

Language in tuberculosis services: can we change to patient-centred terminology and stop the paradigm of blaming the patients?

R. Zachariah,* A. D. Harries,^{††} S. Srinath,[§] S. Ram,[¶] K. Viney,[#] E. Singogo,^{**} P. Lal,[§] A. Mendoza-Ticona,^{††} A. Sreenivas,[§] N. W. Aung,^{††} B. N. Sharath,^{§§} H. Kanyerere,^{¶¶} N. van Soelen,^{##} N. Kirui,^{***} E. Ali,* S. G. Hinderaker,^{†††} K. Bissell,[†] D. A. Enarson,[†] M. E. Edginton[†]

*Medical Department, Médecins Sans Frontières, Operational Centre Brussels, MSF–Luxembourg, Luxembourg; [†]International Union Against Tuberculosis and Lung Disease (The Union), Paris, France; [‡]London School of Hygiene & Tropical Medicine, London, UK; [§]The Union, South-East Asia Office, New Delhi, India; [¶]Fiji National University, Suva, Fiji; [#]Secretariat of the Pacific Community, Nouméa, New Caledonia; ^{**}Dignitas International, Zomba, Malawi; ^{††}Instituto Nacional de Salud, Lima, Peru; ^{†††}Health Services Department, PSI/Myanmar, Yangon, Myanmar; ^{§§}Revised National Tuberculosis Control Programme, Delhi, India; ^{¶¶}National Tuberculosis Control Programme, Lilongwe, Malawi; ^{##}Desmond Tutu TB Centre, Department of Paediatrics and Child Health, University of Stellenbosch, Cape Town, South Africa; ^{***}Academic Model Providing Access to Healthcare (AMPATH)/Moi Teaching & Referral Hospital, Eldoret, Kenya; ^{†††}Centre for International Health, University of Bergen, Bergen, Norway

SUMMARY

The words ‘defaulter’, ‘suspect’ and ‘control’ have been part of the language of tuberculosis (TB) services for many decades, and they continue to be used in international guidelines and in published literature. From a patient perspective, it is our opinion that these terms are at best inappropriate, coercive and disempowering, and at worst they could be perceived as judgmental and criminalising, tending to place the blame of the disease or responsibility for adverse treatment outcomes on one side—that of the patients.

In this article, which brings together a wide range of authors and institutions from Africa, Asia, Latin America, Europe and the Pacific, we discuss the use of the

words ‘defaulter’, ‘suspect’ and ‘control’ and argue why it is detrimental to continue using them in the context of TB. We propose that ‘defaulter’ be replaced with ‘person lost to follow-up’; that ‘TB suspect’ be replaced by ‘person with presumptive TB’ or ‘person to be evaluated for TB’; and that the term ‘control’ be replaced with ‘prevention and care’ or simply deleted. These terms are non-judgmental and patient-centred.

We appeal to the global Stop TB Partnership to lead discussions on this issue and to make concrete steps towards changing the current paradigm.

KEY WORDS: TB; language; defaulter; suspect; control; loss to follow-up

IT WAS IN PARIS, at a recent operational research training course organised by the International Union Against Tuberculosis and Lung Disease (The Union) and Médecins Sans Frontières (MSF), that the issue of language in tuberculosis (TB) services came up. Facilitators and participants included operational research scientists, policy makers, health workers and activists from Africa, Asia, Latin America, Europe and the Pacific. The desire was unanimous: to avoid use of the terms ‘defaulter’, ‘suspect’ and ‘control’ in the language of TB services.

The words ‘defaulter’, ‘suspect’ and ‘control’ have been used in national TB programmes (NTPs) for many decades, and today they continue to be used in international guidelines and in the published literature.^{1,2} From the patient’s perspective, it is our opinion that these terms are at best inappropriate, coercive and disempowering, and at worst they may be

perceived as judgmental and criminalising, as they tend to put the blame of the disease and the responsibility for adverse treatment outcomes on one side, that of the patient. Despite strong objections to the use of such terminology by some health workers, patient associations and activists, it is we, the health practitioners, who by continually using these terms perpetuate their existence.

In contrast to TB, there has been considerable evolution of terminology in the human immunodeficiency virus (HIV) world, where it has long been recognised that pejorative language can have detrimental effects leading to the stigmatisation and discrimination of patients. It has therefore become customary to be very careful about the choice of words, and the Joint United Nations Programme on HIV/AIDS (UNAIDS) has even published a dictionary of politically correct terms.³

So what do the terms defaulter, suspect and control