Stop TB Partnership

SUGGESTED LANGUAGE AND USAGE FOR TUBERCULOSIS (TB) CARE, COMMUNICATIONS AND PUBLICATIONS

PREFACE

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 published literature.

The detrimental effect of such negative language was detailed by TB experts from around the world in an article in the June issue of the *International Journal of Tuberculosis and Lung Disease,* "Language in tuberculosis services: can we change to patient-centred terminology and stop the paradigm of blaming the patients?"

The authors describe how judgmental terms, such as referring to a person who might have tuberculosis as a 'TB suspect' can powerfully influence attitudes and behaviour at every level – from inhibiting patients to seek treatment to shaping the way policy-makers view the challenge of addressing the disease. They call for the Stop TB Partnership to lead discussions on this issue and make a change.

The article also observes that the powerfully negative connotation of words such as 'defaulter' and 'suspect' tend to place blame for the disease and/or responsibility for adverse treatment outcomes on one side — that of the patients.

Bringing together the opinions of authors and institutions from Africa, Asia, Latin America, Europe and the Pacific, the article proposed that the current terms be replaced with non-judgmental and patient-centred terms.

The Stop TB Partnership has responded positively to this call to action as needed to build on the *Patients' Charter for Tuberculosis Care*, published in 2006, as well as the goals outlined in the Global Plan to Stop TB 2011–2015.

In October 2012 a request to complete a survey about the best way forward was sent to the Stop TB Partnership's news subscriber list and all 1000 partner organizations. The result was clear – three-quarters of the 435 respondents agreed or strongly agreed that some language used in TB care, publications and communications has a detrimental effect on attitudes towards people affected by TB; some of the language commonly used in TB care creates stigma or discourages people from seeking/continuing treatment; that the Stop TB Partnership Secretariat should support and advance the development of a handbook of language, designed to provide helpful advice on adopting alternatives to detrimental language currently used in TB care and publications; and that it should take the form of a "style" guide, with definitions of terms and possible alternatives

On the basis of this endorsement, the Stop TB Partnership Secretariat moved ahead with developing and publishing the handbook. We wish to emphasize that we see this as a living document – one that will be available only in electronic form and that will remain supple, evolving as language changes

behaviour change communication

Behaviour change communication promotes tailored messages, personal risk assessment, greater dialogue, and an increased sense of ownership. Behaviour change communication is developed through an interactive process, with its messages and approaches using a mix of communication channels in order to encourage and sustain positive, healthy behaviours. It may also involve encouraging healthcare providers to perform certain actions, such as TB screening. See also 'social change communication'.

case

The definition of a TB case is currently under review by the World Health Organization. Although the term will doubtless continue to be used widely in public health, it should be used with sensitivity in health care settings to avoid dehumanizing patients. A person is not a case but a fellow human being. People seeking or receiving care may find it demeaning if they overhear a health worker describing them as 'cases'.

case detection

This term means that TB is diagnosed in a patient and is reported within the national surveillance system and then to WHO.

cocktail

This term is used colloquially to describe the mix of drugs that TB patients – especially those with MDR-TB – need to take to achieve a cure. This term is not recommended, because it could be perceived as making light of the often harsh difficulties associated with MDR-TB treatment.

community systems strengthening

The term 'community systems strengthening' refers to initiatives that contribute to the development and/or strengthening of community-based organizations in order to increase knowledge of and access to improved health service delivery. It usually includes capacity-building of infrastructure and systems, partnership-building, and the development of sustainable financing solutions.

defaulter

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 person whose diagnosis of TB disease has been confirmed, but who does not appear in the TB patient register and is therefore not registered as having started treatment. 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. The term *treatment defaulter* is used to describe a patient who starts TB treatment that is interrupted for two consecutive months or more. The third attribution, *treatment after default*, refers to a patient who is declared as having interrupted TB treatment for two months or more, and then returns to the TB services. In all three of these situations, it is generally poor quality of health services and lack of a

patient-centred approach that leads to treatment interruption or failure to begin treatment, and it is incorrect to shift the blame and place it on the patients by labelling them *defaulters.* The term *person lost to follow-up* is recommended as an alternative.

definite case of TB
This term is defined by having *Mycobacterium tuberculosis* complex identified from a clinical specimen, either by culture or by a newer method such as Xpert MTB/RIF or molecular line probe assay. In countries that lack the laboratory capacity to routinely identify *M. tuberculosis*, pulmonary TB with one or more initial sputum smear examinations positive for acid-fast bacilli is also considered to be a "definite" case, provided that there is a functional external quality assurance system with blind rechecking.

disabilities
People with disabilities are individuals whose prospects of securing, retaining, and advancing in suitable employment are substantially reduced as a result of a duly recognised physical or mental impairment.

empowerment
Empowerment is action taken by people to overcome the obstacles of structural inequality that have previously placed them in a disadvantaged position. Social and economic empowerment is a process aimed at mobilizing people to achieve equality of welfare and equal access to resources and become involved in decision-making at the domestic, local, and national level.

endemic
Common diseases that occur at a constant but relatively high rate in the population are said to be 'endemic'

epidemic
An epidemic is an unusual increase in the number of new cases of a disease in a human population. The population may be all the inhabitants of a given geographic area, the population of a school or similar institution, or everyone of a certain age or sex, such as the children or women of a region. Deciding whether an increase in the number of cases constitutes an epidemic is somewhat subjective, depending in part on what the usual or expected number of cases would be in the observed population. An epidemic may be restricted to one locale (an outbreak), be more general (an epidemic), or be global (a pandemic). Widely known examples of epidemics include the plague of mediaeval Europe known as the Black Death, the influenza pandemic of 1918–1919 and the current HIV and TB epidemics.

epidemiology

Epidemiology is the scientific study of the causes, distribution, and control of diseases in populations.

extensively drug-resistant TB (XDR-TB)

This is a form of drug-resistant TB in which bacteria are resistant to isoniazid and rifampicin, the two most powerful anti-TB drugs, plus fluoroquinolones and at least one injectable second-line drug.

extrapulmonary TB

This term refers to TB involving organs other than the lungs, such as pleura, lymph nodes, abdomen, genitourinary tract, skin, joints and bones or meninges. Diagnosis should be based on at least one specimen with confirmed *M. tuberculosis* or histological or strong clinical evidence consistent with active extrapulmonary TB, followed by a decision by a clinician to treat with a full course of TB chemotherapy. Unless a case of EPTB is confirmed by culture as caused by *M. tuberculosis*, it cannot meet the "definite case" definition (see page 4).

gender-sensitive

Gender-sensitive policies, programmes, or training modules recognise that both women and men are actors within a society, that they are constrained in different and often unequal ways and that consequently they may have differing and sometimes conflicting perceptions, needs, interests, and priorities.

gender-specific

The term 'gender-specific' refers to any programme or tailored approach that is specific for either women or men. Gender-specific programmes may be justified when analysis shows that one gender has been historically disadvantaged socially, politically, and/or economically.

health care

Health care includes preventive, curative, and palliative services and interventions delivered to individuals or populations. In most countries these services account for the majority of employment, expenditure, and activities that would be included in the broader health sector or health system (see following entries).

health sector

The health sector encompasses organized public and private health services (including those for health promotion, disease prevention, diagnosis, treatment, and care), health ministries, health-related nongovernmental organizations, health-related community groups, and health-specific professional organizations, as well as institutions that directly provide inputs into the health-care system, such as the pharmaceutical industry and teaching institutions.

health system

A health system consists of all organizations, people, and actions whose primary intent is to promote, restore, or maintain health. It involves the broad range of individuals, institutions, and actions that help to ensure the efficient and effective delivery and use of products and information for prevention, treatment, care, and support to people in need of these services.

health systems strengthening

This term refers to a process that enables a health system to deliver effective, safe, and high-quality interventions to those who need them. Areas that require strengthening are typically the service delivery system, health workforce, health information system, systems to guarantee equitable access to health products and technologies and health financing systems, as well as leadership, governance and accountability.

high-burden country

The term 'high burden' refers to one of the 22 countries that together have 80% of all new TB cases arising each year. This expression should be used with caution and sensitivity in order to avoid stigmatization.

HIV-infected

People should be referred to as 'HIV-positive' if they know they are HIV-positive or as 'having undiagnosed HIV infection' if they do not. The term 'HIV-infected' is not recommended.

HIV-negative

A person who is HIV-negative shows no evidence of infection with HIV on a blood test (e.g., absence of antibodies against HIV). Synonym: seronegative. The test result of a person who has been infected but is in the window period between HIV exposure and detection of antibodies will also be negative.

HIV-positive

A person who is HIV-positive has had antibodies against HIV detected on a blood test or gingival exudate test (commonly known as a saliva test). Synonym: seropositive.

human immunodeficiency virus (HIV)

HIV is the virus that weakens the immune system, ultimately leading to AIDS. Since HIV means human immunodeficiency virus, it is redundant to refer to the 'HIV virus'

three 'I's

The three 'I's—isoniazid preventive treatment, intensified case finding and TB infection control—are key public health strategies to decrease the impact of TB on people living with HIV, their partners and family and the community.

intervention

The term 'intervention' means different things in different contexts. In medical treatment, an intervention may save a person's life. When describing programmes at the community level, use of the term 'intervention' can convey 'doing something to someone or something' and as such undermines the concept of participatory responses. Preferred terms include 'programming', 'programme', 'activities', 'initiatives', etc. The word 'intervention' occurs in three other definitions: structural interventions, health care interventions and health care strengthening. Its use in these contexts is appropriate.

latent TB infection

About one-third of the world's population has latent TB, which means people have been infected by TB bacteria but are not (yet) ill with disease and cannot transmit the disease. People infected with TB bacteria have a lifetime risk of falling ill with TB of approximately 10%. However persons with compromised immune systems, such as people living with HIV, or people with malnutrition or diabetes or who use tobacco have a much higher risk of becoming sick with active TB disease.

malnutrition

A state of malnutrition, or undernutrition, refers to the situation of people whose diet does not provide adequate calories and protein for growth and maintenance or who are unable to fully utilize the food they eat due to illness. Malnutrition increases risk of developing TB disease.

MDR-TB

See multidrug-resistant TB.

migrant worker

A migrant worker is a person who migrates from one country or area to another in pursuit of job opportunities. This includes any person regularly admitted as a migrant for employment, as reflected in the Migration for Employment Convention (Revised) 1949, No. 97. Accessing and completing TB treatment is often difficult for migrant workers. Cross-border lapses in care have been an especially thorny problem that a number of countries are starting to address.

migration

The term 'migration' is used mainly for economic migration, while the term 'forced displacement' applies to asylum seekers, refugees, internally displaced persons, and stateless persons. The term 'populations in humanitarian crisis situations' refers

to both forcibly displaced populations and non-displaced populations that are in crisis settings.

Millennium Development Goals (MDGs)

Eight goals were agreed at the Millennium Summit in September 2000. Goal 6 refers specifically to halting and reversing HIV and to halting and reversing the incidence of malaria and other major diseases, with specific mention of TB, by 2015. Lack of progress across other MDGs may seriously curtail progress in tackling TB and, conversely, success in attaining other MDGs is being hampered by the TB epidemic. See http://www.un.org/millenniumgoals/aids.shtml.

mobile worker

The term 'mobile worker' refers to a large category of persons who may cross borders or move within their own country on a usually frequent and short-term basis for a variety of work-related reasons, without changing place of habitual primary residence or home base. Mobile work involves a range of employment or work situations that require workers to travel in the course of their work. Mobile workers are usually in regular or constant transit, sometimes in (regular) circulatory patterns and often spanning two or more countries, away from their habitual or established place of residence for varying periods of time.

multidrug-resistant tuberculosis (MDR-TB)

MDR-TB is a specific form of drug-resistant TB, due to bacilli resistant to at least isoniazid and rifampicin, the two most powerful anti-TB drugs.

nutritional support

Nutritional support aims at ensuring adequate nutrition and includes assessment of the dietary intake, nutritional status, and food security of the individual or household, offering nutrition education and counselling on how to ensure a balanced diet, mitigate side-effects of treatment and infections and ensure access to clean water, and providing food supplements or micronutrient supplementation where necessary.

notification

This term refers to the obligation of health workers to register the name of each person diagnosed with TB, usually in a district registry. Data on the number of cases are then reported at regular intervals to national health authorities. This process is important because it allows every country to track the TB epidemic and progress in addressing it. However, people working in health services should be sensitive to the implications for people affected by TB if they should overhear that their 'case' has been 'notified'. They should be prepared to explain why notification is important for the whole society; and also that there is no shame in having their illness 'notified'.

patient with suspected TB
This is a highly preferable term to 'TB suspect', the term currently under wide usage, to describe a person who presents with symptoms or signs suggestive of TB. (See TB suspect.)

patient-centered approach to TB care
It is now widely recognized that the simple act of watching a person affected TB swallow pills every day does not represent comprehensive care. There is convincing evidence that patient-centered approach improves treatment outcomes while respecting human dignity. This approach considers the needs, perspectives and individual experiences of people affected by TB, while respecting their right to be informed and receive the best quality of care based on individual needs. It requires the establishment of mutual trust and partnership in the patient-care provider relationship and creates opportunities for people to provide input into and participate in the planning and management of their own care. The elements of the patient-centered approach are fully outlined in the Patients' Charter for Tuberculosis Care (http://www.who.int/tb/publications/2006/istc_charter.pdf).

people affected by TB
This term encompasses people ill with TB and their family members, dependents or communities who may be involved in care-giving or are otherwise affected by the illness.

people living with HIV
With reference to those living with HIV, it is preferable to avoid certain terms: 'AIDS patient' should only be used in a medical context (most of the time a person with AIDS is not in the role of patient); the term 'AIDS victim' or 'AIDS sufferer' implies that the individual in question is powerless, with no control over his or her life. It is preferable to use 'people living with HIV' (PLHIV), since this reflects the fact that an infected person may continue to live well and productively
for many years. Referring to people living with HIV as 'innocent victims' (which is often used to describe HIV-positive children or people who have acquired HIV medically) wrongly implies that people infected in other ways are somehow deserving of punishment. It is preferable to use 'people living with HIV' or 'children living with HIV'. The term 'people affected by HIV' encompasses family members and dependents who may be involved in caregiving or otherwise affected by the HIV-positive status of a person living with HIV.

person lost to follow-up
A person lost to follow-up is a person who meets the following criteria.
I. someone whose diagnosis of TB disease has been confirmed, but who does not appear in the TB patient register and is therefore not registered as having started

treatment. In practice, such a person has sought care from health services, and has been diagnosed with TB, but does not end up being registered for treatment.

II. A person who began TB treatment that is interrupted for two consecutive months or more.

III. A patient who is declared as having interrupted TB treatment for two months or more, and then returns to the TB services.

The term *defaulter* has been used to describe people in all three of these situations, but this term unfairly places blame on patients. Generally it is poor quality of health services and lack of a patient-centred approach that leads to failure to begin treatment or treatment interruptions. (See 'defaulter.)

person to be evaluated for TB
This is a highly preferable term to 'TB suspect', the term currently under wide usage, to describe a person who presents with symptoms or signs suggestive of TB. (See TB suspect.)

prevalence
Usually given as the number of affected individuals per 100 000, TB prevalence quantifies the proportion of individuals in a population who are ill with TB at a specific point in time.

prison settings
Prison settings can include jails, prisons, pre-trial detention centres, forced labour camps and penitentiaries. It is critical that access to TB prevention, treatment, care and support extend to these settings.

programme integration
This term refers to joining together different kinds of services or operational programmes in order to maximize outcomes, e.g. by organizing referrals from one service to another or offering one-stop comprehensive and integrated services. In the context of TB care, integrated programmes may include HIV testing, counselling and treatment; sexual and reproductive health, primary care and maternal and child health.

public-private mix (PPM)
A comprehensive approach for systematic involvement of all relevant health care providers in TB prevention and care to promote the use of International Standards for TB Care and achieve national and global TB control targets. PPM encompasses diverse collaborative strategies such as public-private (between the national programme and the private sector), public-public (between the national programme and other public sector care providers such as general hospitals, prison or military health services and social security organizations), and private-private (between an NGO or a private hospital and the neighbourhood private providers) collaboration. PPM also implies engaging relevant care providers in prevention and management of MDR-TB and in the implementation of TB/HIV collaborative activities.

pulmonary TB

This terms refers to a case of TB involving the lung parenchyma. Miliary TB is classified as pulmonary TB because there are lesions in the lungs. Tuberculous intrathoracic lymphadenopathy (mediastinal and/or hilar) or tuberculous pleural effusion, without radiographic abnormalities in the lungs, constitutes a case of extrapulmonary TB. A patient with both pulmonary and extrapulmonary TB should be classified as having pulmonary TB.

screening

This refers to the process of identifying persons at in whom TB infection and disease may be present and for whom a TB diagnostic test should be provided. The process involves eliciting a history of TB symptoms through an interview with the patient and checking for typical signs such as fever and weight loss.

smear-positive pulmonary TB

Sputum smear-positive pulmonary TB is defined as the presence of at least one acid fast bacillus in at least one sputum sample in countries with a well-functioning external quality assurance system.

smear-negative pulmonary TB

Sputum smear-negative pulmonary TB is defined by two sputum specimens negative for acid-fast bacilli and radiographical abnormalities consistent with active TB or sputum that is culture-positive for *M tuberculosis.*

social determinants of health

The social determinants of health are defined by WHO as the conditions in which people are born, grow, live, work, and age, including the health system. These circumstances are shaped by the distribution of money, power, and resources at global, national, and local levels, which are themselves influenced by policy choices. The social determinants of health are mostly responsible for health inequities, the unfair and avoidable differences in health status seen within and between countries. It is common practice in public health to use 'social determinants of health' as an umbrella concept incorporating not only social factors influencing health, but also economic, cultural, or environmental factors, including those codified in laws and policies, as well as those operating through community norms. The concept overlaps with 'socio-economic determinants of health' and 'structural determinants of health', however 'social determinants of health' is a useful overarching phrase that is widely used and understood. It is well established that social determinants play a powerful role in the global TB epidemic. Poor nutrition, for example, greatly enhances a person's risk for becoming ill with TB; and overcrowded living conditions enhance TB transmission.

stigma and discrimination

'Stigma' is derived from the Greek meaning a mark or a stain. Stigma can be described as a dynamic process of devaluation that significantly discredits an individual in the eyes of others. Within particular cultures or settings, certain attributes are seized upon and defined by others as discreditable or unworthy. When stigma is acted upon, the result is discrimination that may take the form of actions or omissions. Discrimination refers to any form of arbitrary distinction, exclusion or restriction affecting a person, usually but not only by virtue of an inherent personal characteristic or perceived belonging to a particular group—in the case of TB, a person's confirmed or suspected illness with TB disease—irrespective of whether or not there is any justification for these measures. The term 'stigmatization and discrimination' has been accepted in everyday speech and writing and may be treated as plural.

surveillance

Surveillance is the continual analysis, interpretation, and feedback of systematically collected data, generally using methods distinguished by their practicality, uniformity and rapidity rather than by accuracy or completeness.

TB control

The term "disease control" is widely used use in the public health community to describe population-wide efforts to reduce the impact of disease. Depending on the context, however, the term 'control' may create the perception that TB 'experts', are indeed in full control of all aspects of prevention, treatment and care of individual TB patients. It useful to examine the term 'control' critically so as to avoid neglecting community and patient resources and capacities. The term 'control' is most likely associated with the fact that, for decades, TB services have been more manager- than patient-centred. 'Prevention and care' or 'management' better describes programme activities rather than 'control'. Inclusion of the word 'care' is also useful, as it clearly brings forward the notion of a patient-centered approach.

TB suspect

In TB services language, 'TB suspect' is often used to define a person who presents with symptoms or signs suggestive of TB. This approach transfers the 'suspicion' of the disease to the patient, suggesting the person is guilty of a crime or offence. The terms 'patient with suspected TB' or 'person to be evaluated for TB' are highly preferable.

TB/HIV collaborative activities

There is clear evidence that people living with HIV and are affected by TB are best served when the HIV and TB services work together. WHO recommends the following activities.

I. Establish and strengthen the mechanisms for delivering integrated TB and HIV services

- Set up and strengthen a coordinating body for collaborative TB/HIV activities functional at all levels
- Determine HIV prevalence among TB patients and TB prevalence among people living with HIV
- Carry out joint TB/HIV planning to integrate the delivery of TB and HIV services
- Monitor and evaluate collaborative TB/HIV activities

II. Reduce the burden of TB in people living with HIV and initiate early antiretroviral therapy (the Three I's for HIV/TB)
- Intensify TB case-finding and ensure high quality TB treatment
- Initiate TB prevention with isoniazid preventive therapy and early antiretroviral therapy
- Ensure control of TB Infection in health-care facilities and congregate settings

III. Reduce the burden of HIV in patients with presumptive and diagnosed TB
- Provide HIV testing and counselling to patients with presumptive and diagnosed TB
- Provide HIV prevention interventions for patients with presumptive and diagnosed TB
- Provide co-trimoxazole preventive therapy for TB patients living with HIV
- Ensure HIV prevention interventions, treatment and care for TB patients living with HIV
- Provide antiretroviral therapy for TB patients living with HIV.

universal access

Universal access implies maximal coverage of TB prevention, treatment, care, and support services for those who require them. Basic principles for scaling up towards universal access are that services must be equitable, accessible, affordable, comprehensive, and sustainable over the long term. Because different settings often have distinctly different needs, targets for universal access are set nationally.

vulnerability

Vulnerability refers to unequal opportunities, social exclusion, unemployment, or precarious employment and other social, cultural, political, and economic factors that make a person more susceptible to TB. The factors underlying vulnerability may reduce the ability of individuals and communities to avoid TB risk and may be outside the control of individuals. These factors may include: lack of the knowledge and skills required to protect oneself and others; accessibility, quality, and coverage of services; and societal factors such as human rights violations or social and cultural norms. These norms can include practices, beliefs, and laws that stigmatize and disempower certain populations, limiting their ability to access or use TB prevention, treatment, care, and support services and commodities. These factors, alone or in combination, may create or exacerbate individual and collective vulnerability to TB.

XDR-TB

See extensively drug-resistant TB.