Unveiling the power of neutral and inclusive language in tuberculosis prevention and care

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Abstract
Language plays a crucial role in shaping discourses and responses related to disease, particularly tuberculosis (TB). Stigmatising language and attitudes surrounding TB can lead to discrimination and marginalisation of affected individuals, creating barriers to seeking proper diagnosis and treatment. The terminology used to describe TB-affected individuals can be disempowering and criminalising, reinforcing an "othering" of those affected. To combat this, engaging with TB-affected communities is essential to co-construct a neutral and inclusive vocabulary that respects the dignity of individuals and fosters empathy and support. Thus, an inclusive language approach empowers affected individuals as active participants in their health management, encouraging open communication and the development of support networks. By adopting a neutral and inclusive language system, healthcare providers and communities can work together to remove unnoticed hurdles and align with the World Health Organization's TB care and prevention goals.

Introduction
Language is a critical vehicle through which disease-related discourses and responses become constructed and ingrained [1] and can shape how people interact and engage with healthcare professionals, potentially excluding or empowering them to participate in their care as equal partners [2]. Stigmatising language and attitudes surrounding tuberculosis (TB) can lead to discrimination and marginalisation of TB-affected individuals, which, in turn, may create barriers to seeking proper diagnosis, treatment, and support [3].

Stigma and discrimination of TB-affected communities
Even though medical and technical advances enable a high treatment success rate, TB is still marked by stigma, taboos, and beliefs that affect people and communities and entail experiences of prejudice and discrimination [4]. These processes generate a negative impact that is felt in multiple life contexts by people with TB (*e.g.* at home, in the workplace, in the community), while profoundly impacting TB prevention and care [5].

TB stigma is one of the major social determinants of health and contributes to compounding health inequalities, remaining one of the major challenges to TB prevention and care [6]. TB stigma has been shown to reduce treatment adherence [7], affect diagnostic delays and treatment refusals [5, 8], and negatively impact TB treatment outcomes [5, 7]. Stigmatised TB patients are reluctant to seek and complete treatment [5, 8], resulting in delayed health-seeking behaviour [5, 9].

It appears that no real research effort has resulted in a thorough evaluation of interventions and methods meant to lessen TB stigma [10]. NUTTALL *et al*. [10] demonstrate that, despite a greater focus on

eradicating TB stigma, interventions created to address that problem are not always carried out, assessed, or reported, or are compromised by subpar methodological design, execution, and evaluation. These authors also caution that programmes and strategies centred on people affected by TB are rarely primarily focused on combating or reducing stigma. This dimension supplements the rest of the intervention, functioning as "a bridge towards TB treatment, adherence, completion, and success" [10].

Stigma and discrimination are not only expressed in people's attitudes towards TB-affected communities but are sustained in structures, policies, traditions, and norms [11]. They are also conveyed through a language that is full of dehumanising terminology that reduces those who have TB to the illness that affects them [12]. Regardless of intent, one's belief and value systems and contextual meanings about TB give way to a discourse that normalises labels, stereotypes, and low standards of worth, value, and acceptability that associate the disease with poverty, deviance, and danger [5, 10, 13].

In their findings, ALFAIATE *et al*. [14] reported that "the word TB has a very, very heavy weight, and people generate stigma around it. […] I felt the word as stigmatizing despite everyone trying to demythologize the disease around me […] for me, the word TB had a huge weight".

Stigmatising language in TB

According to ZACHARIAH *et al*. [15], from the perspective of people with TB, the terminology used to characterise them can be disempowering, with the risk of being viewed as judgmental, marginalising, and even criminalising. The language used with people with or affected by TB is equivalent to that used to refer to key populations in vulnerable circumstances (*e.g.* people who use drugs, sex workers, and people with or affected by HIV), as it does not account for the dignity of the people themselves [2].

This highly stigmatising discourse triggers deep social reactions: from disdain, horror, and guilt to sympathy and apathy, and is often dismissed as a "disease of the other" [13]. Terminology such as "suspect" or "suspicion" when referring to individuals exhibiting symptoms of TB can inadvertently shift blame onto the affected person, despite their innocence of any wrongdoing, and may inadvertently contribute to the criminalisation of vulnerable individuals, adding an undue burden to their already challenging circumstances [15]. Additionally, while emphasising TB's connections to a specific country, race, ethnicity, gender, living condition, legal status, or income group is important for health programming and resource allocation, it may also reinforce its "othering", especially if the opportunity to expose and amplify the structural violence that sustains those connections is missed [13].

Given the harmful effects of using an inappropriate and marginalising discourse [13, 16], it is critical to engage with TB-affected communities to: 1) recognise the barriers to which they are subject; and 2) co-construct a complete vocabulary that not only allows a clear description of TB phenomena but is also free of any terminology founded on prejudices or misplaced beliefs about the disease and the affected people.

Currently, some resources are available to assist researchers and healthcare professionals in data reporting using neutral, inclusive, and person-centred language. MARJADI *et al*. [17] present practical suggestions to help in the creation of inclusive healthcare environments, emphasising the importance of 1) being wary of assumptions and stereotypes, 2) replacing labels with appropriate terminology, 3) using inclusive language, 4) ensuring appropriate communication methods, 5) self-education about diversity in all its forms, and 6) building individual and institutional commitments. Other resources encourage, for example, the description of participants as having a condition or disease, experiencing a circumstance, or engaging in a specific behaviour rather than linking these experiences to their identity (*i.e.* the use of terms such as "people with HIV" instead of "HIV positive" or "HIV patient" are advocated) [18].

Some resources and guidelines are specifically tailored to those involved in TB prevention and care and emphasise the need to use inclusive and neutral language, presenting alternatives created according to the experience and perspective of people with or affected by TB (table 1).

Although the examples presented offer healthcare professionals a new and more inclusive way of addressing and/or referring to people with TB, it is recommended that this exercise be co-constructed, beginning with an invitation to each person with TB to participate in the dialogue about the language to be used in each setting. In this sense, it is advocated that healthcare professionals proactively strive to disengage from commonly used language and involve themselves in the adoption and adaptation (where necessary) of the resources made available for this purpose or the creation of a new set of discourse guidelines that may be used in their context of TB management and care (given that neutral and inclusive language resources/guidelines seem to be scarce and not suited to all languages or idioms) [18].

TABLE 1 Examples of inclusive language in tuberculosis (TB) prevention and care	
Terms that should be avoided	Inclusive alternative terms
"Suspect" Generally employed in criminal settings, the use of this word establishes a marginalising relationship between TB and the people who might be infected by it.	**"Person with presumed TB"** An alternative term to "suspect" that does not have the negative connotation of crime that frequently produces guilt and humiliation and encourages discriminatory behaviours against people with TB.
"TB patient" This phrase minimises those who have TB to their illness, disregarding the many dimensions of a person's existence. It also implies that the person is under the health system's authority, promoting unequal power dynamics between healthcare providers and people with TB who are receiving care.	**"People with TB"** This people-centred alternative emphasises that people with TB are more than their disease. Other alternative terms include "person on treatment" or "person receiving healthcare".
"Defaulter" This term attributes treatment failure to the person receiving it, ignoring the underlying causes of a person's loss to follow-up.	**"Person lost to follow-up"** Provides an alternative that does not disregard the various causes and determinants, as well as the obstacles that people with TB encounter, which may contribute to treatment failure.
"Risk groups" Although the term typically refers to groups of people with a higher prevalence/incidence of TB than the general population, it ignores the circumstances and factors which increase the risk of exposure to TB.	**"Key and vulnerable populations"** Alternative term for populations whose living conditions increase their risk of contracting TB. It shifts the blame from people to the risk factors that enhance TB exposure.
Terms that should be used carefully	
"Compliance"/"compliant" These terms are intended to characterise whether or not a person follows the prescribed treatment regimen. **"Adherence"/"adherent"** These terms describe the extent to which each required dose of medicine is taken throughout treatment.	These terms unfairly ascribe sole responsibility for treatment completion to people with TB, even though many external factors beyond a person's control may influence their ability to complete the treatment as intended. It is critical to comprehend any obstacles that may jeopardise the individual's ability to complete the prescribed course of treatment.
Information from [19].	

The road towards a neutral and inclusive TB language

A neutral and inclusive language makes use of language resources to progressively abolish and transform the use of words and expressions that may be considered discriminatory and stigmatising towards people, groups, or communities that are socially underrepresented, unprotected, or vulnerable to stereotypes, perceptions, and negative attributions [20]. It acknowledges the dignity of people affected by TB, generating compassion and empathy, and fostering a more understanding, supportive, and people-centred approach to care [13]. It also creates an open and nonjudgmental environment in which affected individuals feel safe to come forward, ultimately encouraging them to seek medical attention and disclose their TB diagnosis without fear of discrimination or shame [13]. Neutral and inclusive language provides a collaborative approach among healthcare providers, communities, and individuals, acknowledging everyone's equal role in TB prevention and care, bridging the gap between the scientific community and "knowledge users" (or those for whom the study will ultimately be useful) [21], deconstructing the scientific community's patronising tone [22]. Through inclusive language, people affected by TB are empowered as active participants in their health management [12, 23]. Inclusive language encourages a sense of belonging and community, promotes open communication and sharing of experiences, and develops support networks, all of which are essential for coping with the challenges connected with TB.

Developing a neutral and inclusive language requires using participatory action research approaches that make TB-affected communities jointly responsible [24]. In this regard, the community-based participatory research framework acknowledges the expertise of TB-affected communities, values their perspectives, and fosters a collaborative environment in which everyone's voices are heard and respected [25]. The core principles of community-based participatory research (co-learning, long-term partnerships, capacity building, community empowerment, and building sustainable systems) allow for a better alignment of

scientific research with community needs (in this case, people affected by TB) [25]. This framework advocates for the inclusion of communities in all stages of the research/intervention, allowing them to co-create programmes and strategies aimed at them [25], while empowering communities affected by TB to actively participate in research, stigma reduction efforts, and the development of inclusive and neutral language that is respectful, accurate, and free from judgment [26].

Community-based interventions have been shown to have a significant impact on TB prevention and case detection (relative risk (RR) 3.1, 95% CI 2.92–3.28), with a marginal effect shown for treatment success rate (RR 1.09, 95% CI 1.07–1.11) [27]. Pairing community-based interventions with existing healthcare infrastructure and/or programmes appears vital for active case finding and treatment continuation, as the involvement of influential community and family members acts as a facilitator of trust for treatment engagement while providing mechanisms for closer supervision and thus maximising adherence [27]. CHAVEZ-RIMACHE et al. [28] also reported the significant impact of active community participation in strengthening TB prevention and care programmes, highlighting the necessity of departing from traditional scientific research approaches dominated by academic researchers and embracing a comprehensive and ecological framework that incorporates the community and other social actors.

The Denver Principles provide a broader example of the impact of community-based interventions in the HIV field [29]. These principles, in effect, established the value of patient involvement in medical and policy decision-making, urging people living with HIV and those from affected communities to be active participants in their own care and to be treated as people first, patients second [29].

This collaboration could be substantially fruitful in developing and implementing a neutral and inclusive language system. This system will create and promote a safe space in which the lived experience of people with and affected by TB is taken in its entirety and is free of prejudice, stigma, and marginalising power dynamics. Adopting collaborative techniques informed and directed by a neutral and inclusive language could bring all those involved in TB care and prevention closer to the World Health Organization's aims, removing hurdles previously unnoticed or unaccounted for.

Conclusion

Neutral and inclusive language centred on people with TB may help to break down the existing barriers to treatment-seeking behaviours, by fostering an environment of acceptance and support, ultimately encouraging the best possible therapeutic outcomes. In this regard, all TB care providers must be responsible for identifying and deconstructing stigmatising and discriminatory discourses and actions, working alongside TB-affected communities to eradicate TB stigma and, ultimately, TB in general.

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