The long shadow post-tuberculosis: “when we started TB treatment, no-one told us that it would never leave us”.

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To the editors,

The meta-analysis on the excess mortality after tuberculosis published by Romanowski et al,1 is important work confirming the long-held belief by workers in the field to this end. However, death frequently comes only at the end of prolonged periods of suffering and morbidity, and we would like to emphasise the hidden epidemic of chronic disease and impairment after microbiological “cure” in tuberculosis, that is discussed in the accompanying editorial.2 The world health organization (WHO) estimates that 54 million people have survived tuberculosis since 2000 alone,3 with estimates of residual damage ranging from 18 to over 80%.4 Post-tuberculosis damage straddles the intersection of communicable and non-communicable disease, and is likely one of the most important causes of chronic lung disease globally, yet has received little attention as a non-infectious complication of TB primarily affecting the world’s poor.

The First International Post-Tuberculosis Symposium ([www.post-tuberculosis.com](http://www.post-tuberculosis.com)) referenced in the Datta and Evans editorial, was held in Stellenbosch, South Africa 22-23 July 2019, to address some of the deficiencies and provide leadership in this neglected area. This symposium involved 68 delegates across 12 disciplines from 5 continents, representing more than 27 institutions. The conference proceedings will be published in due course, however as described in the paper above, inconsistency and lack of consensus in nomenclature and terminology has historically hampered work in this field. Using the Delphi process, the Symposium voted to embrace the non-discipline specific adjective “post-tuberculosis” for future work in this area, with a majority vote of 84% after three rounds.

A number of important aspects were highlighted during this meeting, firstly the heterogeneity between patients, in terms of severity and phenotypic outcomes,4 remains largely unexplained and contributes to difficulties in accurately estimating disease burden. Secondly, to develop prevention strategies, the mechanisms of damage during tuberculosis require further elucidation. Further, TB-survivors, which include large numbers of children, are known to have a heightened risk of recurrent TB,5 while there is scant evidence to guide clinical management of post-tuberculosis disease in adults and children alike.

Seen through the eyes of a number of our patient representatives, there is a need to advocate for wellness assessments after tuberculosis treatment completion, and to consider socio-economic consequences including stigma post-tuberculosis. The shadow of tuberculosis is long for many tuberculosis survivors, and in the words of Mr Goodman Makanda, “when we started TB treatment, no-one told us that it would never leave us”.

[398 words]

References:

1 Romanowski K, Baumann B, Basham CA, Ahmad Khan F, Fox GJ, Johnston JC. Long-term all-cause mortality in people treated for tuberculosis: a systematic review and meta-analysis. *Lancet Infect Dis* 2019; **3099**: 1–9.

2 Datta S, Evans CA. Healthy survival after tuberculosis. *Lancet Infect Dis* 2019; **3099**: 1–2.

3 World Health Organization. Tuberculosis Fact Sheet. https://www.who.int/en/news-room/fact-sheets/detail/tuberculosis (accessed Aug 11, 2019).

4 Ravimohan S, Kornfeld H, Weissman D, Bisson GP. Tuberculosis and lung damage: from epidemiology to pathophysiology. *Eur Respir Rev* 2018; **27**.

5 Panjabi R, Comstock GW, Golub JE. Recurrent tuberculosis and its risk factors: adequately treated patients are still at high risk. *Int J Tuberc Lung Dis* 2007; **11**: 828–37.