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Tuberculosis related stigma

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ABSTRACT

While tuberculosis is a preventable and curable disease, it still remains to be a major cause of morbidity and mortality across the world. Research reveals that stigma impacts tuberculosis control negatively through delaying diagnosis and impairing treatment compliance. It also causes enormous suffering since, it results with isolation of patients and their families from social life. In this review; the magnitude, origins, correlates and consequences of tuberculosis related stigma are discussed and some examples of public health interventions to combat stigma are presented.

Keywords: Tuberculosis, Stigma, Public Health implications

INTRODUCTION

While tuberculosis (TB) is a preventable and a curable disease, it still continues to have a high burden particularly in low and middle income countries. World Health Organization (WHO) estimated that in 2016, there were more than 10 million new TB cases globally. In the same year, TB lead to 1.3 million deaths and was among the top ten causes of mortality worldwide [1]. The most effective public health approach to prevent and control TB is the early detection and effective treatment of the patients. However, TB related stigma poses an important barrier to the prevention and control efforts through delaying diagnosis and impairing treatment adherence.

Patients suffering from TB might be reluctant to seek care and apply for diagnostic services with the fear of getting stigmatized. Stigma acts as a barrier to early diagnosis and patients remain infectious within the community for longer periods of time transmitting the disease. Stigma also impairs treatment adherence. Non-compliance to therapy contributes both to the increased risk of transmission and the development of multidrug resistant TB, of which treatment options are limited, toxic and very expensive [2-9]. Furthermore, due to the stigma attached to TB, some of the patients conceal their diagnosis from their family members and/or co-workers which hinders contact-tracing and detection of new cases [10]. Therefore, in order to control TB effectively, it is crucial to fully explore, understand and address disease related stigma [11].

Stigma is initially defined by Goffman as the situation of the individual who is disqualified from full social acceptance [12]. Link and Phelan broadened this definition and conceptualized it as a social process that exists when elements of labelling, stereotyping, separation, status loss, and discrimination occur in a power situation that allows them to unfold [13,14]. There are mainly two types of stigma defined; enacted and perceived (internalized) stigma. Enacted stigma refers to the discrimination or devaluation experienced by the TB patients on the grounds of their perceived unacceptability or inferiority. Felt (perceived or internalized) stigma is a sense of shame or withdrawal of TB patients which results from the fear of enacted stigma [15,16]. Stigma is not only experienced by the patients. Patients' connections, for example family members also suffer from TB related stigma. Goffman describes courtesy stigma as society degrading or losing respect for a person because the person associates with someone who is stigmatized [12].

Magnitude of TB stigma

Stigma is a social process that has multi dimensions and unclear borders, so it cannot be quantified explicitly [17]. There is not a standard method of measurement; while some studies use validated stigma scales others rely only on a few questions. Due to these methodological differences, it is neither possible to give a global figure nor to make comparisons across studies

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concerning the magnitude of stigma. Still, research reveals that although there are wide variations, TB related stigma is present in different cultures across the world [18-25].

Studies mostly evaluate stigma among TB patients who apply for care. A study carried out among newly diagnosed TB cases in seven countries of the WHO Eastern Mediterranean Region showed that 85 to 95% of the patients felt ashamed that they had developed TB and tried to conceal the disease [20]. A survey among patients attending to Directly Observed Treatment Short-Course (DOTS) clinics in a municipality in Nepal revealed that two thirds of the patients had experienced some kind of TB related stigma. Among the participants, 60% desired not to disclose their disease to other people and 43% thought that others had avoided them because of their disease. More than one third of the patients indicated that they were asked to stay away from work [18]. Another study carried out among TB patients in a district in India revealed that approximately half of the participants had experienced some form of TB related stigma [22].

Studies from Turkey, which is a low incidence country, also reveal that stigma is experienced among TB patients. A study evaluating internalized stigma of TB patients who had registered to a TB dispensary in a province located in western Turkey determined that more than one third of the patients did not disclose their diagnosis to other people [23]. Another study evaluating stigma among patients attending a TB clinic in a province of Turkey also showed that half of the participants did not disclose their disease [24].

Although, relatively few in number, there are also studies that evaluate the extent of stigma community members attached to TB patients. A community based survey which was carried out in 30 districts in India revealed that the proportion of respondents in the general population having stigmatizing and discriminating attitudes to TB sufferers were 73% and 98%, respectively [26]. A study analyzing surveys from 13 different countries that evaluated TB courtesy stigma revealed that about one fourth of the participants would not disclose the TB status of their family members to others [21].

Studies show that health care workers might also have stigmatizing and discriminating attitudes towards TB patients [19, 27, 28]. A study carried out among resident doctors in India revealed that half of the respondents experienced fear, lack of compassion and tendency to avoid TB patients. Unfavorable attitudes were more prevalent among doctors who knew a colleague with TB compared to the ones who did not. The authors suggested that the doctors who had a colleague with TB perceived the occupational transmission more real, which showed the importance of improving the occupational safety measures [28]. TB patients also confirm that they experience stigmatizing attitudes of health care workers. In a study in Nepal, some patients stated that they felt to be discriminated by health care workers particularly at the time of diagnosis [27].

As discussed above, most of the stigma research evaluates TB patients who apply to health care centers. The magnitude, determinants and the impact of stigma are not explored

explicitly among the patients who do not seek care and also the community members [29]. In order to build effective interventions to combat stigma Macintyre et al., suggest the need of widening the TB stigma research to the general public, policy makers, media actors and also to health care workers [29].

Origins and correlates of TB stigma

Research show that the perceived risk of transmission of TB to family members, friends and to the other loved ones is the main determinant leading to stigmatization [3, 27]. Some patients are deeply concerned about transmitting the disease particularly to their children [27].

Other bases of stigma are mostly related to the socioeconomic determinants of TB. In some cultures, TB in a way serves as a marker for poverty, malnutrition and being foreign-borne which are also stigmatized conditions [3, 27, 30, 31]. In Nepal, TB is related to being poor and of low caste [27]. In South Africa, TB is believed to have resulted from dirt, poor sanitation and squalor [31]. In some cultures having a family member with TB is linked to not being able to meet the economic requirements of the family. A study conducted among Haitians showed that having a family member diagnosed with TB indicated one's inadequacy to fulfill the needs of the family for food or sufficient living space which had led to shame and guilt [30].

Some communities view TB as a "dirty disease" and believe that it has resulted from immoral practices or bad behavior [32]. A study in Nepal revealed that TB was linked with "immoral behavior", which meant smoking, drinking alcohol and visiting prostitutes [27]. A qualitative study in Tanzania showed that TB was believed to be sexually transmitted and linked to promiscuity for women [33]. Such perceptions result with the feelings of shame and embarrassment both among the patients and the family members. In relation to this, in some cultures the disease is perceived as a result of a "divine curse" due to immoral practices [27, 32].

Patients might face a greater level of stigma if they have resistant forms of TB [29, 34]. Macintry et al., indicate that if a patient has multi-drug resistant TB (MDR-TB) or extensively drug-resistant tuberculosis (XDR-TB), then the perceived dangerousness increases and contributes to the stigma experienced. Also, since these forms of TB might originate from non-adherence to treatment, patients might be accused of contributing to the development of drug resistance. Drug adverse effects and high economic impact might also increase the vulnerability to stigma [29].

Comorbidity with HIV contributes to the TB related stigma [3, 21, 30, 31, 35]. Patients fear that if they are identified with TB, community members would assume that they also have HIV [30]. A qualitative study carried out in South Africa revealed that TB led to some physical symptoms as weight loss, which also caused HIV to become more noticeable. The authors indicate that co-infection with HIV and TB created an overlapping double stigma which consequently facilitated new forms of TB stigma and intensified the existing stigma against HIV [36].

The impact of TB knowledge regarding symptoms, transmission and curability on stigma does not show a consistent relationship across different communities. While, some studies indicate that better knowledge on TB is associated with a lower level of stigma, others do not show such an association [21, 25, 26, 35]. So, there is also a need to clearly understand whether providing more information about TB would reduce stigma [3].

Consequences of TB stigma

Having TB is mainly linked to the feeling of shame and guilt which consequently leads TB patients to isolate themselves from social life [20, 32, 33, 37, 38] . Isolation from social life occurs by two means; while some patients withdraw themselves from interaction, some others are shunned, not being welcomed in the community [32]. Isolation might last throughout the whole treatment period, although, patients are told that they are not infective after the first couple of weeks of the treatment initiation [27]. So, eventually both the patient and the patient's family get detached from the community. If there is stigmatization also within the family, the family members become isolated from each other [32]. The patient might be obliged to have separate utensils and sleep in a separate bedroom [6]. Females having TB might have lower chances of getting married or if married can be rejected by their partners and may be at an increased risk for divorce [19, 20, 33, 38]. In a study which was carried out in seven countries of the WHO Eastern Mediterranean Region, 96% of females and 90% of males believed that the chances of a girl diagnosed with TB getting married were low [20].

Self-stigmatization, fear of discrimination and also trying to protect the family from TB related stigma mostly result with the concealment of the disease. Patients do not disclose their disease to the community; neighbors, relatives, co-workers and in some instances even to their own family members [4, 6, 27, 30, 38-41]. Keeping TB diagnosis as a secret from the family and friends increases the social isolation even more and prevents the patients to get the social support they need [41]. Stigma also increases the psychological burden on patients. A study carried out among TB patients in a rural area in China determined that experienced stigma was independently associated with psychological distress [42].

Tuberculosis related stigma can also impact economic opportunities [3, 37]. A study carried out in Sri Lanka showed the huge impact of TB diagnosis on economic status. The study pointed out that among the participants 62.8% changed their job due to TB and 52.3% had changes to their income level [40].

Tuberculosis stigma has a negative impact on initiating a diagnostic process and also treatment adherence. A multicountry study carried out in seven countries of the WHO Eastern Mediterranean Region indicated that stigma was one of the main determinants of delay to access care [20]. A qualitative study in Eritrea showed that fear of being recognized in the community prevented TB patients to attend health care services and also take their medications [6]. A study in Tanzania showed that stigma resulted with a delay in health care seeking behavior with the fear of getting diagnosed with TB [33]. Even health care workers might be reluctant to use diagnostic services because

of the TB related stigma. A study in South Africa evaluated TB related stigma of health care workers working in six hospitals and their willingness to use occupational health services for TB screening, treatment and prophylaxis. The study revealed that perceived TB stigma among health care workers decreased the willingness to use occupational health services particularly for TB screening [43].

Stigma might also have an impact in low TB incidence countries. A contact investigation in a workplace in Italy determined three additional cases and 33 latent infections that had occurred among the employees during the previous five years. The source case claimed to be unemployed so contact-tracing had not been carried out at the time of the diagnosis in the workplace. It was revealed that the source case had a temporary work contract and feared that her contract might not be renewed if she had disclosed her disease. The authors indicated that job insecurity as the predominant factor leading to this outbreak [10].

It is also important to note that the impact of stigma is not the same on every group. Courtwright and Turner indicated in their study that the impact of TB stigma was more prominent on women and socioeconomically disadvantaged group [3]. A study in Tanzania showed that TB stigma operated differently among men and women. While, for women TB related stigma leads to problems in partner relationships, for men it threatens their survival through affecting their daily activities [33]. So, TB stigma might deepen the already existing disparities in health resulting with a higher burden on the most deprived groups [3].

Public Health interventions to reduce TB stigma

Although, TB stigma is prevalent across the world, studies evaluating the impact of stigma reduction strategies are limited in number. Sommerland et al., reviewed interventions to reduce TB stigma and identified only seven studies published between 1950 and 2015. These studies implemented different methods to combat stigma; while some used knowledge shaping or attitude changing approaches, others relied on patient-support activities. The authors indicated that some of these studies showed promising results, but still most of them were lacking reliable information due to deficiencies of using rigorous evaluation methods. Also, the interventions showing a reduction in stigma levels were not replicated. The authors highlighted the need to conduct studies which evaluated interventions objectively using evidence based tools and also to replicate the successful interventions in different parts of the world [43].

Among the stigma reduction strategies, "TB clubs" is an innovative approach deserving special attention. The effectiveness of TB clubs in improving adherence to treatment and decreasing stigma were studied initially in a rural region in Ethiopia. TB clubs were formed from a group of patients residing in the same region. The clubs met on weekly bases to share information and provide mutual support. Monthly meetings were also held with health care workers. TB club members also interacted with leaders and members of the community to exchange information and disseminate educational materials. The authors documented that the intervention was successful in reducing TB related stigma and improving treatment adherence.

While patients were not disclosing their disease previously, with the introduction of the intervention they started talking about their disease in public gatherings [5]. A similar intervention in rural Nicaragua also yielded positive results for reducing internalized stigma of TB patients. In this study, the authors utilized two approaches to combat stigma; TB clubs and patient centered home visits. TB clubs were designed as self-help groups to empower patients. Patient centered home visits were performed with the aim of understanding the patients' lives and their socio-cultural context in order to plan activities to support them. The authors documented that after two months, internalized stigma scores in the intervention group decreased significantly while a difference was not observed in the control group [16].

Although, these studies show promising results in empowering patients to resist stigma, Courtwright and Turner underline the need to study the impact of TB clubs in other regions of the world [3]. It is important to remember that a successful intervention in a community might not necessarily generate similar results in another region because different meanings are attached to stigma based on the social context for different ethnic and cultural groups [44]. Even within the same cultural group, TB related stigma might be perceived and experienced differently among men and women and across different age groups. So, interventions addressing stigma should take into account gender, age, social context and their interaction with stigma [33,44]. It is also essential to explore how these strategies impact the end results. We need to understand whether the reduction of stigma results with a rapid access to care and treatment, whether it increases treatment adherence and decreases morbidity and mortality [3].

Daftary et al., indicated that to confront TB related stigma we need to understand how the HIV community confronted HIV related stigma and take lessons from that experience. The authors argued that consciousness raising as a form of activism is necessary to mitigate TB related stigma. In this context, people affected by TB are expected to come together and form a movement of consciousness raising. This collective movement, through sharing their experiences can begin organizing forces of change that will reduce TB related stigma [45].

Conclusion

Although, TB related stigma is a global problem, studies evaluating interventions to reduce it are insufficient both in number and quality. There is a need to form innovative methods to combat TB related stigma based on the cultural context of the community and evaluate them using evidence based methods in different parts of the world.

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