

## Measuring TB-related stigma

WE ARE FAILING IN THE FIGHT against tuberculosis (TB). This is obvious to anyone paying attention. The complex, overlapping, and intersectional reasons why, however, may not be as obvious. One thing is clear: we have ignored and devalued the experience and knowledge of people with TB and TB survivors for far too long. This is a core reason for our failure. And the consequences of our inability to think outside the box of our shortsighted, top-down approach are myriad.

Chief among these is our failure to identify, understand, and eliminate the entrenched stigma and discrimination faced by people with TB, TB survivors, and their family members. This is why as TB survivors and human rights lawyers we enthusiastically welcome the 11 papers in this supplement on measuring TB stigma. They represent a meaningful step in the right direction—toward a human rights-based, people-centered approach to TB driven by community.

But more must be done. While TB incidence decreased long ago in dramatic fashion in many parts of the world—even before medicines were available—the disease and its drug-resistant forms have killed more people during the last two years than any other infectious disease, including HIV/AIDS. Just as shocking is the fact that we simply missed more than four million people with TB; we could not even find or diagnose them.

Although an array of factors contributes to this intolerable situation, reducing and eventually eliminating TB stigma and discrimination are necessary conditions for any sustainable intervention. As Rood et al., Sommerland et al., and Chikovore et al. demonstrate, stigma impedes the utilization of TB testing and treatment services in some groups.<sup>1–3</sup> Sommerland et al., in particular, show that TB stigma has a negative effect on health care workers' use of occupational health services for TB in South Africa, where the disease is the leading cause of death and health care workers are disproportionately affected.<sup>3</sup> Other studies have shown how stigma negatively impacts TB contact tracing during outbreak investigations and hinders treatment initiation and treatment adherence.<sup>4,5</sup>

Chikovore et al. and Miller et al. show that TB stigma erects barriers to intimacy and social networks, depriving people with TB of full and equal participation in their families and communities.<sup>3,6</sup> And Rood et al. find that carry-over stigma of people connected to people with TB, including family members, is negatively correlated with knowledge about the curability of TB, as well as accepting attitudes toward people living with HIV.<sup>1</sup> Rood et al.

also demonstrate that overlapping exclusions and structural challenges vary by country but contribute significantly to TB stigma. In particular, they find that secrecy about familial TB is higher in countries with greater alcohol use disorder, greater HIV prevalence, and greater incarceration rates.<sup>1</sup>

In response to the need to identify and understand TB stigma, Bond et al., Wouters et al., and Zwerling et al. present tools to develop indicators, to measure stigma, and to incorporate social justice into cost-effectiveness analysis for MDR-TB.<sup>7–9</sup> Bond et al. also demonstrate, importantly, that TB stigma is not reduced simply by increasing the quality of TB services and care; instead, we need stigma-specific interventions.<sup>7</sup> Finally, Macintyre et al. present a TB stigma research agenda that discusses what is known, highlights where the knowledge gaps are, and offers a prioritized list of topics and potential research approaches to address them.<sup>10</sup>

But how do we move forward, in light of the evidence and sophisticated tools represented in this much-needed supplement? Here we strike a cautionary tone: if the evidence on the impact of TB stigma and the instruments to identify, measure, and eliminate stigma are not developed and utilized by people with TB and TB survivors, we will continue to fail in our efforts to defeat the disease. People directly affected are uniquely placed to contribute to the identification and measurement of stigma because of their experiences and understanding. As peers, they are best situated to conduct interviews and obtain full and accurate information when respondents comprise affected individuals and communities. Involvement of technical experts also contributes to identification and measurement of TB stigma when respondents include the stigmatizers themselves.

We highlight the People Living with HIV Stigma Index as an instructive example of a community driven tool. We also draw attention to the recently released TB Stigma Measurement Guidance. The guidance includes a variety of new tools to measure TB stigma, including structural stigma and measurement for advocacy, and it holds promise to move forward this urgently needed work.<sup>11</sup>

In sum, while we commend the editors and authors of this supplement, we urge them and other decision-makers in national TB programs, the World Health Organization, and donors such as the Global Fund to Fight AIDS, TB and Malaria to take seriously the following principle: nothing about us without us. Until this simple but powerful lesson is learned, even our best efforts will continue to fall short.

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