

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

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### 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.<sup>1,2</sup> 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.<sup>3</sup>

So what do the terms defaulter, suspect and control

really mean, and why do we think it is detrimental to continue using them?

## THE DEFAULTER

Let us start with the word defaulter. The Oxford English dictionary defines a defaulter as a person who fails to fulfil a duty, obligation or undertaking.<sup>4</sup> In the context of banking, 'to default' means to fail to repay a loan; in a legal context, it refers to the failure to appear in a law court when summoned by the judge; and in the sphere of competition, it refers to the failure to take part in or complete a scheduled contest.<sup>4</sup>

In all cases, the common feature is that blame is designated by someone in a decision-making position upon another—a person in the community.

From a TB services perspective, the word default(er) is used in three different ways, all of which unnecessarily and unfairly place blame on the patient. The first is the 'initial defaulter'. This refers to a patient documented as sputum smear-positive for acid-fast bacilli in the laboratory sputum register (i.e., confirmed as having TB in the laboratory), but who does not appear in the TB patient register and is therefore not registered as having started treatment.<sup>5</sup> In practice, such a person has sought care from the health services, and has been diagnosed with TB, but does not end up being registered for treatment. It is well known that important causal factors of initial defaulting are related to poor quality of the health services or errors committed and made by health workers.<sup>6–10</sup> It is thus the health care system that has failed to meet its obligations to the patients, and it is incorrect to shift the blame and place it on the patients by labelling them initial defaulters. NTPs furthermore shy away from including initial defaulters when reporting on NTP outcomes. This is because if this group was included in reporting, it would adversely affect the desired outcomes of cure and treatment completed and result in an apparent decline of these important indicators of NTP performance.<sup>5</sup>

Second is the 'treatment defaulter'. This refers to a patient who starts anti-tuberculosis treatment that is interrupted for 2 consecutive months or more.<sup>1</sup> Many studies have revealed that shortcomings of health systems as well as physical, financial, social and cultural obstacles to continued treatment are to blame.<sup>8,11–14</sup> Some of these obstacles include the lack of a regular, uninterrupted supply of drugs; patients having to pay for their drugs; lack of accessible ambulatory treatment centres in rural and urban settings, resulting in increased travel costs and time; inconvenient clinic hours, with long waiting times; lack of adequate numbers of motivated and friendly health workers; inappropriate patient education; lack of various alternative forms of treatment support (in the community, workplace or elsewhere) if facility-based treatment poses an obstacle to the patient;<sup>7,10,15–17</sup> and lack of readily accessible joint HIV and TB services.<sup>7,9,11–14,18</sup>

These challenges are clear pointers to the lack of a strong, patient-centred approach in TB services—probably the most important reason for poor treatment completion rates.<sup>1,15,19</sup> We need to recognise that the failure of patients to complete treatment represents not patient failures, but rather health system failures.<sup>20,21</sup>

The vital programme components of treatment education and awareness merit attention. As Zakie Achmat put it in 2005, on delivering the special guest lecture at the 36th Union World Conference on Lung Health in Paris,<sup>22</sup> 'we need to change our paternalistic public health approaches that make the public health official the decision-maker on behalf of the patient and the community'. The key take-home message was that patients should be regarded as independent and autonomous, with the dignity and the ability to take control of their own health or illness.<sup>23</sup> The World Health Organization (WHO) Stop TB strategy has clearly recognised that enhancing patient-centred approaches, with a strong focus on education about TB treatment, is an important way to enhance treatment completion.<sup>1,23,24</sup> Although this is laudable, maintaining the term 'defaulter' ascribes the fault to the patient, and goes against these concepts.

The third attribution, 'treatment after default', refers to a patient who is declared as having interrupted anti-tuberculosis treatment for 2 months or more, and then returns to the TB services.<sup>1</sup> The arguments discussed above for moving away from this terminology are also valid for this group of patients.

In light of the above, we propose that the words 'default' and 'defaulter' be replaced by 'loss to follow-up', a non-judgmental term that merely describes an outcome, highlighting the responsibility of the services to maintain an enabling environment in which patients are less likely to be lost to follow-up. These terms are already used for cohort reporting of patients on life-long antiretroviral treatment.<sup>25</sup> Adaptations to initial default, treatment default and return after default could then be, respectively, 'pre-treatment loss to follow-up', 'loss to follow-up (on treatment)' and 'return to treatment after loss to follow-up'.

## THE TB SUSPECT

In English, the word 'suspect' is used as a verb, adjective and a noun.<sup>26</sup> As a verb, it has several meanings and usages. The first is 'to have an idea or impression of the existence, presence or truth of (something) without certain proof'. As an adjective, the meaning of the verb 'to suspect' gives the commonly used medical term 'suspected', for example, a suspected heart condition. This refers to the disease, not the patient. Another meaning of the verb, however, is 'to believe or feel that (someone) is guilty of an illegal, dishonest or unpleasant act, without certain proof'. It is this second meaning that is linked to the noun, 'a suspect', which is defined as a person thought to be guilty of a crime or offence.<sup>26</sup>

In TB services language, 'TB suspect' is used to define a person who presents with symptoms or signs suggestive of TB.<sup>1</sup> Why did the TB community decide to transfer the 'suspicion' of the disease to the patient? By presenting with symptoms and signs of TB, TB patients are surely not guilty of any crime or offence. In contrast, today, in the HIV world, no clinician, policy maker or public health researcher would dare speak about HIV 'suspects'.<sup>3</sup>

The continued use of such a term may add to stigma and exclusion and, at worst, to a perception of criminalisation of vulnerable individuals. This is particularly relevant for patients with multidrug-resistant TB. We thus propose that the term 'TB suspect' be replaced with much simpler and neutral terminology, such as 'a patient with possible TB', 'a patient with presumptive TB' or a 'person to be evaluated for TB'.

### NATIONAL TUBERCULOSIS 'CONTROL' PROGRAMME

The word 'control' is used in different ways, principally to limit, regulate or restrict an activity or a process (mechanical or scientific), or to maintain influence and authority over behaviour.<sup>27</sup> Synonymous terms include 'power, to dominate, and be in charge of'. The notion of control is potentially dangerous, for two main reasons.<sup>28</sup> First, it tends to put us, as the 'experts', in the driving seat, and assumes that we have the answers to the patient's health problems. This can lead us to neglect community and patient resources and capacities. It can also result in our overestimating the power of our interventions.<sup>28</sup> Second, the 'control of tuberculosis' may inadvertently lead to programmes trying to take control of tuberculosis patients by infringing on their rights and autonomy.<sup>23,29–31</sup> The term may be interpreted as something done to, rather than for, the patient or client,<sup>27</sup> thus providing an apparent justification for coercive action to control client/patient behaviour.<sup>28</sup> The term 'control' is most likely associated with the fact that, for decades, TB services have been more manager than patient-centred. One could say that 'control' is also related to trying to achieve epidemic control (so called disease control). However, disease 'control', from the perspective of preventing and treating a disease, should logically be a direct spin-off of the prevention and care services offered by TB programmes. We thus offer two solutions for change. First, it is our opinion that the terms 'prevention and care' or 'management' better describe programme activities than 'control'. Inclusion of the word 'care' is also useful, as it clearly brings forward the notion of a patient-centred approach. One could therefore argue that terminology such as National TB Control Programme could be better phrased as National TB Prevention and Care Programme. The latter is client/patient-centred,

and provides a much clearer sense of what we wish to achieve. Moreover, replacing 'control' with 'prevention and care' has no obvious negative connotations, and better reflects the standard of practice that the Stop TB Partnership is now aiming for.<sup>32</sup>

We do concede, however, that the broad term 'care and prevention' might not fully capture the goal and objectives of NTPs, which seek not only to provide services but also to achieve outcomes against targets (TB patients detected, TB patients cured) as cost-effectively as possible. An alternative could be to merely delete the word 'control' and simply talk about 'National TB Programmes' (in the same way as we talk about National Malaria Programmes or National Schistosomiasis Programmes). The key point is that the word 'control' in the title of National Programmes gives undue emphasis to one of many programme activities. We feel this is unnecessary, that it does not bring any specific gain due to its potential negative connotation and that it may even hinder efforts to change the programme mind-set across to truly patient-centred approaches.

### CONCLUSION

Worldwide, over 2 billion people—about one third of the world's inhabitants—are infected with *Mycobacterium tuberculosis*. In 2010, there were an estimated 8.8 million new cases of TB and 1.45 million deaths due to TB or HIV-associated TB.<sup>33,34</sup> These figures bear striking witness to the humble reality of the failures of our health systems, and thus our failure to prevent TB and improve care services in TB programmes.

So why do we, as health practitioners, continue to refer to our patients as defaulters and suspects and our services as control? Is it simply the hesitation to change from the terminology we are so used to? The argument seems to be that because we have used these terms for years, why not just continue in the same way, since these terms are understandable and we thus do not need to embrace new words. For TB patients, however, who are often already poor, vulnerable, excluded and stigmatised, and who now also carry the additional burdens of HIV/AIDS and multidrug-resistant TB, the last thing they need from the health system is to be referred to in a manner that is disempowering and detrimental to their acceptance in society.<sup>31,35</sup>

TB services are not just about the science of treatment, they are also about something much more fundamental: dignity, social fairness, social justice and a willingness to serve—all values that need to be embraced as core aspects of TB programmes in the new millennium.<sup>23,31</sup> We appeal to the global TB community, and in particular to the global Stop TB Partnership, to lead discussion on this issue and make concrete steps towards changing the current paradigm of detrimental language in TB services.

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**R É S U M É**

Les termes « abandon », « suspect » et « contrôle » ont fait partie du langage des services de tuberculose (TB) depuis de nombreuses décennies et ils continuent à être utilisés dans les directives internationales et dans la littérature publiée. Dans la perspective du patient, nous pensons que ces termes sont pour le moins inappropriés, coercitifs et décourageants, et au pire, pourraient être perçus comme un jugement ou une culpabilisation tendant à situer le reproche de la maladie ou la responsabilité des mauvais résultats du traitement d'un seul côté, celui des patients.

Dans cet article, qui rassemble une large variété d'auteurs et d'institutions d'Afrique, d'Asie, d'Amérique Latine, d'Europe et de la région du Pacifique, nous dis-

cutons l'utilisation des mots « abandon », « suspect » et « contrôle » et argumentons les raisons pour lesquelles il est défavorable de poursuivre leur utilisation dans le contexte de la TB. Nous proposons le remplacement du terme « abandon » par « personne perdue de vue », du terme « suspect de TB » par « personne où la TB est suspectée » ou « personne à évaluer pour la TB » et du terme « contrôle » par « prévention et soins » ou même l'abandon de ce dernier terme. Les termes proposés ne comportent aucun jugement et sont centrés sur le patient.

Nous faisons appel au Partenariat Mondial Stop TB pour conduire des discussions à ce sujet et faire des progrès concrets vers la modification du paradigme actuel.

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**R E S U M E N**

Los términos 'abandono', 'sospechoso' y 'control' han constituido parte del lenguaje de los servicios de atención de la tuberculosis (TB) durante muchos decenios y se utilizan aun en las directrices internacionales y en las publicaciones científicas. Opinamos que desde el punto de vista del paciente, estos términos son cuando menos inapropiados, represivos o desvalorizantes y, en el peor de los casos, se pueden percibir como sentenciosos o punitivos y tienden a asignar la culpa de la enfermedad o la responsabilidad por los desenlaces terapéuticos del lado de los pacientes.

En el presente artículo, que reúne autores de una gran diversidad de instituciones de África, Asia, América Latina, Europa y el Pacífico, se examina el uso de las pa-

labras 'abandono', 'sospechoso' y 'control' y se plantean la razones por las cuales se considera perjudicial la continuación de su uso en el contexto de la TB. Se propone reemplazar 'abandono' por 'persona perdida durante el seguimiento', 'sospechoso de TB' por 'persona con presunción diagnóstica de TB' o 'persona en quien se debe descartar la TB' y sustituir la palabra 'control' por 'prevención y atención' o simplemente suprimirla. Estas expresiones no son sentenciosas y se centran en el paciente.

Se solicita a la Iniciativa Mundial Alto a la Tuberculosis que organice debates sobre el tema y que adopte determinaciones concretas tendentes a modificar el paradigma vigente.

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