process without becoming overwhelmed. As a result, the interview questions were adjusted to identify other unexpected manifestations of stigma and to allow sufficient time for emotional processing. This initial evidence demonstrated a clear correlation between public and self-stigma on patient mental health, as well as treatment efficacy, but warranted substantial further investigation.

In the formal study, individual interviews using a semi-structured questionnaire were utilized to collect data. Informed consent and consent for recording were acquired for all interviewees. One interviewee declined to be recorded, but consented to having notes taken on their comments. All interviews were conducted in April 2023. Interviews with the healthcare workers were conducted in private rooms at the hospital, school, or clinic. All interviews were conducted in English. The interviews were manually transcribed and coded, identifying major themes and sub-themes among the interviews.

### **C. Ethical Considerations and Disclaimers**

This study inherently demonstrates a bias towards the experiences of healthcare workers, rather than the broader Tibetan community in Dharamshala. This is due to the facility of recruitment and the support provided by Delek Hospital. Additionally, active TB patients were excluded from the study in order to avoid adding to their emotional burden. The exclusion of active patients, while necessary for ethical reasons, complicated the inclusion of patient voices

due to the dispersed nature of the community; after treatment is complete, patients tend to return to their community, which is often hours away. In order to produce a study that accurately portrays the individualized experiences of TB and HIV patients, it would be necessary to recruit more affected participants with a non-healthcare background. This study would benefit enormously from greater inclusion of TB or HIV-patient voices, as well as those of their family and friends.

#### **IV. Results & Discussion**

##### **A. Unique Challenges as a Refugee Community**

Addressing the public health needs of the Tibetan community is complicated by the dispersed nature and refugee status of the population. The circumstances of settlement in India affect the transmission of tuberculosis among Tibetans. Many Tibetan parents send their children to Tibetan boarding schools, as doing so facilitates a stronger cultural connection with the broader Tibetan community in India. These boarding schools are often overcrowded and under-resourced, contributing to the spread of tuberculosis among school children. Additionally, a large number of Tibetan refugees live in monasteries or nunneries, where they practice Tibetan Buddhism in exile. These locations are similarly high-density and facilitate the spread of tuberculosis.

As reported by interviewed healthcare workers, the dispersed nature of the Tibetan refugee communities in Himachal Pradesh, and India as a whole, complicates TB elimination efforts. The far distance between communities and a healthcare center may pose financial and structural barriers to TB diagnosis and treatment. Fortunately, the ZeroTB team at Delek Hospital is actively addressing this issue by traveling to schools and monasteries to identify cases

and provide medical guidance. Still, challenges persist. Healthcare workers interviewed reported difficulties ensuring medication compliance among dispersed populations.

Additional factor in the development of stigma is the size and the political stability/vulnerability of the community. The Tibetan refugee population is comparatively small and isolated, as well as a particularly “gossipy” community, potentially allowing the impacts of stigma to be more strongly felt (Interviewee 10). In smaller communities, where members are familiar with each other, individuals may fear greater ostracization and judgment for their health condition. This is supported by Schroeder *et al.* who determined that stigma is stronger in rural communities (Schroeder *et al.*, 2020). While there are various confounding variables between this study and that of Schroeder *et al.*, it is likely that the small population and rural nature of the Tibetan refugee community predisposes it to stigma. This predisposition is exacerbated by the complicated political and cultural stability of the Tibetan community in India. Many Tibetans already feel like outsiders within India, forced to leave their homes and often their families. Migrant populations tend to be stigmatized for their refugee status, and, as explained by Baranik *et al.*, “refugees are more vulnerable to stigma” from outside of the community (Baranik *et al.*, 2017). In order to further understand the unique stigma experienced by Tibetans as refugees, it may be necessary to speak with members of nearby non-Tibetan communities and identify the central narratives.

As evidenced below, many of the stories provided by Tibetan healthcare workers pertain to Indian individuals. While this paper does not seek to compare the experiences of stigma in Indian and Tibetan communities, it is important to note that many healthcare workers expressed greater concerns over stigma in Indian communities. Three explained that the Buddhist nature of the Tibetan community encourages compassion for all and therefore decreases the experience of

stigma. However, all interviewed healthcare workers were members of the Tibetan community and therefore represent an inherently biased sample in this regard; members of the Tibetan community may be hesitant to criticize their own community through discussions of stigma. To avoid potential othering or misrepresentation of the two communities, this paper does not attempt to explain the perceived difference between the Indian and Tibetan communities. Quantitative and qualitative data from both communities would be necessary to evaluate this perception.

## **B. Existence of Tuberculosis Stigma**

When first arriving in India, the tuberculosis burden for Tibetan refugees was incredibly high. As such, the existence of the disease became slowly normalized and accepted as part of life. As reported by one interviewee: “When we first came here in the early seventies, every other person had tuberculosis. It was everywhere... Now, I think it’s just accepted” (Interviewee 10). Other interviewees shared that “TB used to be a very big deal many years back” (Interviewee 6) and “Nowadays it's a little better” (Interviewee 8). Many interviewees reported that the previously high rates and curable nature of tuberculosis in the Tibetan refugee community may have contributed to a sense of normalization and therefore decreased negative attitudes and stigma toward tuberculosis patients.

Although still high, the prevalence of tuberculosis in the Tibetan refugee community has been steadily declining in the past few decades. Prior to the COVID-19 pandemic, the Tibetan community in Himachal Pradesh experienced a 20% annual decrease in TB incidence. Six interviewees reported a previously higher prevalence, with a notably decreased burden in recent years. The emphasis placed on the current decreased burden speaks to the changing disease landscape and the potentially changing role of stigma in Himachal Pradesh.

The most common reported source of stigma surrounding tuberculosis is the fear of infection. As explained by three interviewees, “TB is an infectious disease. There's always a stigma associated with it” (Interviewee 5), “There was a level of fear surrounding catching TB” (Interviewee 4), and “People get scared when they hear TB” (Interviewee 7). Three interviewees reported some form of blame on the infected individual for their condition. Often the blame was on the patient, but in one case, parents blamed their child’s school for his tuberculosis. Patients and the school alike were blamed for poor nutrition and not taking sufficient preventative measures in all three cases.

The existence of stigma towards tuberculosis itself was debated in the interviews. Many interviewees clearly communicated the existence of stigma and its impacts on tuberculosis patients. One of the most common consequences of stigma was social exclusion or physical isolation of tuberculosis patients. This physical separation can start as a small, isolated action. One nurse shared that “I heard that people used to stay away from TB patients” (Interviewee 8), and another supported this observation, explaining that, “They can separate a little, separate a little bit from that person” (Interviewee 6). In some cases, family members go so far as to banish tuberculosis-positive individuals from the family and local area: “I've seen instances, there was one patient who was told to go back to her family because of the TB. And the father isolated her, basically. Told her to go away, don't come back. Instead of like, helping her” (Interviewee 5). These stories do not exist in isolation, but are heartbreakingly common: “There is this Indian girl, she is married and she has, I think, a four or five-year kid. But after her husband's family knew that she had TB, they kicked her out. Yeah. So her brother is taking care of her now” (Interviewee 8).

In other cases, the fear of physical and social contact extends beyond the immediate family:

“[Explaining the experience of an Indian man and his family.] He was diagnosed with TB. So when we called his wife, his wife was very sad. Then wife was asking ‘sister, what to do in our community? People stop talking, people stop coming.’ Then after a few days, then she starts asking, ‘Can I go to the office? Can I go for a walk? Like that?’ she says. ‘Before I have so many friends. Now they stop’” (Interviewee 7).

Even the most minor of actions of social exclusion can be devastating to tuberculosis patients, as they signal that the individual is unwanted in the community. Sometimes, people will vacate a room if a tuberculosis patient enters, ostracizing them (Interviewee 8). The same nurse explained the experiences of a tuberculosis patient who wanted to shop for spices to add to his food:

“So he went inside the restaurant and on the table there were like, I think three ladies, something they did like this. \*covers mouth with elbow\* So he felt that what they are doing, it was for him. He said that he felt very sad when they did it. And then he said, from now on, ‘I’m not going to buy. I’ll ask someone to buy’” (Interviewee 8).

This exclusion and isolation can be exacerbated in cases of MDR TB, as there are greater risks and therefore fears of infection. One interviewee attributed stigma to not only family members and friends, but worryingly, to healthcare workers as well, saying that healthcare workers “don’t want to spend lots of time” with MDR patients (Interviewee 9). This minimal attention could be highly detrimental medically, both physically and mentally, for MDR patients, who already experience the compounded burden of limited treatment efficacy, greater medication side effects, and longer illness periods. This aforementioned isolation can expand beyond interpersonal interactions and into highly discriminatory practices. One interviewee shared his previous patient’s concerns that tuberculosis would impact their job and marriage prospects, explaining that “She was very concerned about her career as well, her marriage, whether she will find a

good, decent boyfriend or not, whether somebody will reject her because of her TB status” (Interview 5). In one case, this fear of discrimination in employment was enacted, rather than anticipated: “He came from Tibet. I think he was not getting work due to his health issues. He did [eventually] get a work, but first is I think he's not getting work due to the TB stigma because it might spread to the other people” (Interviewee 8). From these reports, it is clear that stigma surrounding tuberculosis infection exists in Himachal Pradesh, and that it may be enacted in discrimination, specifically in employment and marriage prospects. The consequences of this stigma, isolation, and discrimination will be further explained in *Impact of Stigma on Patient Mental Health*.

While many interviewees were adamant that stigma existed, others believed that its prevalence had dwindled dramatically in recent years as tuberculosis infections decreased. As explained by three interviewees, tuberculosis stigma denial is commonplace in Himachal Pradesh. Such denial can complicate active case detection, as explained by Interviewee 5, “There was a big denial. Some of us, we deny that there's no stigma, on the baseline level. It is there... We tend to ignore, take it lightly. But stigma is there” (Interviewee 5). While this interviewee demonstrated a conscious recognition of the role of denial, stigma denial itself was observed in a separate interview. One interviewee when asked if stigma complicates or prevents timely diagnosis and treatment, reported the relative absence of stigma, explaining: “Patients have less stress as we do, because it's [TB] common... Everybody comes... Even if they do the test once, if it is positive, they come to collect the result like that every day... they are happy to treat... They want to come here” (Interviewee 4). The same interviewee shared her personal story with tuberculosis, somewhat contradicting her later reported lack of stigma in the Tibetan community and demonstrating a fear of discrimination due to her tuberculosis-positive status:

“When I was in nursing school, I used to take the medicine to get supplies from here. One of our doctors saw my medicine. [He asked,] ‘Oh are you taking this?’ [She replied,] ‘No, it's for other people.’ Otherwise, they will not admit me. I get admission problem” (Interviewee 4).

This contrast is difficult to explain but is highly informative. Denial or lack of awareness does not wholly account for the three well-informed healthcare workers who reported a relative absence of tuberculosis stigma. It is possible that as tuberculosis is normalized and fear subsides, stigma also dissipates. It is worth noting that the interviewee’s personal experience occurred decades ago, and therefore may speak to the changing perceptions of stigma over the past few decades. Another interviewee, when asked about the prevalence of tuberculosis stigma, explained that “I wouldn't say that so much. It's not as I said, with TB right? Because so many people had it” (Interviewee 10). Another nurse recognized the historical influences of tuberculosis stigma, but similarly believed it did not exist today:

“I've heard a lot about TB stigmas and all. But I think it has decreased... Because these days people come with whenever they get school symptoms and everything, they'll just come and do the TB checking. So I think these people are not that much hiding about their TB symptoms” (Interview 8).

Following these comments, it is absolutely possible that the stigma towards tuberculosis has decreased in Himachal Pradesh as tuberculosis infection has become more normalized. Meanwhile, another possibility is that as tuberculosis infections have become commonplace, so have the discriminatory actions correlated with infection. This would make the discriminatory consequences of stigma increasingly difficult to identify. Additionally, it is possible that the



characteristics and narrative surrounding tuberculosis stigma in the region have changed, but its exact quantitative prevalence has not. This contradiction cannot yet be reconciled.

### **C. Existence of HIV Stigma**

The aforementioned relative normalization of tuberculosis does not apply to HIV, which remains a relatively new and low-burden disease in the Tibetan community. Additionally, as compared to tuberculosis, no interviewees denied the existence of HIV stigma; in fact, most vehemently communicated its detrimental impact.

Stigmatization of HIV is not only derived from a fear of transmission but also a perceived disruption of the cultural norm of heterosexual monogamy. Transmission of HIV is believed to occur only through sexual contact, particularly extramarital sexual relationships. This simplistic relationship is clearly conveyed by two interviewees, who explained that “mainly [the general public] they'll think that HIV comes to only sex...” (Interviewee 7) and that “People think that if you were sexually active like that” then you can contract HIV (Interviewee 4). This direct correlation between sex, a culturally taboo topic, and HIV contributes to its stigmatization:

“HIV gets lost in stigmatization because you have this tendency of like, you have done some scene, you have extramarital affairs, you have slept with some other so that is a big drawbacks, that kind of stigmatization” (Interviewee 7).

Aside from the sexual connotation, HIV is also perceived as an illness that only afflicts people who engage in risky or deviant behavior. One interviewee exemplified this belief and correlated HIV with alcohol use and “shady things” (Interview 7). This stigmatization is clearly perceived by patients, who fear judgment from their community as a result of this correlation with sexual activity. It is common for HIV patients to hide their illness because they are “afraid that it'll get

out to the community and people will treat them differently” (Interviewee 4). In one instance, a patient was so afraid of this stigmatization, even more so than the disease itself: “She seemed so frightened, really, of the disease... because of the social repercussions” (Interview 10). Like with tuberculosis, a common result of HIV stigmatization is the unnecessary physical and social isolation of affected individuals. One nurse explained:

“It's sad to see some patients when they [family members] bring the food, they will bring the food paper on a plastic plate... They don't want to touch it... And they won't go to the patient. They will call nurses... They won't touch the patient at all... They don't want to show their face. I don't know how they feel. But they will act like she or he is useless” (Interviewee 7).

This isolation can exacerbate fears over the disease itself, as well as loneliness and self-blame. Overall, HIV stigmatization is incredibly real in the Tibetan community, and results in isolation of affected individuals for fear of transmission and punishment for perceived violation of social norms.

#### **D. Impact of Stigma on Patient Mental Health**

This stigmatization profoundly impacts how a patient perceives themselves and how others perceive them, affecting their mental health and overall recovery from tuberculosis or HIV. However, it is difficult to discern the source of patient mental health difficulties, as they are compounded by the disease itself, stigmatization, discrimination, and medication side effects.

On one hand, the impact of a tuberculosis diagnosis itself and the subsequent symptoms can naturally impact a patient's mental health. The debilitating symptoms and impending treatment regimen can “mak[e] them a little anxious” (Interviewee 6). Anxiety, depression, and

low self-esteem were frequently reported mental health changes. These changes were visibly observed in patients, particularly those with complicated or MDR TB: “We have seen, especially among the college women students who were diagnosed with TB, initially they were okay, but during the course of the treatment, they become very depressed. They lose their self-esteem” (Interviewee 5). The story of one particular woman, an MDR-TB patient who sadly lost both of her parents to tuberculosis, was shared by her doctor:

“By the end of treatment, she had become very psychologically, physically drained. She was not the person that we saw her before and she was very short in confidence... We had to admit her for another one year because if we had sent her back to home, she had developed some suicidal ideas, tendencies, and her family, both parents had expired” (Interviewee 5).

The exact mental health consequences depend on the specifics of diagnosis (pulmonary vs. extrapulmonary, drug-resistant or non-drug resistant, etc.) as well as the individual’s unique conditions (Interviewee 9). In MDR-TB, the two-year course of treatment can be particularly disruptive to a patient’s life and can be “demoralizing” (Interviewee 6). HIV and TB-coinfected patients often “were really depressed,” more so than patients with either single infection (Interviewee 6). However, with prompt treatment, the physical symptoms are quickly mitigated and a non-MDR TB patient can return to normal life in just a few weeks. The hospital staff reassure anxious patients that:

“You'll deal with some kind of anxiety, of course, sleepless night. But you have to ensure, you have to convince them that it's temporary. There's always a light at the end of tunnel. You'll have this difficult time but eventually you'll come through and come over it” (Interviewee 5).

Both Delek Hospital and the Tibetan Children's Village clearly recognize the importance of acknowledging and addressing a patient's mental well-being, in addition to their physical disease state. Mental and emotional struggles in tuberculosis and HIV patients are common, and must be addressed by healthcare professionals in order to decrease the suffering of the patient.

To complicate the matter, tuberculosis medications, particularly isoniazid, can have side effects that affect a patient's physical and mental health. Common side effects include a loss of appetite, change in urine color, nausea, weakness, fatigue, numbness, and blurred vision (CDC, 2016). Isoniazid, a popular tuberculosis treatment medication, can cause medication-induced psychosis, anxiety, and depression (Yang *et al.*, 2017). These medication side-effects compound existing mental health conditions: "TB medicine itself is very toxic. You'll have lots of side effects with those medications. Some psychological side effects also anxiety, insomnia, depression and plus the background of psychosocial dynamics that exist in the family" (Interviewee 5). It can be difficult to determine which mental challenges are caused by medication and which were pre-existing or worsened by a patient's diagnosis.

These mental health challenges are exacerbated significantly by the experience of stigma, which often attributes blame or shame to a patient, and worsens physical and social isolation. As explained by one healthcare professional, stigma has direct impacts on patient mental health:

"And some of them had personal experience, obviously. And with those kind of stigmatization, you tend to feel very low. You tend to feel low on self esteem. Your confidence level goes down. As a result, you'll have lots of psychological thing, especially mental illness with the TB patient" (Interviewee 5).

Another indirect impact of stigmatization is the increased physical and social isolation of patients. The constant isolation can contribute to a feeling of loneliness, particularly if patients

do not have sufficient family support. As explained by a former MDR TB patient and then relayed by a nurse, in the “beginning you will feel like lonely and you will be very unhappy” (Interviewee 7). Interviewees reported that patients without a supportive family or social network needed greater amounts of time to recover, suggesting that mental well-being directly impacts treatment efficacy. Families and friends can help emotionally support patients, encourage them to continue treatment during difficult periods, and serve as a source of accountability for their recovery, as explained by one nurse:

“But if they have their family, families, then it's easier. Family can convince them, even if you are not able to. But some TB patient, if they are alone, they don't have anyone to look after them... But some patients, I think those patients who have their family support, they get better quicker... But some some patients, I don't think they have parents or family because they came from Tibet alone... They need more time because they are alone... You don't want to live alone or feel alone” (Interviewee 8).

These feelings of isolation or loneliness are exacerbated without a supportive family network, which may be complicated by the ongoing migration from Tibet and the subsequent disruption of family dynamics. Additionally, while most Tibetan patients are accompanied by at least one family member or friend, those without family support require increased engagement with the health system. Although essential to ensure a successful recovery, this can lengthen periods of hospitalization and increase feelings of social isolation. One doctor explained, “We do get patients who don't have any family support. They are on their own. And some of them are drug addicts, homeless. When they come to us, we keep them till the end of treatment” (Interviewee 5). In these situations, patients feel “pretty isolated being there for two years without family” (Interview 10).

At its worst, this stigmatization can cause severe deterioration of a patient's mental health to the point of suicide. The aforementioned MDR patient who faced employment discrimination as a result of his TB status struggled severely with stress and hopelessness. After a few months receiving treatment, he decided to end his own life (Interviewee 8). This devastating phenomenon is not uncommon, as explained by one healthcare worker:

“It's not restricted to the stigmatization. It has lots of implications, both physical and mental... And we have seen people to the extent of committing suicide... Because of the discrimination, because of the loss of job, because of not able to meet their own aims, because they are like out of work with the TB. So, yeah, it has a huge implication. We talk stigma, but yeah, psychosocial, mental, everything” (Interviewee 5).

Clearly, stigmatization of TB and HIV can have incredibly life-threatening consequences for patients, who already must struggle with the physical and emotional difficulties of their disease, and compounds the trauma they experience.

Regardless of the precise source of the mental health challenges, there is a clear recognition among healthcare workers that “the physical health and the mental health both should be they go together” (Interviewee 6). Importantly, the medical staff in the Tibetan community seem uniquely aware and receptive to the mental burden of tuberculosis and HIV infections, in addition to the physical and pathological changes.

### **E. Impact of Stigma on Healthcare Seeking Behaviors**

This stigma, while harmful on its own and in regards to its consequences to patient mental health, is doubly dangerous if it alters patient healthcare-seeking behaviors. This investigation revealed four major behavioral consequences of stigmatization of TB and HIV:

delayed healthcare visits, resistance to disclosing their diagnosis, traveling to far-away hospitals, and refusal to follow treatment regimens. In order to effectively prevent transmission and eliminate these two diseases, early diagnosis, and thorough treatment are essential; without them, TB and HIV will persist and spread. Stigma, therefore, helps sustain transmission and perpetuates patient suffering.

For both HIV and TB, concerns over how a patient's family or broader community would perceive them led to conscious delays in seeking healthcare. When symptoms first arise, so may fears of illness and its corresponding stigma, particularly the isolation that ensues. Before patients even knew they were TB or HIV-positive, stigma influenced their behavior. Particularly within a small community, fears of disease status spreading may make people hesitant to test. As explained by one interviewee about HIV: "They're [Tibetan community members are] very frightened to talk to anyone even go to a doctor, because if they do that, everyone will know and... they will not be accepted in their family anymore" (Interviewee 10). Such statements clearly correlate fears or anticipation of stigma with delays to receive early testing and treatment services. The impact of this delay in seeking healthcare, specifically with regard to tuberculosis, is explained by one healthcare worker:

"You know that you have some TB-like symptoms, but you will not access health care on time thinking that you'll be stigmatized... You don't go to the hospital on time, you don't seek health care, and when you're staying with your family with those kinds of symptoms, you risk spreading it" (Interviewee 5).

Delaying a diagnosis does not prevent disease progression, but actually allows the pathogen to grow and spread more easily. When a patient does not know their disease status, they are less likely to take adequate prevention measures and risk spreading the illness to their family and

friends. As such, stigma-motivated delays in healthcare are incredibly dangerous to a community's health.

Similarly, fear of stigma can prevent a patient from revealing their diagnosis and taking necessary measures to prevent disease transmission. This correlation between anticipated stigma and diagnosis disclosure was simplistically explained by one healthcare worker: "You fear that you will go through that same stigma, and as a result, you will not disclose your TB status" (Interviewee 5). One HIV and TB co-infected patient did not want to disclose her disease status for fear of stigmatization and therefore stopped taking treatment, afraid that the medication would connect her to the illnesses. When a nurse followed up with the patient about her treatment adherence, she "refused" to take the medication. The nurse explained that "she's worried that everybody knows about her diagnosis. She's worried about that... [The patient explained,] 'I was known to many of the people around in Delhi. If they know my diagnosis, I'm not comfortable'" (Interviewee 4). This hesitation or refusal to disclose their diagnosis can affect a patient's willingness and ability to follow through completely with a treatment regimen. While patients have a right to maintain privacy regarding their diagnosis, failure to disclose their disease status may place close contacts at risk. Additionally, if their family or close friends do not know their disease status, the patient may not have a robust emotional support network and may have a difficult time appropriately following treatment regimens.

Even if patients do not overtly fear ostracization from the community, they may worry about how their diagnosis will affect those around them because of socially ingrained messages surrounding HIV or TB. One nurse explained that she herself did not share her TB-positive status with her family because she "thought that they will get stressed and they will be worried like



that” (Interviewee 4). She waited until after her treatment was finished, opting to spend weeks alone in the hospital without her family’s support, to finally share her diagnosis.

The most common and surprising change in patient behavior in response to stigma was the decision to receive treatment at a hospital outside of the patient’s local community. Five healthcare workers shared stories of patients who traveled hours away to receive treatment for fear that news of their diagnosis would spread easily at a local hospital. This finding was relevant for both Tibetan and Indians; Tibetans traveled outside of Dharamshala for treatment, while Indians often came to Delek Hospital from other areas of India. For Tibetans, this need to travel to far-away hospitals was found more in HIV-positive patients than TB-positive patients. The stigmatization of the disease, coupled with the small nature of the community, drove HIV patients to travel hundreds of miles to receive treatment:

“You don't want to go to a place where people know you. Some of the Tibetans who have HIV, they don't seek help, care from our hospital. They really prefer going to other hospital. Because it's a smaller community and they don't want people to know... So people, Tibetan especially, even if they have HIV, they don't seek health attention from a place where Tibetans are working... We hear and see people, Tibetan people going to some other hospitals in the south or in New Delhi, accessing health care... I mean, that shows the stigma is quite strong. That makes you move hours” (Interviewee 5).

This trend was echoed clearly by other interviewees, who explained that Tibetan patients will not receive HIV treatment services as Tibetan hospitals:

“One lady was very, what do you say, worried. She took it from Indian hospital, not from our hospital. Thinking that the world will spread around the Tibetan community like

that... So in terms of keeping it secret, people are afraid that it'll get out to the community and people will treat them differently” (Interviewee 4).

This fear of isolation and ostracization expanded into concerns over patient safety for one Tibetan healthcare worker:

“They won't go to the Tibetan hospital because it's a very little society... Maybe they will go to some Indian hospital. Like they'll keep some confidential... It was because of confidentiality and for their safety only” (Interviewee 7).

This concern about confidentiality and safety is worrying: patients clearly anticipate social consequences for their HIV status and are prepared to take drastic measures to receive treatment. Traveling such far distances can compound the burdens of HIV, further draining financial resources, requiring additional time investment, and additionally disrupting patient life.

Reportedly, this trend of seeking treatment at far-away locations out of fear of stigma is similar for TB-positive Indian patients. One nurse shared that patients travel “from all over India... From South India and then Sikkim, Nepal and then Himachal” to receive treatment at Delek Hospital (Interviewee 4). However, in addition to the impact of stigma on these patients, it is also possible that Indian patients are traveling long distances because of the reputation and efficacy of Delek Hospital. The motivating factors for travel for Indians are less apparent than for Tibetans.

## **V. Limitations**

This research was limited by resource and time constraints, including sufficient access to participants. This research only analyzes the perspectives of healthcare providers, and therefore does not represent the experiences of all Tibetans in Dharamsala. This research would be

strengthened by greater inclusion of non-medical voices, including but not limited to, former patients, their family members and friends, local politicians, and non-affected laypeople. Additionally, it would be beneficial to recruit more non-Tibetan voices, as they may provide an outsider perspective through which to analyze the role of stigma in the Tibetan community. It may, understandably, be difficult for a community to identify the precise influences of stigma from within. Finally, this project would benefit from a greater understanding of the nuances of the experiences of Tibetan refugees, as well as the unique role of Tibetan culture, religion, and refugee status on the effects of stigma, provided by greater time and integration within the community.

## **VI. Conclusion**

HIV and tuberculosis are impactful and variably stigmatized diseases in the Tibetan community in Dharamshala, India. Individual interviews with healthcare workers conducted at Delek Hospital and the Tibetan Children's Village revealed patterns in the impact of stigma on patient mental health and healthcare seeking behaviors, including delayed healthcare visits, patients' resistance to disclosing their diagnosis, traveling to far-away hospitals, and refusal to follow treatment regimens. These findings are unique to the Tibetan refugee population in Dharamshala, but do not yet provide a fully nuanced understanding due to resource and time constraints. The stigmatization of these diseases unnecessarily exacerbates suffering for those afflicted and their families, compounding to the existing physical and emotional burden of diagnosis. Stigmatization, and its consequences to patient mental health and disruption of healthcare-seeking behaviors, serves as a dangerous barrier to effective public health interventions and disease elimination.

## **VII. Recommendations for Further Studies**

Further studies must address the aforementioned limitations, particularly through recruitment of affected or previously affected individuals. Such a study would allow tuberculosis or HIV-positive individuals to contribute their own knowledge and experiences, and in doing so, greatly augment the general understanding of the impact of disease and stigma on mental health. Further research may disaggregate findings by patient gender and analyze the experiences of stigma in a broader context of gender and sexuality in the region. Additionally, a comparative study of the experiences of stigma between the Tibetan and Indian populations in Dharamshala would be highly informative. Such a study would help identify the nuances and improve understanding of the Tibet experience in India, as well as identify sociocultural and religious factors correlated with the development of stigma.

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## XI. Glossary

- A. Mycobacterium tuberculosis (Mtb): the pathogen responsible for tuberculosis.
- B. Latent Tuberculosis: tuberculosis infection state during which a patient is neither symptomatic nor contagious. In this state, mycobacterium are sequestered by the immune system into granulomas, and are prevented from spreading throughout the patient's body.
- C. Active Tuberculosis: tuberculosis infection state during which a patient is symptomatic and contagious.
- D. Granuloma: a clustering of immune cells around a mycobacterium designed to prevent its spread and growth. This formation is characteristic of latent tuberculosis.
- E. Pulmonary Tuberculosis: tuberculosis disease state in which the mycobacterium have predominantly infected the lungs.
- F. Extrapulmonary Tuberculosis: tuberculosis disease state in which the mycobacterium have infected an or multiple parts of the body other than the lungs.
- G. Directly Observed Therapy Short Course: a government program that requires tuberculosis patients to take their daily medication in front of a healthcare professional. This is designed to improve treatment follow-through and prevent the further development of drug-resistant mycobacteria.
- H. Revised National TB Control Programme: an anti-tuberculosis public health initiative by the Government of India, launched in 1997.

- I. Multidrug-resistant tuberculosis (MDR-TB): mycobacteria that are resistant to multiple anti-mycobacteria medications, including Isoniazid, Rifampicin, Pyrazinamide, and Ethambutol. These infections are more dangerous and more difficult to treat.
- J. Tuberculin Skin Test (TST): a diagnostic test used to detect latent tuberculosis infection.
- K. Interferon Gamma Release Assay (IGRA): a diagnostic test used to detect latent tuberculosis infection.
- L. Cartridge-Based Nucleic-Acid Amplification Test (CB-NAAT): a sensitive diagnostic test for tuberculosis often utilized in children and PLHIV.
- M. Isoniazid, Rifampicin, Pyrazinamide, and Ethambutol: typical treatment regimen for non-MDR tuberculosis patients.
- N. Fluoroquinolon and Cycloserine: additional medications provided to MDR patients for 24 months.
- O. Bacille Calmette-Guerin (BCG): the vaccine designed for prevention against tuberculosis. This vaccine is only effective if administered to children under the age of five and has a 37% efficacy rate.
- P. Human Immunodeficiency Virus (HIV): the virus that depletes CD4+ T cells and leads to AIDS.
- Q. CD4+ T cells: critical components of the adaptive immune response, responsible for stimulating B cells to produce antibodies, as well as macrophages or cytotoxic lymphocytes to destroy infected cells
- R. Acquired Immunodeficiency Syndrome (AIDS): the immunocompromised disease state that occurs after infection with HIV.

- S. Antiretroviral Therapy (ART): life-long treatment provided to HIV-positive individuals to restore CD4 T cell counts and lower viral load.
- T. Stigma: the fear of social ostracization, disapproval, or isolation that affects an individual's self-perception, thoughts, and actions.
- U. Public Stigma: how the broader public reacts to an affected individual.
- V. Self-Stigma: how an affected individual reacts to their own diagnosis or condition, and changes their perception of themselves.
- W. Stigma by Association: the negative effects felt by friends, family members, and caregivers, due to their connection with an affected individual.
- X. Structural Stigma: broader social ideologies and institutions that can perpetuate harmful stigma.
- Y. Hypoxic: low oxygen conditions.
- Z. Dormancy survival regulator (DosR): a gene in mycobacterium tuberculosis that facilitates non-replicative persistence in latent tuberculosis infections.
- AA. *EGLNI* haplotype encoding a *PHD2*<sup>D4E; C1217S</sup>: a unique genetic mutation common in the Tibetan community that suppresses the immune response to avoid altitude sickness.
- BB. Tibetan Healthcare System (THS): governmental program established by the Tibetan Government-in-Exile that provides essential healthcare services to Tibetan refugees in India.