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Perspective Piece

To End TB, First-Ever High-Level Meeting on Tuberculosis Must Address Stigma

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Abstract. World leaders gather to consolidate their commitment to ending tuberculosis (TB). Vital to the success of renewed efforts is an overdue recognition of the pervasive and pernicious influence of TB stigma. TB stigma is sustained in structures, policies, traditions, and norms. Innovative modifications to infection control, drug dispensing, and surveillance practices are required to increase demand for TB screening and effective therapeutic alliances among those diagnosed. The authors argue that reducing TB stigma requires a scientific and inclusive process, with prominent roles for TB survivors and a willingness to integrate and learn from other stigmatized conditions.

The first United Nations high-level meeting (HLM) on ending tuberculosis is set for September 2018. The HLM seeks the political capital to realize the World Health Organization's End TB Strategy, which envisions zero deaths, disease, and suffering due to TB by 2035. This has paved the way for major political declarations from numerous national leaders in support of biomedical strategies to lower TB incidence and mortality. Commensurate commitments are needed to tackle human suffering, through approaches that address social drivers and specifically TB stigma.

THE ROOTS AND IMPACT OF TB STIGMA

Tackling TB stigma mandates unveiling its roots in policy. Disease control practices that frame persons with TB as threats to the public set the stage for stigma enactment. Many TB programs today name and label patients, and fail to protect their confidentiality and dignity during surveillance and disease prevention activities.[1,2] Laws that predicate migration, marriage, and work on the acceptance of TB testing strip individuals of their basic rights to privacy, association, and autonomy.[3–6] The impacts of stigma on health are profound. Stigmatizing practices in TB thwart health-seeking behaviors, drive away talented health providers, and taint communities disproportionately burdened by TB.[7–9] The mere anticipation of stigma leads people to delay care or resort to unregulated private and informal providers. It delays TB testing and treatment uptake, undermines contact tracing, and compromises TB prevention, diagnosis, treatment, and success for both adults and children.[6,8,10–18] TB stigma prevents us from reaching many of those with "missed" or unreported disease. Furthermore, for many of those that are diagnosed and treated, TB stigmatization does not abate after cure is achieved.[19]

One reason that TB stigma has remained a stubborn obstacle to TB elimination is that discourses of dangerousness and death have been amplified to galvanize resources to the fight disease. In emphasizing the important threat that TB poses, fear-based policies (e.g., preemptive quarantine, involuntary testing, confidentiality breeches) have normalized prejudicial practices and exacerbated the burden of fighting TB, especially in high-burden settings. Such approaches are increasingly recognized as ethically and scientifically indefensible.[20]

REDUCING TB STIGMA—THE TIME TO ACT IS NOW

De-stigmatization mandates shifting established organizational norms and transforming the laws, language, and care cultures that define TB today. Although progress has been made—for instance to update TB terminology—a concerted and multidisciplinary approach is still needed, acting at different levels of society and pooling the talents of all stakeholders, including TB survivors, lawyers, ethicists, human rights experts, nurses, doctors, epidemiologists, psychologists, sociologists, anthropologists, and artists. Lessons from successful TB stigma–reduction efforts, such as knowledge-shaping, attitude-changing, and patient support interventions, can be leveraged.[8,21,22] Health systems and communities, overburdened and overwhelmed with new diagnoses, will require room to experiment, trial, and tailor these bold ideas and practices to their own realities.

A range of measures can be feasibly adopted to reduce stigma among people diagnosed with TB, and within health facilities, communities, and families. Actively involving patients in treatment decisions and incorporating their preferences into TB testing, treatment initiation, and monitoring can be an important first step to bolstering self-efficacy and buffering against self-stigma.[8,23–26] A person-centered intervention should involve allowing patients to collect medicines as their schedules permit, trusting that most will ingest their drugs as prescribed (especially if involved and counseled[27]), and limiting personal protective equipment requirements to the infectious period. Removing idiosyncratic TB treatment rituals such as daily visitation would be hugely symbolic, signaling a new and more equal therapeutic alliance.[22] Differentiated service delivery models in human immunodeficiency virus (HIV) have used this approach successfully.[28] Applied to TB programs, they can send a

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message that people with TB are not deviant but rather logical, busy, and most of all, normal.[29] Peer support is also effective in building resilience to stigma.[26,30,31] Empowerment-based approaches that draw on concepts of justice and self-determination can go a long way in spurring early care seeking and sustaining patients' engagement in treatment.[8,23–25]

At the facility level, providers can be trained to prevent deductive disclosure, treatment coercion, or detention.[5,6,32] They should also be recognized for empowering patients, upholding patient rights, and contesting stigmatizing norms and policies among their peers.[33,34] Administrators must do more to make prisons, health services, and mines safe for workers. "Safe air," achieved through environmental controls (e.g., ultraviolet germicidal irradiation, ventilation), is also a key ingredient of a mutually respectful therapeutic alliance and less likely to be stigmatizing because it does not lead to deductive disclosure or social isolation.[35]

Within communities, "carefully crafted" messaging is needed to deter gossip, neglect, and social exclusion.[21] Public health campaigns must emphasize on the efficacy of TB treatment over the risks of transmission.[21,36–39] Survivor testimonials and advocacy messages from influentials further normalize TB and can help catalyze cultural shifts.[40–42] Similar efforts helped to overcome societal prejudices related to race, sexual orientation, body size[43] and improve public attitudes toward leprosy, HIV, and mental illness.[42,44,45] Stabilizing the economic status of families affected by TB, through financial aid, also renders them less vulnerable to the consequences of losses in social capital caused by stigma.[46–49]

Crucially, stigma mitigation efforts do not need to be, and should not be, TB stigma specific. Trials of syndemic stigma-reduction efforts are underway.[50,51] Stigmatizing laws, attitudes, and behaviors tend to cluster.[32,39] Integrated interventions that fight the criminalization of TB treatment nonadherence, HIV transmission, illicit drug use, and same-sex behavior are likely to be synergistic.[52] TB occurs more often in groups that are already disparaged on account of their class, race, gender, comorbidities, immigration status, or justice system involvement. In addition, TB stigma routinely mimics, compounds, and potentiates other forms of systemic social exclusion.[53–55] The syndemic nature of stigmas and the clustering of disadvantage is not only a challenge, but also an opportunity for TB to leverage the stigma-reduction expertise available in other fields of practice.

CONCLUSION

TB stigma compounds the suffering of people with TB. The returns from investments in the End TB Strategy will not be realized until the structural basis for TB stigma is removed, and many of the harmful labels, policies, and practices are reimagined. Broad engagement with newly recognized stakeholders and openness to innovation will be necessary.

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