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LETTER

TB and women: a call to action

Dear Editor,

We would like to draw your attention to the particular problems faced by women with TB. We describe below the experiences of Yasmin, Nirupa and Busisiwe.

Yasmin limps into a clinic in Dushanbe, Tajikistan for her daily anti-TB therapy. Her left eye is bruised, but she assures the nurses that she is "just fine". At age 40, Yasmin was diagnosed with drug-resistant tuberculosis (DR-TB). Initially she refused to have treatment without permission from her husband, who was working in Russia. She was afraid to share her Xpert® MTB/RIF (Cepheid, Sunnyvale, CA, USA) test result and risk divorce, losing her home and children. As her weight plummeted and she began to cough blood, her sister convinced her to start treatment. Despite side effects, Yasmin steadfastly takes the pills. Now as the nurses tend to her, they learn she is anything but fine. Her husband returned over the weekend, drunk, took one look at her skin–now a dark orange shade of brown–and knew something was wrong. He beat her for hiding her condition and for starting treatment without his consent. Yasmin's last five cultures are negative, but this is the last the clinic sees of her. A health worker visits her home and learns the family has left town.

A thousand miles away, Nirupa, a 16 year-old girl living in Mumbai, India, cares for her mother and brother who are sick with DR-TB. Her father left the family after her brother became sick, blaming their mother for his illness. Shortly after being abandoned, her mother also fell ill. Nirupa dropped out of school to become her brother's primary caregiver. She helps him wash and takes him to the clinic every day for medication. Otherwise she hardly leaves the house.

In Cape Town, South Africa, Busisiwe, a 27 year-old woman is pregnant and not gaining weight. At her antenatal visit, the nurse notices Busisiwe is coughing and collects a sputum sample. The next day, the nurse phones to tell her she has TB and must go to the TB clinic for treatment. She cannot return to antenatal care because she might infect other pregnant women. Busisiwe is scared and worried for her health and that of her baby. At the TB clinic, she is told to go to a more specialized clinic, but cannot afford the transport to get there.

These women's names have been changed but their stories reflect a collective suffering facing women living with and affected by TB, the world's deadliest infection among adults. Most people diagnosed with TB are men (63%) and one million die of TB,[1] but TB is also in the top 10 causes of mortality in women.[2] Although the statistics show a predominance of the disease in men, we can miss the gravity of the situation for women with TB (e.g., Mukherjee, et al. 2012).[3] Recent work has eloquently detailed the structural barriers to TB care-seeking and adherence faced by men,[4] and adds to our prior understanding of outcomes in women and men.[5,6] To further contextualize the challenges and circumstances faced by women, and to help guide funding, advocacy, research and interventions, we draw attention to four crucial issues facing women with TB:

1) Risks and changing responsibilities across women's life course can compromise their health care-seeking and health outcomes in general, with some increasing the risks for TB including: pregnancy and childbirth; marriage and family care; mental illness; interpersonal violence; alcohol, tobacco and drug misuse; progesterone-containing contraception; extra pulmonary disease; vulnerability to HIV (especially in southern Africa); and old age.[7–9] These risks operate through diverse mechanisms. For example, heavy alcohol use compromises immunity and increases TB risk, but is often underestimated in women.[9] Extra-pulmonary disease, possibly due to endocrinal factors, is frequent in women, and tied to greater diagnostic and treatment complexity.[3] As primary caregivers, the consequence of anyone in the family having TB often impacts women–such as Nirupa–the most.[5] Women also form the bulk of the informal, nurse and community health workforce, where they may face undue risks due to poor occupational health support,[7,10] as is recently highlighted by the COVID-19 pandemic.[11]
2) TB in pregnancy poses risks to the health of women and their unborn children, including prematurity, low birth weight and infant mortality.[12] The estimated rate of TB in pregnant women is 2.1/1000 globally, translating to over 215 000 annual cases.[13] TB prevalence in HIV-positive pregnant women is higher, between 0.7–7.9% in high incidence countries, and with an associated risk of TB and HIV transmission to the unborn child, as well as higher maternal and neonatal mortality.[12] Investments into maternal health often omit integrating services for TB, endangering pregnancy outcomes in women such as Busiswe.

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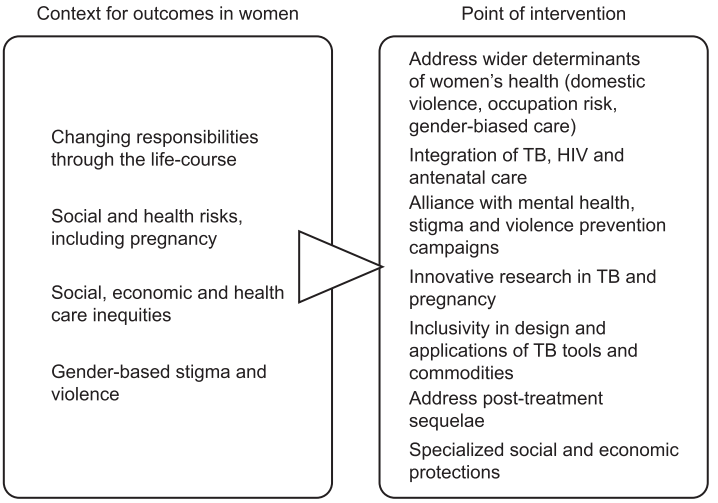

Figure Guidance for gender-transformative interventions to address the needs of women affected by TB.

These exclusions may be rooted in sparse data on TB interventions in pregnant and lactating women, which reflect their exclusion from TB research.[8] Postpartum, TB risk can be doubled due to biological changes during pregnancy.[12]

3) Women face economic, social and health care inequities.[7] Countries most affected by TB have some of the lowest literacy rates for women, and highest indices for gender inequality and gender-based violence.[10] Lower levels of financial autonomy, health literacy and social status leave women in these settings with less agency to seek care or receive treatment support.[5,6] Gender bias in TB testing (including poor guidance around test methods), seeking care outside the public sector, and requiring partner/family permission to access care (as in Yasmin's case) also contribute to 'missed' and delayed diagnoses in women.[5,6,14] Given women's lower access to resources pre-treatment, the financial burden of TB treatment may be proportionally greater.[5] A digital divide may also keep women from benefitting from newer interventions for TB, not because of lower affinity but rather access, education and income inequity.[10]
4) Women experience distinct stigma from TB, tied to aforementioned gender-based inequities.[5,6,15] In poorer settings, women with TB self-blame and self-stigmatize, prompting delays in care-seeking, and face discrimination in their community and home, challenging retention-in-care. TB has triggered divorce, domestic violence, forced separation from children, and women's exclusion from marriage.[5,15,16] Disease or treatment sequelae, such as changed skin colour, hearing loss and infertility can disrupt their lives long after cure.[16]

TB exposes women's vulnerability and exacerbates gender-based inequalities, many of which contribute distinct challenges to timely diagnosis, successful treatment and post-survival wellbeing. The Global Fund, Stop TB Partnership and UNAIDS, among other institutions, now ask TB programmes and services to integrate a rights-based approach to correct this gender imbalance. This resembles recent calls amidst the unfolding COVID-19 pandemic,[11] and will require intersectional, human rights-centred, transdisciplinary research frameworks and methods, and community-driven approaches (see Figure). We also stress the need to avoid reinforcing a gender dichotomy and in parallel call for services to address the unique needs of men.

As outlined above, women requiring TB care face a range of critical issues – issues we cannot continue to ignore – and we urge innovators and researchers to draw on these examples to develop gender-transformative interventions for TB.

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