

Correspondence

Language in tuberculosis services

We welcome the call by Zachariah et al. for a move towards more patient-centred terminology in tuberculosis (TB) care.¹ We suggest, however, that the changes proposed do not go far enough. In parallel with terminology used in the world of the human immunodeficiency virus, we propose replacing the phrase ‘TB patient’ by ‘person with TB’. ‘TB patient’ puts emphasis on the disease, but it is imperative to remember that first and foremost we are talking to and about *people*, generally with a whole host of problems, of which TB is only one—and we should note that the situation is even worse for those suffering from multidrug-resistant TB. If we do not acknowledge that people receiving care for TB also have to feed their families and themselves, look after their children and other dependents and have some quality of life, the TB care we provide will damage all of these essential facets of life. We should not be complacent. Although a high proportion of people with TB achieve a treatment outcome that we call ‘success’, this is at substantial cost—high debts, sale of long-term means of survival such as land, animals and equipment, and withdrawal of children from school to send them to work. We wonder whether people with TB would describe this as ‘success’.

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<http://dx.doi.org/10.5588/ijtld.12.0370>

Reference

- 1 Zachariah R, Harries A D, Srinath S, et al. Language in tuberculosis services: can we change to patient-centred terminology and stop the paradigm of blaming the patients? *Int J Tuberc Lung Dis* 2012; 16: 714–717.

In reply

We are grateful for the positive responses we are receiving from the Stop TB Department, the World Health Organization and authors such as Drs Baral and Newell on our call for action as regards language

in tuberculosis (TB) services.¹ As Ditiu and Blessina so eloquently put it in their recent editorial, ‘language is more than words: it has the power to transform the way people think and behave’.¹ The ‘people’ who perhaps most need to think around this and transform their way of thinking are us, those who work in the health services. There is no denying that ownership of some of the diminishing words used in TB care belong to us: we have perpetrated their use over the many decades² and have never taken the trouble to ask the persons affected about their opinion. Clearly, this was an era reigned by the dichotomy between ‘us’ in the health system and ‘them’—those who come to seek care. However, better late than never, and hopefully that era is now over.

Baral et al. urge us to consider the ‘person’, i.e., the individual nature of those who seek our help, and they add their voice to our call for change. The endless list of challenges related to the indirect costs borne by persons with TB when they eventually manage to access TB services in the developing world also diminishes lives. Put simply, when we achieve the parameters we have set as hall-marks of ‘programme’ and ‘treatment success’, the reflection of success is but one side of what appears to be a bright coin. This tarnishes quickly when contrasted against the stark reality of the struggle often faced by persons with TB before accessing TB services. This aspect is often not seen, nor looked for, nor judged from the programme perspective.

In TB programmes, true success will be achieved when all those who need our services can reach and receive them, in a manner that is universal and equitable and that does not diminish them in any way. Achieving that is what we should judge as ‘success’ and what we should strive to reach.

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<http://dx.doi.org/10.5588/ijtld.12.0370-2>

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Measuring stigma: are we looking in the right places?

Stigma has major implications on the efficacy of programs of many types, including human immunodeficiency virus (HIV) and tuberculosis programs.¹ At the same time, measuring stigma in populations has been difficult given the (until recently) lack of validated measurements and the great heterogeneity of these measures within a population, depending on the group(s) targeted.^{1,2}

We read with great interest the article recently published by Kipp et al. in the *Journal*.³ Due to the intrinsic difficulties in quantifying the effect of stigma on adherence to tuberculosis (TB) treatment and the paucity of literature in this regard, we commend the authors on their effort. Although we agree with their conclusions, we also believe they need to be interpreted cautiously, given that the study was conducted in a highly self-selected population: patients enrolled on TB care.

The literature suggests that only a fraction of patients with active TB seek medical attention.⁴ Although the reasons for not seeking medical attention among this sub-population are multiple, stigma is one of them. Patients already in care are likely to have overcome or appropriately coped with stigma as a barrier to care, compared to patients who fail to seek care due to fear of stigmatisation.

We performed a prospective cross-sectional study among three different populations in Botswana: multidrug-resistant (MDR) patients with TB, patients with active pulmonary TB (PTB) and women from the general population. All TB patients were recruited from the TB clinics where they were receiving care. Women from the general population were identified by stratified proportional random sampling in their households (community). Key outcome variables were perceived TB or HIV stigma, experienced/felt TB or HIV stigma, and overall perception of stigma against patients infected with TB or HIV in the community; they were measured by scales similar to those used by Kipp et al.^{1,2} In our analyses we differentiate between stigma scores (which ranged from 0 to 7) and social support (which ranged from 0 to 27).^{1,2} Predictor variables included demographics, socioeconomic and clinical factors, knowledge about TB and HIV/AIDS, history of seeking medical care for reasons different from HIV or TB in the previous year, and alcohol use.² Analyses were performed to determine

the level of stigma within each population, factors associated with higher levels of stigma and whether there were differences across different study groups. Multivariable linear regressions were performed among patients with TB (perceived and experienced/felt stigma) and community members (community stigma) to determine which factors were associated with higher mean TB or HIV stigma scores.

We interviewed 114 MDR-TB cases, 114 PTB cases and 239 women from the community. With the exception of sex (all participants from the general population were females), the three study groups were highly comparable (data not shown). Stigma and support levels were similar between the MDR-TB and PTB groups (4.28 and 4.04, respectively). However, women from the general population reported a significantly lower level of stigma towards people infected with TB, PTB or HIV than what either group reported as self-perceived stigma (0.75, $P < 0.01$). The level of family and community support was similar across all groups (scores of 19.87, 19.61 and 19.82, respectively). After adjusting for confounders, lower scores of self-perceived or community-perceived TB-HIV stigma (by the general population) were highly correlated with age ($P < 0.001$) and being married or having a stable partner in all groups. When participants were asked about their history of HIV testing, very significant differences were found between TB patients and the general population (100%, 85.4% and 40.2%, respectively, $P < 0.001$).

As opposed to the study published by Kipp et al., our study did not look into the relation between stigma levels and adherence. However, it does highlight major differences in terms of the relation of major outcomes and measures of stigma across different populations. Despite the perceived 'low' level of stigma towards TB-HIV in the community, women in our study were highly reluctant to undergo HIV testing and to disclose the results to their partners and family members ($P < 0.001$). Individuals were not only unwilling to test voluntarily for HIV, they were also reluctant to seek help when they tested positive. Although these findings may seem contradictory, we believe they reflect the presence of self-perceived stigmatisation that was not captured by our interview and data collection approach, but which is present in the community.⁵ It is possible that poor adherence correlates with stigma in populations not included in Kipp et al.'s study, such as patients not self-referring to care. Our results also highlight that, despite the lower measurements of stigma and the high support from family and community, different populations may have very significant attitudes towards major health outcomes. While Kipp et al. looked into TB adherence as opposed to willingness to test for HIV, results suggesting that stigma does not play an important role in the success of TB or HIV programs should be