

## Bitter pills: care givers navigating stigma, stock outs, and unfriendly formulations in Botswana

WE HAVE ALWAYS HAD ELOQUENT technical voices decrying the lack of focus on children. We hear less often from the people responsible for children's daily survival—those who mind their health before, during, and long after they are 'tuberculosis patients'. In this issue of the *Journal*, Stillson and colleagues provide a useful prism through which to view the service provision for pediatric tuberculosis. Their article reveals a rather ambivalent parental view of tuberculosis services.<sup>1</sup>

The article pulls back the curtain on the contingent value of some of our approaches and systems, revealing the ironies of pediatric directly observed treatment (DOT) in Botswana. The requirement to travel daily for treatment is juxtaposed against a backdrop of chronic pediatric drug shortages. Policy makers expect care givers to perform the rituals of responsible citizenship via directly observed anti-tuberculosis treatment—sacrificing jobs and schooling to reach health facilities—despite the absence of a reciprocal responsibility to stock the treatment.

Stillson et al.'s work yields local translational thinking to apply to old dilemmas. For example, the time and transport burden on families is a well-established vexing aspect of TB treatment, but one mother offered a transgressive proposal: can we develop long-acting injectables like contraception? This mother's potential product profile is unconventional because we have invested a lot of resources in figuring out how to substitute injections in our treatment regimens. But have we looked at this from all angles? The development of new target product profiles may benefit from such care giver input.

Despite reporting infrequent provision of treatment literacy, these care givers also voiced an elegant understanding of nosocomial risk. Care givers framed the health care facility as a place of risk that offers potential social and physical harms. Prolonged waiting in such a space posed dangers of moral contagion (stigma) or actual contagion. The fear of courtesy stigma (devaluation via familiar ties to or associating with a person with a disparaged identity) was one of the reasons care givers opposed frequent presence in health care facilities.<sup>2</sup>

While stock outs, DOT and stigma are hardly new

to us, the way these mothers and grandmothers frame the issues invites a humbling reflection on the consequences of our well-intentioned policies.

If we could speak with them we might share some of our newfound optimism for tackling pediatric TB. The roll-out of the pediatric fixed-dose combination and the possibilities of shorter regimens for latent tuberculous infection and multidrug-resistant TB have many feeling bullish. The encouraging news about the use of less invasive tests, such as stool and nasal washes for GeneXpert, raises hopes for expanding access and reducing delays to diagnosis.<sup>3</sup> We are stocking the pediatric TB toolbox with powerful diagnostic and treatment options. Would these mothers and others around the world share our enthusiasm? Yes. Particularly if we can also take seriously care givers' concerns about commodity management, stigma and patient costs. While we remain fixated on diagnosis and treatment, these care givers remind us that our End TB strategy also contains the crucial goal of zero suffering—a concept we still have only begun to define. Stillson and colleagues give us food for thought for the further elaboration of policies and metrics to reflect our progress in this area and reinforce the voices that need to be at the table when these are debated.

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### References

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- 2 Pescosolido B A, Martin J K. The stigma complex. *Annu Rev Sociol* 2015; 41: 87–116.
- 3 Banada P P, Naidoo U, Deshpande S, et al. A novel sample processing method for rapid detection of tuberculosis in the stool of pediatric patients using the Xpert MTB/RIF assay. *PLOS ONE* 2016; 11(3): e0151980.