

WHO

operational  
handbook on  
tuberculosis

Module 4: Treatment

Tuberculosis care  
and support



World Health  
Organization



# WHO operational handbook on tuberculosis

Module 4: Treatment

**Tuberculosis care  
and support**

WHO operational handbook on tuberculosis. Module 4: treatment - tuberculosis care and support

ISBN 978-92-4-005351-9 (electronic version)

ISBN 978-92-4-005352-6 (print version)

© World Health Organization 2022

Some rights reserved. This work is available under the Creative Commons Attribution-NonCommercial-ShareAlike 3.0 IGO licence (CC BY-NC-SA 3.0 IGO; <https://creativecommons.org/licenses/by-nc-sa/3.0/igo>).

Under the terms of this licence, you may copy, redistribute and adapt the work for non-commercial purposes, provided the work is appropriately cited, as indicated below. In any use of this work, there should be no suggestion that WHO endorses any specific organization, products or services. The use of the WHO logo is not permitted. If you adapt the work, then you must license your work under the same or equivalent Creative Commons licence. If you create a translation of this work, you should add the following disclaimer along with the suggested citation: "This translation was not created by the World Health Organization (WHO). WHO is not responsible for the content or accuracy of this translation. The original English edition shall be the binding and authentic edition".

Any mediation relating to disputes arising under the licence shall be conducted in accordance with the mediation rules of the World Intellectual Property Organization (<http://www.wipo.int/amc/en/mediation/rules/>).

**Suggested citation.** WHO operational handbook on tuberculosis. Module 4: treatment - tuberculosis care and support. Geneva: World Health Organization; 2022. Licence: CC BY-NC-SA 3.0 IGO.

**Cataloguing-in-Publication (CIP) data.** CIP data are available at <http://apps.who.int/iris>.

**Sales, rights and licensing.** To purchase WHO publications, see <http://apps.who.int/bookorders>. To submit requests for commercial use and queries on rights and licensing, see <https://www.who.int/copyright> <http://www.who.int/about/licensing>.

**Third-party materials.** If you wish to reuse material from this work that is attributed to a third party, such as tables, figures or images, it is your responsibility to determine whether permission is needed for that reuse and to obtain permission from the copyright holder. The risk of claims resulting from infringement of any third-party-owned component in the work rests solely with the user.

**General disclaimers.** The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of WHO concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted and dashed lines on maps represent approximate border lines for which there may not yet be full agreement.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by WHO in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

All reasonable precautions have been taken by WHO to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either expressed or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall WHO be liable for damages arising from its use.

Design by Inis Communication

# Contents

Acknowledgements .....	v
Abbreviations .....	vi
Definitions .....	vii
<b>1. Introduction .....</b>	<b>1</b>
<b>2. People-centred approach .....</b>	<b>3</b>
<b>3. Care and support interventions to enable TB treatment adherence .....</b>	<b>5</b>
3.1. Social support in TB management .....	6
3.2. Treatment administration and digital adherence technologies .....	11
3.3. Selecting a suitable package of care and support for a patient .....	14
<b>4. Health education and counselling for people affected with tuberculosis .....</b>	<b>17</b>
4.1. Guiding principles for health education and counselling .....	18
4.2. Effective communication skills to provide health education and counselling .....	18
4.3. Counselling to provide information about TB and the responsibilities of affected individuals and communities .....	22
4.4. Counselling to provide information about TB treatment and to ensure adherence to treatment .....	25
4.5. Counselling to provide psychological support .....	29
4.6. Counselling on nutritional care and support .....	32
4.7. Counselling at the end of TB treatment and on palliative care .....	33
<b>5. Models of care for TB services .....</b>	<b>37</b>
5.1. Models of care for all TB patients .....	37

5.2. Decentralized and integrated family-centred models of TB care for children and adolescents .....	42
5.3. Models of service delivery for people with TB, HIV and comorbidities.....	45
5.4. Private-sector involvement in TB care.....	46
5.5. TB and health emergencies .....	46
<b>6. Palliative care.....</b>	<b>49</b>
6.1 What is palliative care?.....	49
6.2. Planning and implementing palliative care for people affected by TB .....	51
6.3. End-of-life care for people with TB.....	55
<b>References.....</b>	<b>59</b>

# Acknowledgements

This operational handbook was prepared and coordinated by Linh Nguyen and Fuad Mirzayev, with input from Ernesto Jaramillo and Matteo Zignol, and under the overall direction of Tereza Kasaeva, Director, WHO Global Tuberculosis Programme. The WHO Global Tuberculosis Programme gratefully acknowledges the contributions of all experts involved in the production of the latest updates of the WHO guidelines on tuberculosis care and support, on which this handbook is based, as well as other contributors listed below.

WHO staff and experts who contributed to the drafting of the handbook include the following:

- Elizabeth Haraus drafted Chapter 1 (Introduction), Chapter 3 on care and support interventions to enable TB treatment adherence, including material support and companionship support, treatment support, selecting an optimal treatment plan and a suitable package of care and support for a patient (sections 3.1.3, 3.1.4, 3.2.1 and 3.3), and sections 5.1, 5.3 and 5.4 on models of care for TB services.
- Asma Humayun drafted Chapter 2 on people-centred care, Section 3.1 on social support, including introduction, information and educational support, psychological and emotional support (sections 3.1.1 and 3.1.2), and Chapter 4 on health education and counselling.
- Dennis Falzon drafted Section 3.2.2 on digital health technologies.
- Eric Krakauer drafted Chapter 6 on palliative care and provided input to Section 4.7.2 on counselling on palliative care.
- Kerri Viney contributed to adapting Section 5.2 on decentralized and integrated family-centred models of TB care for children and adolescents from the chapter on models of TB care for children and adolescents in the *WHO operational handbook on tuberculosis. Module 5: management of tuberculosis in children and adolescents*, which was originally written by Moorine Sekkade (National TB and Leprosy Programme, Uganda), with contributions from Annemieke Brands, Monica Diaz, Dennis Falzon, Ernesto Jaramillo, Farai Mavhunga, Liana Oganezova, Sabine Verkuijl and Kerri Viney, and Section 5.3 on models of service delivery for people with TB, HIV and comorbidities from a respective chapter in the *WHO Framework for Collaborative Action on TB and Comorbidities*, which was written by Annabel Baddeley and Anna Carlqvist with contributions from Kerri Viney and Farai Mavhunga.

Peer reviewers of this handbook include: Anurag Bhargava (Yenepoya Medical College Hospital, Mangalore, India), Yuliya Chorna (WHO Civil Society Taskforce, TB Europe Coalition, Ukraine), Mike Frick (Treatment Action Group, United States of America) and Carrie Tudor (International Council of Nurses, South Africa), as well as Vineet Bhatia (WHO Regional Office for South-East Asia, India), Ireneaus Sebit Sindani (WHO Country Office, Somalia), and Medea Gegia, Ernesto Jaramillo, Avinash Kanchar, Lana Syed and Kerri Viney (WHO Global Tuberculosis Programme, Switzerland).

Production of the handbook was funded by grants provided to WHO by the United States Agency for International Development (USAID).

# Abbreviations

<b>AIDS</b>	Acquired immunodeficiency syndrome
<b>DR-TB</b>	Drug-resistant tuberculosis
<b>DS-TB</b>	Drug-susceptible tuberculosis
<b>EMM</b>	Event monitoring device for medication support
<b>HCW</b>	Health-care worker
<b>HIV</b>	Human immunodeficiency virus
<b>IMCI</b>	Integrated management of childhood illness
<b>MDR-TB</b>	Multidrug-resistant tuberculosis
<b>NTP</b>	National tuberculosis programme
<b>PHC</b>	Primary health care
<b>PTB</b>	Pulmonary tuberculosis
<b>SDG</b>	Sustainable Development Goals
<b>SMS</b>	Short Message Service or text message
<b>TB</b>	Tuberculosis
<b>VST</b>	Video-supported treatment
<b>TPT</b>	Tuberculosis preventive treatment
<b>WHO</b>	World Health Organization
<b>XDR-TB</b>	Extensively drug-resistant tuberculosis



# Definitions

**People-centred (or person-centred) care** is defined as “providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions”.

**Social support** in this document is defined as support to TB patients that includes informational and educational support (health education and counselling), psychological or emotional support, material support and companion support.

**Treatment adherence interventions** include social support such as: patient education or information support and counselling; material support (e.g. food, financial enablers, transport fees); psychological support; tracers such as home visits or digital health communications (e.g. short message service [SMS], telephone calls); medication monitors; and staff education. The interventions should be selected on the basis of the assessment of the individual patient’s needs, values and beliefs, and the provider’s resources and conditions for implementation.

**Treatment administration options** include: various suitable forms of treatment support, such as regular community- or home-based treatment support and video-supported treatment; and less preferable forms of treatment administration such as health facility-based treatment support and self-administered or unsupervised treatment.

**Treatment support** terminology in this document is used to describe an approach to supporting patients who are taking prescribed doses of TB medicines in order to help ensure adherence to treatment and maximize its efficacy. Treatment support needs to be provided in the context of people-centred care and should be based on the individual patient’s needs, acceptability and preferences. It includes aspects of support for, and motivation and understanding of, patients without coercion. Historically, this group of interventions were labelled as “directly-observed treatment”.



# 1. Introduction

Tuberculosis (TB), including its drug-resistant forms, can affect people in all parts of society. However, its effects are often most devastating among the poorer and more marginalized members of a society. A person's quality of life, social status and financial situation can be made worse both by the disease and by its treatment, namely: adverse drug reactions produced by the treatment, the high costs he or she may have to pay while undergoing care and treatment, having to miss work due to illness, and the stigma and discrimination linked to the disease. People who are poorer or have less social support may suffer these effects the most because they may have fewer resources to help them through the illness. The delivery of person-centred care and social support is essential to the management of TB and should protect human rights and support ethical standards, reducing the patient's and family's social and economic costs and using the most effective methods to prevent and treat the disease. Person-centred care and social support also contribute to improving the treatment outcomes and quality of life of people with TB. In many cases it also makes a difference in enabling the patient and family to access health care.

This module addresses the person-centred care approach to treatment administration and the social support framework for programmatic management of TB – both aimed at improving the quality of life of patients, enabling their adherence to treatment and reducing social and economic costs. The scope of the social support recommended in this operational handbook includes several elements of the social assistance recommended in forthcoming guidance on social protection for people affected by TB. This module, however, emphasizes the interventions recommended to improve TB treatment outcomes.



## 2. People-centred approach

In view of the high burden of disease, death and suffering associated with TB, Standard 9 of the *International standards for tuberculosis care (1)* states: "A patient-centred approach to treatment should be developed for all patients in order to promote adherence, improve quality of life, and relieve suffering. This approach should be based on the patient's needs and mutual respect between the patient and the provider." In 2016, the World Health Organization (WHO) advocated a people-centred care approach which is focused on, and organized around, the health needs and expectations of people and communities rather than focusing on patients or diseases (2). As a result, a people-centred model of TB care was defined as "an efficient and integrated set of affordable, accessible and acceptable health services, provided in a supportive environment to prevent, diagnose and treat TB" (3).

A people-centred (also referred as person-centred in this section) approach recognizes that TB care should be designed to address the needs, values and preferences – and protect the rights of – the people who suffer from TB in order to ensure successful treatment outcomes and improve their well-being and financial risk protection. People-centred or person-centred care "reflects care that is holistic, individualised, respectful and empowering, and considers the person as central to the process of care, encouraging informed, shared decision-making and self-determination. It means that a person and a health-care provider work together, discussing care options, treatment risks and benefits, to reach collaborative care decisions. Rather than being a passive recipient of health-care, the person is an active participant." (4).

In contrast to a disease-centred approach where the focus was on medication treatment only, a people-centred approach also focuses on supporting people to overcome the social economic, cultural, legal and psychological difficulties that can affect their response to the diagnosis and treatment of TB. Through person-centred care, the patient with TB is the most important person in the care plan; therefore the social and personal needs and preferences of the patient – not just the immediate requirements of medical treatment – are also focused on. This approach should also allow people to know and use their patient rights and fulfil their treatment responsibilities while being treated with respect and dignity and having their values and needs reflected in their treatment and care whenever possible.

Person-centred care is defined as "providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions". Pillar 1 of the End TB Strategy (5) clearly endorses this approach which treats patients as the most important element when providing TB treatment.

A people-centred approach focuses on the overall well-being, choices, convenience and safety of the individual patient. Thus, it takes account of the social and personal circumstances of the person, and not just the immediate requirements of medical treatment (6). A people-centred approach helps to build a partnership between the people suffering from TB and health-care providers, allowing care to be adapted to individual patient needs with the goals of improving the ability of patients to take all their medications and curing them from TB. The ability of a person to take all their medications is influenced by a number of factors, namely: the person's knowledge, attitudes and beliefs about the disease, the treatment and the health-care system; family experiences and beliefs; economic concerns (e.g. the ability of a patient to pay the costs associated with treatment); the health-care system's ability to support the patient; and available community resources to deal with the stigma and discrimination surrounding TB. These concerns can be resolved by making sure that patients have the support they need to complete their treatment. The types of support are described later in the module.

TB care is not just about the science of treatment but also about human rights and social justice. The ethical values recommended for TB programmes include equity, the common good, solidarity, reciprocity, the harm principle, trust and transparency, the duty to care, effectiveness, efficiency, proportionality, participation and community engagement, respect and dignity, autonomy, privacy and confidentiality (7).

Frequently, TB most strongly affects people who are already marginalized and can worsen existing inequalities and discrimination. The marginalized include persons who are homeless, persons who use drugs, persons living with HIV, people who are incarcerated, indigenous persons and undocumented migrants. These persons experience stigma and discrimination in their day-to-day lives and care must be taken to ensure that this is not worsened in the context of TB. In addition, health-care providers should keep in mind that gender may also be a driver of stigma in people with TB (8).

The violation of human rights of people with TB is well recognized (9, 10). Persons with TB often experience stigma and discrimination in many areas of life, including work, social activities and family life. They may also have difficulties in following medical advice due to social, economic, cultural and legal reasons. Consequently, it is important that the health-care services are aware of all the barriers faced by people affected by TB and provide appropriate and comprehensive social support to help them cope successfully with the hardships of treatment. TB stigma can be defined as the negative labelling or rejection of people with TB, and often also their families, due to stereotyping or other negative traits associated with TB and the affected communities. As a result of a diagnosis of TB, people may experience feelings of shame, self-hatred, guilt or blame which may affect their ability to accept the diagnosis and to follow their care and treatment plans.

Health-care workers may also be prejudiced against people with TB, and this may affect their interactions with patients with TB. They may do things that further stigmatize these patients, either through how they interact with the patient, the language they use or even the practices that are built into the health-care system. If health-care providers are not well supported and TB services lack resources, the health-care workers may feel undervalued, which may reinforce stigma and prevent them from delivering quality care. Fear of infection can also serve as a driver of stigma in health-care workers and may have an adverse impact on their relationships with people affected by TB.

In order to support people with TB during their treatment, health policies must reflect the fact that TB affects all aspects of peoples' lives. Caring for each person as an individual should be the basis of treatment and care. The following principles can be followed for person-centred care and support (11, 12):

1. Focus on the patient's concerns and priorities.
2. Refer to the 5 A's aspects of care: Assess, Advise, Agree, Assist and Arrange.
3. Link the patient with a suitable TB treatment supporter.
4. Screen, assess and manage undernutrition.
5. Recognize and address poverty and food insecurity by linking TB patients to national social protection measures and ensure their inclusion in appropriate national legislation.
6. Organize proactive follow-up and maintain regular communication with the patient in order to work as a team.
7. Involve former patients, peer educators and health-care workers providing support in health facilities or communities.
8. Link the patient to community-based resources and support.
9. Provide integrated care in collaboration with other public health programmes, such as those for HIV, diabetes care, maternal and child health, lung health and mental health services.
10. Assure continuity of care, including palliative and end-of-life care whenever needed.

Although building person-centred high-quality TB care as outlined in the *International standards for tuberculosis care* will often require additional human resources, a lot can be achieved by training health-care providers to respect patients' rights and by developing communication skills to involve patients and their families actively in TB care (5, 13, 14).

# 3. Care and support interventions to enable TB treatment adherence

Ensuring adherence to TB therapy is one of the important challenges for achieving a successful treatment outcome, particularly for patients with drug-resistant TB (DR-TB). This is because of the large number of medications, the frequent and serious adverse drug reactions, and the social and financial costs to patients related to TB treatment. Because DR-TB and extensively drug-resistant TB (XDR-TB) treatment are often the last chance for treatment for many patients, and because there are serious public health consequences if treatment fails, it is important that all patients are supported using a person-centred approach to ensure full adherence to treatment (7).

Good adherence to TB treatment (taking all the medications at the correct time) is essential to prevent the development of resistance and increase the chances of cure. Taking all the medications for TB therapy is difficult, particularly for DR-TB, because treatment regimens can sometimes be long, the daily pill burden is high, there are frequent and serious adverse drug reactions, and access to care can cause social and economic costs to patients. A person-centred approach is needed to maximize treatment adherence and enable early intervention with patients who are not responding to treatment, who are not able to take their medications or who are having adverse effects from treatment. Optimal person-centred care consists of multiple interventions, including social support (informational/educational, psychological and emotional, and material support), treatment administration options and digital adherence technologies. Staff education and support that allow health-care workers to provide health education and counselling on TB disease and treatment adherence are strongly recommended. It is also recommended that all patients receive medicines under an appropriate treatment administration option and that they benefit from social support interventions that ensure full adherence to treatment, with a person-centred approach based on sound ethics and with respect for human rights.

National TB programmes (NTPs) need to improve patient access to quality treatment adherence interventions and optimal treatment administration options. Although all people with TB should receive appropriate care and support interventions, particular attention should be paid to patients being treated for DR-TB because DR-TB treatment is often the last therapeutic option for many patients and there are serious public health costs if treatment fails.

The following recommendations from the WHO guidelines on TB care and support (15, 16) continue to apply to patients with drug-susceptible (DS) and drug-resistant (DR) TB.

## Recommendations:

- 1.1. **Health education and counselling on the disease and treatment adherence should be provided to patients on TB treatment** (*strong recommendation, moderate certainty of evidence*).
- 1.2. **A package of treatment adherence interventions<sup>1</sup> may be offered for patients on TB treatment in conjunction with the selection of a suitable treatment administration option<sup>2</sup>** (*conditional recommendation, low certainty of evidence*).
- 1.3. **One or more of the following treatment adherence interventions (complementary and not mutually exclusive) may be offered to patients on TB treatment or to health-care providers:**
  - a) **tracers<sup>3</sup> and/or digital medication monitor<sup>4</sup>** (*conditional recommendation, very low certainty of evidence*)
  - b) **material support to patient<sup>5</sup>** (*conditional recommendation, moderate certainty of evidence*)
  - c) **psychological support<sup>6</sup> to patient** (*conditional recommendation, low certainty of evidence*)
  - d) **staff education<sup>7</sup>** (*conditional recommendation, low certainty of evidence*).
- 1.4. **The following treatment administration options may be offered to patients on TB treatment:**
  - a) **Community- or home-based treatment support is recommended over health facility-based treatment support or unsupervised treatment** (*conditional recommendation, moderate certainty of evidence*)
  - b) **Treatment support administered by trained lay providers or health-care workers is recommended over treatment support administered by family members or unsupervised treatment** (*conditional recommendation, very low certainty of evidence*)
  - c) **Video-supported treatment (VST) can replace in-person treatment support when the video communication technology is available and can be appropriately organized and operated by health-care providers and patients** (*conditional recommendation, very low certainty of evidence*).

### 3.1. Social support in TB management

TB causes suffering and even death. Despite highly effective treatment, there are many psychological, social, medical and economic factors that can prevent people from accessing diagnosis, following care plans and successfully completing a course of treatment. The following is an adapted summary

<sup>1</sup> Treatment adherence interventions include: social support such as patient education and counselling; material support (e.g. food, financial enablers, transport fees); psychological support; tracers such as home visits or digital health communications (e.g. SMS, telephone calls); medication monitoring; and staff education. The interventions should be selected on the basis of an assessment of the individual patient's needs, the provider's resources and the conditions for implementation.

<sup>2</sup> Suitable treatment administration options include various forms of treatment support, such as video-supported treatment and regular community- or home-based treatment support.

<sup>3</sup> Tracers refer to the communication with the patient, including home visits or via SMS, telephone (voice) calls.

<sup>4</sup> A digital medication monitor is a device that can measure the time between openings of the pill box. The medication monitor can have audio reminders or send an SMS to remind the patient to take medications, along with recording when the pill box is opened.

<sup>5</sup> Material support can be food or financial support such as: meals, food baskets, food supplements, food vouchers, transport subsidies, living allowance, housing enablers, or financial bonus. This support addresses indirect costs incurred by patients or their attendants in order to access health services and, possibly, tries to mitigate consequences of income loss related to the disease.

<sup>6</sup> Psychological support can be counselling sessions or peer-group support.

<sup>7</sup> Staff education can be adherence education, charts or visual reminders, educational tools and desktop aids for decision-making and reminders.



of how these factors may have an impact on psychological health, health-seeking behaviour and adherence (8):

1. Stigma, fear of discrimination, social isolation and lack of social support can affect screening, access to care and the ability to complete a treatment plan.
2. The poorest and most marginalized communities that are at high risk of TB are also most likely to experience significant health and economic inequalities which further limit their access to care and treatment.
3. The diagnosis of TB may cause distress and have an impact on self-worth that may affect patients' sense of agency.
4. Financial worries and limitations on everyday activities associated with TB (e.g. time off work) and its treatment (e.g. diagnostic and treatment costs, transport costs) add to the burdens on the patients.
5. Long treatment duration may cause frustration and possible side-effects may make treatment intolerable or unpleasant, leading people to interrupt treatment.
6. Life situations (e.g. financial challenges, a death in the family or marital difficulties) may have a negative impact on psychological health and on patients' ability to take their medication.
7. TB often presents with comorbidities (e.g. diabetes, HIV/AIDS) which may cause further difficulties for the patient.
8. People with TB may also have mental disorders – such as opioid or alcohol use disorders or depression – that may complicate their ability to adhere to treatment or tolerate medication without additional support. Similarly, some TB medications may also worsen mental health conditions.
9. Poor-quality medical care without rights-based, people-centred and respectful care can also add to the psychological burden of illness and treatment.
10. When treatment fails, people grieve and may suffer and feel hopeless.
11. Lack of support from services, friends and family may harm the patient's emotional health.
12. TB and its long-term treatment affect families and caregivers. Their anxieties and burden of work taking care of the patient can make it difficult to support treatment adherence, infection control and the patient's needs over time.

Several populations are particularly vulnerable to TB and at higher risk of having poor outcomes, namely: children, miners, migrant populations, people who are incarcerated, and people who suffer from opioid or alcohol use disorders. Health-care providers who deal with vulnerable populations need to have skills to assess and respond to the psychological and social needs of these people when TB is detected (17).

Social support is very important to a people-centred approach to improve the well-being of people infected with TB and to support treatment plans by addressing the barriers described above. Social support must be available for people throughout TB treatment, from diagnosis to the conclusion of the treatment.

Social support refers to the amount of perceived and practical care received from family, friends and/or the community (18). It aims to provide care to patients to show that they are part of a social network that cares for them. Social support improves health outcomes and reduces death. Adding social support to the medication treatment regimens can improve treatment outcomes for people suffering from TB (15, 16).

Social support is made up of four resources, namely (11):

1. Informational support is information or education that helps a person to solve problems and reduce stress; it includes training and education on the medications a person is taking, their possible side-effects, how treatment is monitored, and how the success of treatment is determined.

2. Psychological (emotional) support refers to all types of care that strengthen self-esteem through understanding, trust, encouragement and care, and that help to deal with the psychological challenges in life.
3. Material support includes financial support which could be money (e.g. grants from the government), food support, travel support or anything that helps the patient with the financial costs of TB disease and its treatment.
4. Companionship support is help that makes a person feel that he or she belongs to the social system, and that he or she can rely on it for certain needs.

Creating a way for the TB programme to deliver these four social support resources to patients, taking into consideration any specific age- or gender-sensitive concerns, is necessary for a person-centred approach that makes sure patients are doing well and can complete their TB treatment. The principles of social support described here should be ensured for vulnerable populations, including older persons, people who are incarcerated, internally displaced persons or refugees, people with substance use disorders, indigenous communities and ethnic minorities.

Many programmes use a multidisciplinary “support to adherence” team (social workers, nurses, health educators, community treatment supporters and doctors). Support may focus on problems related to different stages of treatment, social stigma of the illness, treatment adherence, side-effects, financial and social difficulties, other comorbidities or special situations and death.

The type of support should be selected on the basis of an assessment of the patient’s needs, the health provider’s resources and conditions in the community. A single type of support or a combination of different types of social support can be chosen for each patient according to the individual needs. Social support should be available to people in in-patient or out-patient care, including home- or community-based treatment and care, peer support and community TB support programmes.

### 3.1.1 Informational and educational support

This support includes all information necessary to help patients and their caregivers understand TB, including the biological and social determinants of the disease, and agree on the steps for following the treatment plan and participating in local activities to engage communities in the response to TB. As an example, the Guide on the standardized package of community-based support services to improve TB outcomes describes many of the possible services for adherence support in detail (19). Provision of information and education should begin as soon as diagnosis is made and should continue throughout the course of treatment. Patient information and education take place over several visits with different health-care providers, including physicians, nurses and community health workers. Materials should be appropriate to the literacy levels of the patient, available in local languages and should be gender-, age- and culturally-sensitive. Information and educational pamphlets with reminders of the main points, in the local language, are helpful. For patients with literacy limitations, efforts should be made to use e-health tools based on audio or visual support.

Patients should also be provided with material to help them understand their rights in their local language (9, 10). The Patients’ Charter for Tuberculosis Care also describes the responsibilities of patients and will help the provider to educate the patient about the disease, the treatment and the overall response of the government and civil society to the TB epidemic.

The NTP and all health-care providers should use methods of “communicating with” (and not “talking at”) patients and their caregivers in a way that builds a positive partnership towards successful improved quality of life and treatment completion. For patients with literacy limitations, e-health tools based on audio or visual support should be used.

Although implementing patient-centred high-quality TB care as outlined in the *International standards for tuberculosis care (1)* will often require additional time to be spent by health-care workers, a lot can

be achieved with simple changes in the attitudes and language used by health-care providers and by communicating key information about the disease.

The ethical and person-centred approach of the End TB Strategy is to be reflected as well in the language used by all TB stakeholders, including health care providers. Language is a well-known method of exerting power and control. Words such as “defaulter”, “suspect” and “control” contribute to disempowering TB patients despite the good intentions of the health-care providers. It is still not uncommon to find expressions such as “patient failed treatment”, which puts the blame only on the patient as if he or she were the only person responsible for failure of treatment. WHO has recommended replacing such language with words that are more respectful of patients and reflect better the values of the patient-centred approach to care that is now widely accepted in the TB community. Some examples include replacing “defaulter” with “person lost to follow-up”, “TB suspect” with “person with suspected TB” or “person to be evaluated for TB”; and “control” with ‘prevention and care’. This handbook and future TB documents of WHO are taking note of this suggestion to prevent derogatory and judgemental tones in the language used with patients and within TB prevention, diagnosis, treatment and care (20). For further details, see Section 4.2 on Effective communication skills and Section 4.3 on Counselling to provide information.

### 3.1.2 Psychological and emotional support

Dealing with TB and its treatment can be emotionally devastating for patients and their families. As a result, there is immense distress that affects the quality of life of patients and that may also interfere with the way they follow their treatment.

Emotional support usually refers to having close relationships with family and friends, with whom one can talk and feel loved and cared for. Psychological support is based on a skill set whereby trained personal can help alleviate distress. Psychological support tries to help with thought, emotional and behavioural concerns that may arise because of the stress of being diagnosed with TB, because of the treatment, or because of other life situations or stresses caused by TB. Informal psychological support can be provided by physicians, nurses, treatment supporters, family or community members by building a relationship with patients based on understanding and compassion to help them deal with psychological challenges in life, solve problems and lessen sources of stress. This kind of support may also help patients to follow their treatment plans and gain the skills needed to deal with stigma and discrimination. Details of techniques to provide psychological support are further discussed in Section 4.5.

For formal psychological support – particularly if informal support is not successful, the impact of the challenges is severe or mental health problems are suspected (e.g. depression, substance and alcohol misuse, and persons experiencing post-traumatic stress disorder) – some TB patients may need to be referred to mental health services. There is also a close association between common mental disorders, including substance use disorders, which is described in Section 4.5. Therefore, it is essential to have a comprehensive assessment and referral system between TB, mental health services and community support.

Formal methods of providing psychological support can be one-to-one counselling sessions or support groups assisted by counsellors. Support groups may allow patients with TB to meet and socialize with other patients, including those who have recovered from TB, and provide support to each other as well. Further details are discussed in Section 4.5 on Counselling to provide psychological support.

## Support group

A support group should be guided by a counsellor, social worker or someone trained in guiding support groups. A trained community nurse or health worker may also help with the group.

- Some groups may be for patients with specific needs or concerns (e.g. women, young people).
- Psychological support is important for patients who may still be infectious, and infection control measures should be established to enable such persons to gather in support groups safely or in a way that minimizes the risk of TB transmission to other patients or health-care staff (e.g. outdoor or virtual meetings).
- Patients who have recovered may also be invited to support groups as they provide hope to patients who are still on treatment.
- Support groups may need help in inviting participants or finding a safe meeting place and may face other organizational challenges.
- At the end of each support group meeting, the facilitator and co-facilitator should stay behind to discuss and evaluate the lessons learned in the process and to plan the next session.

For patients with serious psychological problems, the group may require to be facilitated by an appropriately trained mental health professional.

### 3.1.3 Material support

Socioeconomic problems should be addressed to enable patients and their families to be able to complete TB treatment and reduce the impact that the disease and treatment have on their quality of life. These challenges can be successfully tackled through socioeconomic interventions, such as food baskets or transportation vouchers, that enable patients to complete the treatment and which usually work best when they are adapted to a patient's specific needs. Some NTPs and health-care providers have used these as enablers – i.e. as a means to help patients to address hurdles in taking medication and completing therapy. While enablers may improve outcomes, it is most important to use material support to overcome barriers that otherwise would be impossible for patients to overcome without some form of support.

Material support can be services or commodities – e.g. financial support, food baskets, food supplements, food vouchers, transport subsidies, living allowance, housing enablers or cash transfer. This support helps patients or caregivers with the costs they face in order to obtain health services and tries to lessen the stress of income loss related to TB. At the beginning of treatment, the financial resources of the patient should be evaluated in order to support those in need of assistance using material support. The most support should be given to patients with the most need. Health-care workers, treatment supporters, social workers or other professionals can help evaluate needs and make sure the material support reaches the patient. Cash transfers and microfinance support can improve household food security, which has been shown to increase access to health care. When prolonged hospitalization is necessary, supporting the patient and their family financially with a minimum “living-allowance” would be a helpful step under the patient-centred care approach.

Nutritional support is particularly important and can be part of material support. Not only does nutritional support help to lessen the financial stress of TB disease, but malnutrition/undernutrition can make TB disease worse, and TB can cause malnutrition. People who are malnourished/undernourished and who have TB disease are more likely to have worse outcomes and are more likely to die of TB than others. Children and pregnant/lactating women are at particular risk from malnutrition. Treatment of

malnutrition/undernutrition through material support should be considered just as important as other TB medications when managing patients with TB. Indeed, nutritional support should be included as part of a standard treatment and care plan for TB. Further details on nutritional care and support can be found in the *Guideline: nutritional care and support for patients with tuberculosis (21)* and *WHO framework for collaborative action on tuberculosis and comorbidities (22)*.

The involvement of civil society – such as patient support groups and nongovernmental organizations, as well as community- or faith-based organizations – is necessary to provide social support services. A more long-term way to provide material support to TB patients is to include all patients who qualify in the social protection programmes (such as unemployment benefits if the patient cannot work) that many countries have for vulnerable populations.

### 3.1.4 Companionship support

On-site social support for patients, their families and friends through peer counselling can improve the effectiveness of TB programmes. TB programmes can develop support activities that identify patients who have been cured (“community champion” or “ex-patient”) and provide them with training to be a peer supporter. This worker engages in support, treatment literacy and communication with other patients under treatment. These community champions or ex-patients should follow each patient from diagnosis through to cure, and they should act as both friend and educator. From the patient’s perspective, having this companion available reduces the psychological burden of the long duration of treatment and provides them with skills to cope with TB stigma and discrimination.

Peer support groups, community champions or ex-patients and trained health workers can offer information-sharing sessions to educate patients, help with better detection of risk factors for default (e.g. understanding adverse effects of medication) and identify other warning signs that can affect treatment outcome.

Companionship support provides the basis for developing a social network within the care facility, which can play an essential role in improving rates of treatment completion. Working together, a health worker, a peer supporter and the patient can build a spirit of collaboration and innovation aimed at reducing stigma and can reaffirm that TB can be successfully treated within an environment of mutual respect among all involved.

## 3.2. Treatment administration and digital adherence technologies

### 3.2.1 Treatment support

Treatment administration options that are effective and suitable should be considered for each patient at the start of the patient’s treatment. Treatment support (an updated adaptation of directly observed treatment) is defined as another person (either a health-care worker or a lay person) helping a patient with TB take his/her TB medications, providing emotional support and medical intervention (or recognizing when medical intervention is necessary) in the case of non-response to therapy or adverse effects from treatment. However, some subgroups of patients with factors affecting treatment adherence are more likely or less likely to benefit from certain forms of treatment support than other patients are; or certain types of delivery of treatment support (e.g. location of treatment support or type of treatment support provider) are likely to work better than others. Consequently, an assessment is required at the start of treatment in order to choose the most appropriate treatment administration option for each patient. Treatment provided closer to the patient normally offers convenience for the patient and, therefore, achieves better outcomes. Treatment support delivered at home or in the community, near the patient’s home or workplace, should be considered as the preferred options as

they have shown better outcomes than treatment support provided at a health-care facility, which is normally further away from the patient than the other options (15, 23).

The TB treatment supporter should maintain strict confidentiality regarding the patient's disease and treatment. In some cases, this may require working out a system whereby the patient can receive medication without the knowledge of others. The TB treatment supporter should be someone whom the patient is comfortable with. The TB treatment supporter should have the appropriate training and skills. Although evidence shows that treatment support by a health-care worker, trained lay provider and family member displays advantages compared to unsupervised treatment, treatment support provided by trained lay providers and health-care workers are the preferred options and the least preferred treatment support provider is a family member (15).

In some settings and circumstances treatment support may be provided by health workers and in others by community members trained to deliver treatment for all forms of TB. While family-based treatment support has shown effectiveness in several settings, health-care workers should be aware that family relationships can be complicated for the TB patient, and as a result either the patient or the family TB treatment supporter may encounter subtle manipulation or abuse that can jeopardize adherence to treatment, management of adverse drug reactions and access to social support services. Training and education for health-care workers and treatment support providers are necessary to ensure the quality of treatment administration. Training and education can be done through many types of educational sessions, charts or visual reminders, educational tools and desktop aids for decision-making and reminders.

When in-person treatment support is not possible for the patient and treatment provider, digital adherence technologies, such as video-supported treatment (VST), short message service (SMS), telephone calls or other means of communication can be considered when they are available and can be used by both health-care providers and patients.

### 3.2.2 Digital adherence technologies

Various digital health products are being used to support different elements of TB programmes, such as electronic health records, direct data transfer from diagnostic systems and eLearning modules on mobile applications (24). Digital adherence technologies fit into the larger landscape of information technologies and are intended to help improve communication between patients and health-care workers (25). Three technologies have been studied in TB patients and are used to support treatment on a large scale, namely SMS or mobile text, event monitoring devices for medication support (EMMs) and VST for TB (26, 27).

SMS is a standard, built-in function found in all types of mobile telephones worldwide and is generally inexpensive and easy to use. It is thus widely applied for communicating with outpatients. SMS can provide regular, automated message reminders to patients to take their medications, can provide information related to their health or condition (unidirectional) or provide opportunities to interact as well (bidirectional). Most randomized controlled trials of SMS reminders in TB care in different geographical settings failed to show improved patient outcomes when compared with standard care. However, the control groups in these trials achieved high levels of adherence through varying scales of in-person support. The results also suggest that SMS could, to some degree, support adherence at times during treatment when in-person treatment support by a health-care provider is not possible, thus increasing efficiency if not effectiveness. SMS could also be used when there is less necessity to see the patient face to face but there is still a need to keep in contact with the patient in case any concerns arise, such as during the continuation phase of treatment or when a patient has been on stable treatment for a long time without any problems. Research has yet to look more creatively at how SMS can influence adherence behaviour other than just by reminding people to take their pills, such as by channelling cash transfers when treatment milestones are achieved, by combining SMS reminders with other digital solutions and by targeting other points along the patient pathway. The

popularity and affordability of SMS present a compelling case for further studies to investigate its potential more exhaustively. Instant messaging via installed mobile software may be used instead of SMS.

EMMs aim to provide more patient flexibility when following up treatment; to support patients with dosing and refill reminders and instructions; and to compile patient-specific dosing histories to enable counselling and differentiated care. EMM boxes consist of automated electronic devices that record and inform the health-care provider about the regularity with which a medicine container is opened. Older devices recorded usage on the container itself, but mobile telephones now allow patient reminders and alerts to be sent to the caregiver when medicine boxes remain unopened for a day or more. A large cluster-randomized trial showed a statistically significant effect of EMM boxes on adherence relative to the standard of care; however, the effect on successful treatment completion was less clear (28). Various technological advances with EMMs, such as requiring patients to dial in (to toll-free numbers) codes revealed when daily blister packs of medications are opened can be used to verify adherence. Under trial, a prototype brand of this technology – 99DOTS (29) – showed similar treatment completion rates when compared to the traditional adherence monitoring and support used by the sites, suggesting that this EMM could be a viable alternative to more labour-intensive forms of medication adherence monitoring (30). Nonetheless, more evaluation is needed of the feasibility and utility of this technology (31).

VST is the form of digital adherence technology that most closely replicates human interaction. The increasing availability of Internet-enabled smartphones and tablet computers equipped with free or customized video communication software has increased options for both real-time (synchronous) and recorded (asynchronous) interactions. Observational studies and trials of VST for TB treatment from different settings suggest that the technique can produce similar outcomes to those produced by in-person monitoring and can improve efficiency (32–35). Given the potential benefits of VST, studies are needed to evaluate it against different standards of care, including self-administered treatment, and to evaluate the acceptability of VST in different population subgroups and in more resource-limited geographical settings.

The advantages of using VST are its potential to provide treatment support from a distance – and even when people travel and cannot visit or be visited by a TB treatment supporter. VST could help achieve better levels of patient interaction at a much lower cost and less inconvenience when compared with in-person treatment support. VST can be used in addition to, or interchangeably with, in-person treatment support or other treatment administration options.

Another option for providing care to patients when face-to-face visits are difficult is to schedule appointments to talk with them by telephone. Questions regarding treatment can be answered, symptoms can be monitored and counselling can be provided. Care should be taken to make sure that patients are able to find a place to talk where they have privacy. Also, if airtime is expensive, the length of time needed for these discussions may be too costly for the patient.

The performance of digital adherence technology under study conditions needs to be translated into programmatic realities. Health-care practitioners and patients require practical aids that can adapt to a patient's treatment course across a wide variety of different treatment conditions and at distinct time points when treatment interruption is more likely to happen. Technologies for treatment adherence support should be part of an integrated approach that complements the delivery of quality care. For instance, it is unrealistic and undesirable for patients on a longer DR-TB regimen to be placed on exclusive VST for 18–20 months. The risk of interruption is not uniform between patients or even during the treatment of the same patient. Treatment support therefore needs to be flexible throughout a patient's course of treatment. Special attention is needed when there is a change in the treatment regimen which increases the risk of developing adverse medication reactions when: 1) the patient questions the need to continue the prescribed treatment as symptoms disappear and when she or he feels better; 2) conversely, when the patient may not be feeling better and may feel that treatment

is hopeless; 3) when the patient travels far away from the usual treatment centre; or 4) when other events affect a patient's daily routine and make daily treatment more difficult.

The three digital approaches discussed have specific strengths and weaknesses, which may make them work better in some circumstances rather than in others, as well as differing preferences of the patient and health-care workers. On the basis of the different characteristics of each of the adherence support technologies and the patient's individual situation, multiple options might be suitable. Two additional issues to consider are access to smartphones and to broadband Internet via mobile subscriptions. Smartphones and tablet computers, given their computing power and storage space, could be a valuable resource for multiple aspects of TB care. These can be useful even when broadband Internet is unavailable or erratic (e.g. recording of asynchronous VST, storage of patient medical records and e-Learning applications). SMS and EMM – which can operate without mobile broadband Internet coverage – are currently the most accessible, affordable and easily expandable treatment support approaches in resource-limited settings. Where mobile Internet is reliable and computer hardware available, solutions with more connectivity requirements can be considered as options.

The increasing range of technologies available for treatment support helps improve person-centred care. Nonetheless, digital technologies are still to be regarded as tools and should not replace face-to-face interactions when these are more appropriate. Another important consideration is that digital adherence technologies depend on the regular observation of a person's behaviour in order to follow up adherence. This poses a number of ethical issues (7). Some technologies may affect a patient's privacy more than others – such as receiving a daily SMS text message that asks for a reply, the automated monitoring of the opening of a medicine box, or a video recording of a medicine being swallowed. The benefits of having recordings of patients taking their medications and the ability to text or speak with patients have to be balanced against potential downsides – such as patients feeling they are being controlled, a sense of being tracked and distrusted, loss of empowerment and concerns about confidentiality. These issues need to be discussed at length with the patients (see Section 4.1. on Guiding principles for health education and counselling). Further issues to consider when determining which treatment support technology may be best for a patient include the ability and willingness to learn to use the technology. Visual impairment and literacy may make it difficult for patients to use mobile telephones correctly. Another concern is that the cost of airtime or data may be too expensive for patients to use some of these technologies. Acceptability and preferences should be explored with each patient as part of her or his adherence plan.

### 3.3. Selecting a suitable package of care and support for a patient

To support people with TB during their treatment, health policy-makers and practitioners must appreciate that TB affects all aspects of patients' lives. A focus on caring for each patient as an individual should underlie all aspects of treatment and care. Overall, the principles for person-centred care and support (described in Section 2) should be followed.

The evidence reviewed and WHO recommendations suggested that a combination of appropriate care and support interventions improves outcomes for patients (15, 23). Selecting appropriate interventions for each patient is very important and requires proper assessments and consultation with each patient to identify her or his needs and preferences. This should be done both prior to the start of the TB treatment and during the treatment. All the recommended interventions should be considered as part of this process – including social support, treatment administration options, digital adherence technologies and the model of TB care.

Box 1 describes the use of the 5 A's (Assess, Advise, Agree, Assist and Arrange) that help to facilitate a process for identifying the best treatment plan together with the most appropriate package of care and support interventions that best suits the patient.



## Box 1. The 5 A's: Assess, Advise, Agree, Assist and Arrange

### ASSESS

- Assess the patient's knowledge, beliefs, concerns and daily behaviours related to TB and its treatment.
- Assess the patient's goals at the start of any consultation.
- Assess the patient's clinical status, identify relevant current or previous TB treatments or other diseases and provide education on TB disease and treatment and infection control.
- Assess the patient's ability to take medication.
- Assess factors associated with the patient's lifestyle that might prevent them from taking their medications (e.g. opioid or alcohol use disorders).
- Assess for any comorbidities that may need special attention or may affect treatment (in particular HIV, diabetes, hepatitis or other liver disease, kidney disease, tobacco use, mental health illnesses).
- Assess for the presence of adverse effects from medications.
- Assess the financial situation (job, education, dependents, patient's living conditions (if s/he has a stable place to live)).
- Assess the patient's capacity and available conditions for using digital adherence technologies.

### ADVISE

- Use neutral and nonjudgemental language. Speak in a language that the patient understands and use words the patient understands (avoid complex medical terms).
- Correct any inaccurate knowledge (as assessed above) and complete gaps in the patient's understanding of his/her conditions and/or risk factors and treatments.
- Discuss the treatment plan options (including different treatment regimens, different medication delivery/pick up options, treatment administration options, treatment adherence support options, palliative care) that are available to the patient to help them complete treatment.
- Discuss any proposed changes in the treatment plan, relating them to the patient's concerns (as assessed above).
- Evaluate the importance the patient gives to the indicated treatment.
- Advise on the social protection schemes the patient is eligible to benefit from.
- Evaluate the patient's confidence and readiness to adopt the indicated treatment.

### AGREE

- Negotiate a treatment and care plan from the different options.
- Agree upon treatment options that reflect the patient's priorities.

## **ASSIST**

- Provide a written or pictorial summary of the plan.
- Provide or identify a TB treatment supporter.
- Provide TB treatments/medication.
- Provide other medical treatments to help manage side-effects.
- Provide psychological support.
- Provide skills and tools to assist with self-management and with completing treatment.
- Provide a sickness certificate to facilitate access to social protection schemes.
- Provide equipment to help patients take their medications (e.g. pill box).
- Provide self-monitoring tools (e.g. a calendar or other ways to remind and record the treatment plan and next appointment).
- Address obstacles.
- Help patients anticipate barriers to completing treatment and identify strategies to overcome them.
- If the patient is depressed, treat the depression; if the patient has substance use disorder, link with appropriate care services.
- Link to available support:
  - TB treatment supporter
  - friends and family
  - expert patients/community champions
  - peer support group
  - community services.

## **ARRANGE**

- Arrange follow-up care to monitor treatment progress and to reinforce key message.
- Arrange a way for the patient to contact a health-care provider if problems arise before the next patient visit.
- Schedule for group appointments or relevant support groups, if available.
- Record what happened during the visit.
- Refer to existing social services for enablers and other social support measures.
- Ensure that patients receive their preferred treatment options to help them take all their medications.

# 4. Health education and counselling for people affected with tuberculosis

This section focuses on a key recommendation on patient care and support by providing health education and counselling on the disease and treatment adherence to TB treatment (15, 16).

## Recommendation:

- 1.1. Health education and counselling on the disease and treatment adherence should be provided to patients on TB treatment**  
(*strong recommendation, moderate certainty of evidence*).

This recommendation is based on evidence from extensive literature which shows better rates of treatment adherence and completion, and lower rates of loss to follow-up, in patients who received health education and counselling prior to and during the course of TB treatment (15, 23, 36–41). Health education and counselling on TB and its treatment should be provided to all patients.

The goal of health education is to provide accurate information so that patients have the information to make the best choice for themselves. Education can be provided by talking with the patient, distributing written materials, sharing video recordings, or through arts and performance with participation of people affected by TB. The education should discuss TB as a disease, its treatment and the services for which the patient is eligible. The education can and should be given at multiple times during TB treatment both to remind patients of information and also to provide specific information for treatment changes that may be coming up. Education could occur right before or at the start of treatment, when finishing the intensive phase of therapy, or at each presentation or interaction for follow-up care. It can be provided by different types of health-care workers or pharmacists. Educational sessions might include the patient alone or might involve the patients' family members and/or friends. (15, 16).

While health education aims to equip people with the right knowledge, counselling helps them to apply that knowledge by changing their attitude and behaviour. The term "counselling" refers to a two-way interaction between the patient and the health-care provider. It is an interpersonal, dynamic communication process that involves a kind of contractual agreement between a patient and a health-care provider who is trained in counselling skills and who is bound by a code of ethics and practice. It requires understanding and concern for the patient without any moral or personal judgement. To achieve this, health-care providers should be taught interpersonal skills in order to build a partnership with patients and to have good communication skills in order to talk with them and strengthen their understanding of TB. The goal is to make the patients feel strong enough to do what they need to do for treatment of their TB disease.

## 4.1. Guiding principles for health education and counselling

With regard to the rights of patients outlined in the declaration of the rights of people affected by TB (9), the following are particularly pertinent as the guiding principles for patient education and counselling:

- the right to be treated with respect and dignity;
- the right to information;
- the right to confidentiality.

People have a right to complete and correct information related to TB and the suggested treatment's risks and benefits explained in simple language that patients can easily understand. If possible, written information should also be shared. The goal of counselling is to make sure that people have understood the information and to answer any questions they might have. The health-care provider should also correct any commonly held misconceptions or myths about TB.

A person's independence and right to choose should be respected. The health-care providers should respect the patient's choices and beliefs and not make decisions for the patient. All efforts should be made to involve the patient in making a treatment plan. WHO clearly states that every person affected by TB has the right to liberty and security of person and that involuntary detention, hospitalization or isolation of a person with TB is a deprivation of liberty and violation of the security of the person (9). WHO also narrowly defines the circumstances in which this right can be overridden but makes clear that this must be for the shortest duration possible and in accordance with strict guidelines.

Section 2 on the people-centred approach described how people suffering from TB might face stigma, prejudice or discrimination from the community as well as from health-care providers. All efforts should be made to protect people from discrimination and to engage them in the most inclusive way. They should be treated with respect and dignity no matter what their age, gender, financial status, social situation, religion, sexuality or any other factors. In order to reduce stigma and discrimination, patients should be reminded that TB is not the result of any wrong behaviour and that most people completely recover after completing treatment.

People suffering from TB should have personal privacy and confidentiality. It is important that they are seen in a private space for health counselling. They should be assured that information about their care is confidential and that it will not be shared with another person without the patient's permission. Other family members should be invited to join the discussion only after receiving permission from the patient.

## 4.2. Effective communication skills to provide health education and counselling

Communication is best when it is a discussion between the patient and the health-care provider, and not just the health-care provider giving instructions or information to the patient. Good communication skills are very important for the treatment of TB. Not only can good communication help patients to understand the disease and treatment, but it can also help the community to better understand TB and correct misinformation that contributes to stigma (42).

Some important elements of communication needed for health education and counselling are discussed below.

## 4.2.1 Forming a therapeutic alliance

The first step of counselling is to build a partnership with the patient and, if present, with his/her family. This partnership is the foundation that encourages people not just to participate in health education meetings, but also to engage in all aspects of treatment and care. Developing a trusting and caring environment is needed for this partnership, so that people are more likely to talk about their situation and concerns and receive necessary information. Forming a partnership allows for the sharing of information which is important to the process of counselling. Trust and a feeling of understanding should develop between the patient and the health-care provider.

Understanding is one of the most important elements in forming a partnership. A health-care provider should try to understand a patient's problems and feelings in a particular situation and should be able to communicate that understanding back to the patient. In order to build understanding, the health-care provider should: 1) listen and observe carefully, without making judgements, in order to gather information; 2) focus and understand how the patient feels; and 3) talk with the patient to make sure he/she has been understood correctly. This is particularly important because it shows the health-care provider's sincere desire to help, develops a full understanding and provides an opportunity for the patient to explain further. This can be achieved by statements such as "it sounds as if the pain is unbearable..." or "have I got it right that you are unable to sleep because of the cough" or "let me just check that...".

Empathy is not the same as sympathy. Sympathy means, for instance, that a health-care provider feels sad or becomes tearful when a person starts to cry. Understanding does not mean that a health-care provider has to actually "feel" like the person. Instead, the health-care provider has to "understand" how the person might feel (43). For a complete understanding, health-care providers should understand the cultural values and health beliefs of the patients they treat. They need to constantly check that they have understood what the patient explained. This might be a reason why patients continue to seek health advice from faith healers who share a better understanding of the patients' experiences.

Many of the skills of good communication are important when providing counselling – including active listening, the language used, gestures and body language, and showing genuine interest and care.

## 4.2.2 Active listening

Actively listening is a specific communication skill which involves giving undivided attention to both verbal and non-verbal cues. It requires intense concentration; the health-care provider should show a deep interest in and respect for patients and should not interrupt them. In health counselling it is very important to listen to patients carefully so that the conversation can be adjusted to their individual needs.

Active listening is more than just hearing someone else's words; it means paying attention and showing that you have heard and understood what is being said to you. If health-care providers can show that they really are listening, this increases the patient's trust and confidence in the health-care provider and the patient will feel more comfortable. This will make it easier to form a partnership.

To show that the health-care provider has understood what has been said, it helps to repeat to the patient or summarize what has been said using different words. Paraphrasing or summarizing a patient's responses or questions may also help to verify information. Some helpful examples of summarizing a conversation are:

*"Let me check if I have understood you correctly. You understand what TB is; you also understand about the treatment that has been recommended for you and why this treatment is so important for you. But you are worried about the side-effects of the medicines, especially because you will be taking these medicines for a few months, is that right?"*

These skills also show the participation of the health-care provider in the conversation. Another communication skill is called reflection. For example, if a patient is describing his or her concerns, the health-care provider should observe the patient's emotional reaction and then comment *"It looks as if you are very worried about these symptoms."* Acknowledging a patient's feelings also shows understanding and helps build an effective relationship.

### 4.2.3 Using non-verbal communication

Non-verbal communication includes eye contact, facial expressions, gestures, looking attentive, posture, nodding one's head and other movements.

Non-verbal communication also involves both the patient and the health-care provider. The behaviour of the health-care provider can give strong messages to show respect for and interest in the patient: It also builds a relationship, shows that the health-care provider is listening carefully and shows that they want to help the patient understand about TB and treatment. Health-care providers should use non-verbal communication to show that they are actively listening; this includes eye contact, smiling, nodding, and sitting down while talking. The health-care provider should avoid doing things like looking at their watch or fidgeting.

A patient's expressions also communicate emotions. Movements of eyes, mouth, eyebrows, forehead or even nostrils in different combinations signal happiness, sadness, anger, surprise, disgust, fear and interest. A slightly furrowed forehead will usually mean that the person either disagrees with what is being said or does not understand. That simple expression alone can show that they need more explanation. Because tension and anxiety may be reflected in body language, a reasonable guess at a person's state of mind can be made simply from looking at their posture. People who are anxious or worried about something tend to adopt characteristically tense positions of the hands, which may be clasped tightly together, or of legs, which may be wrapped around each other or the feet may tap repeatedly on the floor. Often without the need for any words, these clues can alert an observant health-care provider to investigate further.

### 4.2.4 Asking questions

Asking questions appropriately is an important technique that can help to:

- identify what is already known and reveal any information gaps;
- identify specific needs;
- explore the attitudes and beliefs of a patient;
- generate discussions and options for problem-solving;
- help to understand the reasons behind decisions or actions.

An understanding of a patient's existing knowledge about TB and its treatment is important before giving further information. In this situation, asking questions is important. A balance between "closed" and "open" questions can help to collect the necessary information in a short time.

A closed question is one to which the only answer is "Yes" or "No". Some examples are: Do you have a cough? Do you have fever? The trouble with using closed questions is that "Yes" or "No" often does not describe fully what the person wants to say.

That is where the "open" question has value. This type of technique lets people describe their experience in their own words. Open questions are short and suggest no specific answer. They begin with words like "What", "Why", "How" and are very short. Some examples are: How do you feel after you take your medicines? Why do you have trouble taking your medicines every day?

Ideally, a problem should be explored with open-ended questions and then closed-ended questions should be asked in order to complete the information. Sometimes, however, people may go into

unnecessary details and health-care providers need to maintain some control over the interaction by gently moving on.

## 4.2.5 Providing information

Health education and counselling must be given in very simple and clear language. Even medical information should avoid technical terms and medical jargon. Sometimes a limited amount of information is shared in one meeting so that the patient can understand it and then can think about it and is prepared for further information at the next meeting. Sometimes, important information needs to be repeated to help the patient understand it.

Health-care providers should use language that is respectful towards patients and caregivers. It is important to not use derogative or judgemental language. Terms such as “defaulter”, “suspect” and “control” are disrespectful and disempowering. These are best replaced with “person lost to follow-up”, “person with suspected TB” or “person to be evaluated for TB”. The term “control” can be replaced by “prevention and care”. Similarly, expressions such as “patient failed treatment” or “failed to comply” reflect the view that the patient is to blame for the failure of treatment (44).

The volume and tone of the voice of the health-care provider is also important during health counselling. A very loud volume might be intimidating, and a very low volume may be difficult to hear or may give the impression that the health-care provider is unsure of him/herself. Similarly, if the health-care provider is speaking too fast, it seems as if they are in a rush and can also be difficult to understand. Table 1 summarizes effective communication skills for a clinical encounter (45).

**Table 1. Effective communication skills**

<b>1</b>	Create an environment that helps with communication	Meet the person in a private space, if possible.
		Be welcoming and conduct introductions in a culturally appropriate manner.
		Use culturally appropriate body language, facial expressions and eye contact to help to build trust.
		Explain that information discussed during the visit will be kept confidential and will not be shared without permission.
		If caregivers are present, suggest speaking with the person alone (except for young children) and obtain consent to share clinical information.
		If a male health-care provider is interviewing a young woman, consider having another female staff member or caregiver present.
<b>2</b>	Involve the person	Include the patient (and with their consent, their caregivers and family) in all aspects of assessment and management as far as possible. This includes children, adolescents and older adults.

<b>3</b>	Start by listening	Actively listen. Avoid distractions.
		Be understanding and sensitive.
		Use non-verbal communication to show that you are listening.
		Allow the person to speak without interruption.
		If the history is unclear, be patient and ask for explanations.
		For children, use language that they can understand. For example, ask about their interests (toys, friends, school).
		For adolescents, show that you understand their feelings and situation.
<b>4</b>	Be friendly, respectful and nonjudgemental at all times	Always be respectful.
		Do not judge people by their behaviours and appearance.
		Stay calm and patient.
<b>5</b>	Use good verbal communication skills	Use simple language. Be clear and concise.
		Use open-ended questions, summarizing and clarifying statements.
		Summarize and repeat key points.
		Allow the person to ask questions about the information provided.
<b>6</b>	Respond with sensitivity when people disclose difficult experiences	Show extra sensitivity with difficult topics.
		Remind the person that what they tell you will remain confidential.
		Acknowledge that it may have been difficult for the person to talk with you about their thoughts and concerns.

### 4.3. Counselling to provide information about TB and the responsibilities of affected individuals and communities

This section focuses on *what* information about TB needs to be provided to patients and *how* that information should be provided.

The sharing of information with patients and their families should begin as soon as the diagnosis of TB is made. If the patient is being treated for DR-TB, another good time to have an educational meeting is when finishing the intensive phase of treatment. Educational talks should continue over several visits throughout the treatment course. Education can be provided by physicians, nurses, community health workers and other health-care providers.

It can be difficult to provide patients with the information they need. A lot of new information, much of which may be technical, has to be given to someone who may not understand medical language well. The patient may not feel well and may also be emotionally distressed because of the diagnosis. The patient may also have health beliefs that contain incorrect information about TB.



## 4.3.1 What information must be provided?

### 1. Factual information about TB as a disease and its treatment

Information about TB and its treatment should be explained to the patient. This includes:

- what causes TB, how it is spread, the symptoms of TB and what can happen if TB is not treated;
- an explanation that TB is treatable and curable, and how to access treatment for TB;
- how TB is treated: how long the treatment lasts, the types of medicines that are used to treat TB and the possible side-effects of the medications;
- the effects of TB treatment on other comorbidities (e.g. alcohol, illicit drugs etc.);
- what could happen if a patient stops taking TB medications against the advice of the health-care provider;
- why starting treatment quickly after diagnosis reduces the risk of transmission to others;
- the infection control practices that help to reduce the risk of spread of TB;
- what the available support services are and how to make a referral plan and/or organize integrated care at an early stage in case of other comorbidities.

### 2. The rights of people affected by TB

The Patients' Charter for Tuberculosis Care (10) outlined the rights and responsibilities of people with TB. The charter encouraged a person-centred approach in the treatment of TB, and encouraged collaboration between patients, communities and health-care providers in order to improve TB care. In 2019, WHO also declared the rights of people affected by TB (9). These are outlined in Table 2.

**Table 2. The rights of people affected by TB and obligations of state and non-state actors**

	<b>Rights of people affected by TB</b>
Article 2	The right to life.
Article 3	The right to be treated with dignity and respect.
Article 4	The right to the highest attainable standard of physical and mental health (right to health).
Article 5	The right to freedom from torture and other cruel, inhuman or degrading treatment.
Article 6	The right to equality and freedom from discrimination.
Article 7	The right to liberty and security of person.
Article 8	The right to freedom of movement.
Article 9	The right to privacy and family life.
Article 10	The right to confidentiality.
Article 11	The right to information.
Article 12	The right to informed consent.
Article 13	The right to education.
Article 14	The right to work.

Article 15	The right to adequate food.
Article 16	The right to housing.
Article 17	The right to water and sanitation.
Article 18	The right to social security.
Article 19	The right to freedom of expression.
Article 20	The right to freedom of assembly and association.
Article 21	The right to participation.
Article 22	The right to justice and due process.
Article 23	The right to enjoy the benefits of scientific progress (right to science).
<b>Obligations and responsibilities</b>	
Article 24	State obligations under international and regional human rights law.
Article 25	Non-state actor responsibilities under international and regional human rights law.

### 4.3.2 How should this information be provided?

Effective communication skills are described in Section 4.2. These need to be practised by health-care providers before they can share the information outlined above as part of health education and counselling.

1. It is important to form a partnership with the patient before sharing any information. All efforts should be made to have a two-way conversation, rather than the health-care provider just telling the patient facts. Patients should be encouraged to ask questions, information should be repeated to help them understand, and health-care workers should check whether the patients have understood the information by asking short questions. Taking time to make sure that patients understand leads to better treatment outcomes.
2. The first question should be: *"What do you already know about TB?"*  
Once a health-care provider has found out what a patient already knows about TB, the health-care provider can focus the discussion on what the patient still needs to know.
3. The next question should be: *"What questions do you have about TB?"*  
The information about TB can then be personalized to the patient. For instance, it is quite possible that a patient is more interested in treatment options than the cause of TB. Once patients' questions have been answered, they may be more ready to discuss other important TB subjects. Sometimes, it might be difficult to give all the necessary information during one meeting, so the health-care provider needs to prioritize the information so that the most important questions are answered first.
4. Next the health-care providers need to ask themselves: *"What is the most important information that the patient must understand?"*  
The health-care provider should focus on this most important information during the first educational talks with the patient. The health-care provider should still encourage questions from patients and help them understand information by repeating it or asking them short questions.  
Questions like *"What do you know about your rights?"* will communicate better with patients instead of reading them a list of their rights.

- Finally, health-care providers should summarize the gaps and mistakes in the patient’s knowledge about TB.

While respecting a patient’s religious beliefs, it is important to explore their health beliefs – particularly those that might make it difficult for the patient to finish treatment. These questions also help to the health-care provider to understand what patients think about their illness or treatment, especially in their cultural context. Most people already have some understanding of TB because it is a common illness. They might also be anxious about their diagnosis or have some worries about the health-care provider and the treatment. These concerns, beliefs and worries must be dealt with as part of health education and counselling. Families may also have their own ideas which might or might not be shared by the patient. Since families have a strong influence on patients’ behaviour, their views also need to be taken into account. This helps to avoid confusion within families with regard to medical advice. The importance of exploring a person’s health beliefs is also relevant to Section 5.4 on counselling for treatment adherence.

In addition to sharing information during visits, educational pamphlets that clearly state facts about TB and its treatment are very helpful. The educational material should be appropriate for all ages, culturally sensitive, presented in local languages and in reader-friendly formats. Digital tools with audio or visual aids are also likely to help patients who may have difficulty reading. Additionally, specific marginalized populations may require special educational efforts.

## 4.4. Counselling to provide information about TB treatment and to ensure adherence to treatment

This section discusses how to counsel patients about TB treatment to help prevent them from stopping their treatment without medical advice.

### 4.4.1 Counselling to provide information about TB treatment

Patients and their caregivers should be prepared for TB treatment by giving them information (see Table 3) about:

- the treatment administration options; length of treatment; importance of adherence to treatment;
- pharmacological treatment: drug regimen; side-effects; monitoring side-effects;
- infection control at home and in the community;
- follow-up plan: routine appointments; emergency contact;
- support mechanisms: social support and social protection;
- palliative and end-of-life care.

**Table 3. Information about TB treatment**

About the treatment	The treatment setting	Where will the treatment start? If at a hospital, estimate the approximate length of stay and other important things the patient should know about when being in the hospital. If at home, involve the treatment supporter (preferably a community health volunteer) and discuss any changes in the home environment, if needed.
	Length of treatment	Explain how it may differ according to the regimen selected – often 4–6 months for TB without drug resistance.

	Adherence to treatment	Point out the complications of interrupting or not completing treatment.
About the pharmacological treatment	Medicines	Give basic information about different anti-TB medicines used in the treatment regimen, formulations (e.g. tablet or capsule, single dose or fixed-dose combination), preferably by showing each medicine and formulation.
	Side-effects	Give details about potential side-effects (including those that can be serious) and the need and how to report these immediately.
	Monitoring	Explain requirements for treatment monitoring by clinical examinations, radiology, smear, culture or other tests for early detection of side-effects.
Follow-up plan	Routine	Outline the process of routine follow-up and how to make an appointment when needed.
	Emergency	Explain how patients can contact their health-care providers urgently. Explain what to do in case of an emergency (such as severe shortness of breath).
	Referral to other medical services	Show how to make a referral plan and/or organize integrated care at the early stage for comorbid medical (including mental health or substance use) conditions.
Infection control	Principles of transmission	In transmission of TB, when is the highest risk of infectivity?
	Household infection control measures	Note precautions to be taken at home. Note precautions to be taken in the community.
Support mechanisms	Social support and social protection options	Draw attention to existing services and laws in the country, including disability grants etc.
Palliative and end-of-life care		Describe services, laws, mechanisms etc.

As already noted, participate and completely understand that treatment should not be stopped without medical advice.

#### 4.4.2 Counselling to ensure adherence to treatment

The most common challenge in TB care is when a patient discontinues taking medicines or misses treatment appointments. For this reason, it is extremely important to have a plan to quickly follow up with the patient. If possible, this plan should involve a member of the TB treatment centre team (community nurse, doctor, TB treatment supporter) who will visit the patient at home the same day, if the patient has given you permission to visit their home. If they have not given you permission, another plan should be in place to contact the patient (e.g. by mobile telephone or through a trusted friend of the patient who the patient has given you permission to contact).

The following steps should be taken (11):

1. Make a home visit to engage with the patient, if they have given you permission to visit their home.
2. Assess the reasons for discontinuing the treatment.
3. Discuss the concerns that caused the patient's non-adherence.
4. Educate the patient about the need to continue treatment.
5. Counsel and support the patient.
6. Involve family members/caregivers to ensure treatment.

### **1. Home visit to engage with the patient**

The member of the TB treatment centre – such as community nurse, doctor or supervisor – should visit the home (if given permission) of the patient together with, or in addition to, the TB treatment supporter. During the home visit it may be possible to identify more clinical problems than during the monthly clinic evaluation. The patient should be treated in a friendly and sympathetic way by showing that he/she is respected and valued. The guidelines discussed in Section 5.2 on effective communication skills should be followed.

### **2. Assess the reasons for discontinuing treatment**

- Every effort should be made to listen carefully to the patient's reasons for missing treatment.
- The health-care provider should make a list of problems that contributed to the patient being unable to follow treatment.
- The health-care provider should explore the patient's understanding of the illness.
- The health-care provider should be sympathetic and should recognize the difficulties faced by the patient.
- The health-care provider should not just speak *at* the patient but should have a discussion with him/her.

### **3. Discuss the patient's concerns that caused non-adherence**

The health-care provider needs to discuss some of the common reasons why patients are unable to follow up with treatment or take their medications. For instance:

#### *a. Manage side-effects*

The most common reason for stopping treatment is difficulty in tolerating medicines. This is particularly important when people are on second-line medicines for the treatment of DR-TB. It is extremely important to enquire about possible side-effects and to refer to the guide on managing these (46).

#### *b. Explore the person's health beliefs*

People can hold a number of beliefs and ideas – for instance, on what has caused their illness or how can it be treated, which are quite different from those held by the health professionals. If patients believe that there is no cure for TB, or that when symptoms get better it is not necessary to continue treatment, or that cure might be offered by alternative or traditional medicine, they may not continue their treatment.

Some examples of questions that can help explore a patient's health beliefs are:

- *What do you think has caused your illness?*
- *How does your illness affect your body?*
- *How severe do you think it is?*
- *What kind of treatment do you think might help?*
- *What are the major problems caused by your illness?*

- *What are you afraid of most about your illness?*

In such cases, the TB treatment supporter, along with a nurse, doctor or community supervisor, should explore ways to correct the misunderstandings and discuss with the patient how to restart treatment.

#### *c. Address economic problems*

Many people are unable to work when they are ill and may be the primary wage earners for their family. Housing, food and clothing needs should be assessed to find out what types of material support can help (see Section 3.2 for more details).

#### *d. Address substance use or other mental health conditions*

Alcohol and drug use are known to affect treatment adherence. People should be encouraged to reduce or stop consumption if it interferes with their treatment. If this is difficult or other mental health conditions are suspected, consultation with a mental health or other relevant specialist should be considered.

#### *e. Problems with the health-care service*

People may have problems with health-care providers who might arrive late, might not listen carefully, or might make the patient feel not respected or not valued. These issues are also known to affect adherence and must be addressed. The health-care provider should recognize any service problems, apologize and offer a solution.

#### *f. Address social problems*

If there are other social problems, the patient should be referred for appropriate support. This would also include homeless people, or patients who might be shunned by their family or who have to re-locate for immigration, work or economic reasons, in which cases they should be linked to services in the new location.

### **4. Educate the patient about need to continue treatment**

The health-care provider should:

- *Assess if there are gaps in the patient's understanding of the disease and its treatment.*
- *Correct any misunderstandings or misinformation.*
- *Encourage the patient to ask additional questions.*
- *Summarize the diagnosis, treatment and recommended steps in simple terms.*
- *Ask the patient to repeat or describe the treatment terms.*

### **5. Counsel and support the patient to resume treatment promptly**

Once the reasons for discontinuing medication have been discussed, have been dealt with to the best of the health-care provider's ability and the patient has been educated about the need to continue treatment, the health-care provider should reassure the patient and provide realistic encouragement. Follow-up plans should be confirmed with the patient.

Further guidelines for psychological support are discussed in Section 5.5.

### **6. Engage community health workers, family members and caregivers to ensure treatment adherence**

Engagement of community health workers has been demonstrated to be effective in securing favourable treatment outcomes. Family can also be an important source of support for the patient. If it is not possible for a family member to care for the patient, another caregiver should be identified and should also be educated about the need to continue treatment so that they can make sure the

patient takes the treatment correctly at home. Information about measures to prevent the spread of infection, and that a person is usually no longer infectious within two weeks of the start of treatment, is also extremely important.

Community opinion and religious leaders can be helpful if there are community-wide issues – such as stigma towards patients dealing with TB. This option is possible only if the patient allows the health-care providers to share information about his or her TB diagnosis.

## 4.5. Counselling to provide psychological support

Section 3.2.2 describes factors that can affect a person’s psychological health, cause distress, decrease their quality of life, prevent them from following their treatment plan and cause them not to be able to complete a course of treatment.

Being diagnosed with TB and worrying about its impact on what a patient needs to do daily – employment, income, family and taking treatment as prescribed – can be an extremely stressful experience. A stress response can manifest in psychological symptoms, physical symptoms and changes in behaviour (see Table 4).

**Table 4. Symptoms of stress**

Psychological symptoms	Physical symptoms	Changes in behaviour
Constant worry	Headaches, migraine, dizziness	Feeling irritable/aggression
Depression/anxiety	Muscle tension, spasm or cramp	Changes in sleeping pattern (too much or too little sleep, inability to sleep)
Difficulty concentrating	Changes in breathing/panic attacks	Changes in diet (eating too much or too little, loss of appetite)
Feeling overwhelmed	Chest pain/faster heartbeat	Use of alcohol, drugs, tobacco to cope with stress
Forgetfulness	Digestive problems (upset stomach, nausea, constipation, diarrhoea)	Avoiding dealing with difficult situations
Difficulty making decisions	Lethargy/tiredness	Lack of motivation
Feeling disconnected	Increase in blood pressure	Crying

People with TB may be more vulnerable to developing severe stress responses. Common mental disorders and TB are both associated with greater social vulnerability, inadequate living conditions and socioeconomic inequality (17, 47–49). People with mental illness may find it very difficult to take the long treatment course required for TB (50). People with mental illness and TB would particularly benefit from psychiatric care (51). Additionally, some of the TB medications are associated with psychiatric side-effects (52).

It is extremely important to recognize and deal with the stress reactions in people who are at risk by finding out what their worries and concerns are and by offering support. They should be referred to specialist services if necessary. This section focuses on providing basic psychological support, strengthening social support, problem-solving technique, and providing support to caregivers and dependent family members.

## 4.5.1 Basic psychological support

Basic psychological support tries to help people deal with emotional distress and help them recover from stress responses (53). In addition to following the principles of effective communication in Section 5.2, these guidelines should be followed:

1. Distressed people may not always give a clear account of their situation or may take longer to explain themselves. They should be listened to patiently, without interrupting or rushing them. Asking for clarification usually helps. Sometimes, they might find it difficult to open up their feelings; being there and reassuring them is important. If they describe their feelings or difficult experiences, responding with empathy and sensitivity can help. Some examples of responses are:  
*That sounds like a very challenging experience.*  
*I understand how painful this has been for you.*  
*I can see why you are so worried (or frightened).*
2. Sources of stress should be identified. After actively listening and allowing the person to speak without interruption, following questions may be needed:  
*What is your biggest worry these days?*  
*How do you deal with this worry?*  
*What are some of the things that give you comfort, strength and energy?*
3. Their basic needs should be assessed. If they need more information or additional services, simply establishing contact with their family and providing other social support is important.
4. Education should be provided about the normal stress reactions of people diagnosed with TB or experiencing difficulties with treatment or services.
5. If the stress reaction is long or severe, specific stress management techniques should be offered (54).
6. The health-care provider should look for potential signs of sexual or physical abuse (including domestic violence) in women, children and older people (e.g. unexplained bruises or injuries, excessive fear, overly withdrawn behaviour, reluctance to discuss matters when a family member is present, malnourishment in a family with access to sufficient food). When signs of abuse or neglect are present, the patient should be interviewed in a private space and asked if anything hurtful is going on. If abuse or neglect is strongly suspected or confirmed, help should be requested from colleagues with experience of dealing with this. If the patient gives consent, he/she should be referred to relevant community resources for protection (e.g. trusted legal services and protection networks).

## 4.5.2 Strengthen social support

Strengthening social support is important to reduce the many of the harmful effects of stress (45).

1. The first step is to ask about support mechanisms that the patient has now or those that might have helped the patient in the past.  
Some example questions are:  
*What comforts you when you are upset?*  
*Do you talk to anyone about your problems and what you are going through?*  
*Is there any person who you feel can give you support?*  
*Who do you feel most comfortable sharing your problems with? When you are not feeling well, who do you turn to for help or advice?*



*How is your relationship with your family? In what way do your family and friends support you and in what way do you feel stressed by them?*

2. Then identify people who could provide support, such as trusted family members, friends and community members, and talk about how each one can be involved in helping.
3. If the patient is willing, he/she should be referred to other community resources for companion or material support. These include: social or protection services; community centres; self-help and support groups; employment and or other income-generating activities; formal/informal education; shelter, food and non-food items; child-friendly spaces. When making a referral, the patient should be helped to access them (e.g. provide directions to the location, operating hours, telephone number) and provide the patient with a short referral note.

### 4.5.3 Problem-solving technique

Stress can affect a patient's ability to respond well to problems. Patients may feel helpless or lack confidence in managing their problems, or possibly their feelings of anxiety or grief will get in the way of managing their day-to-day problems well. Problem-solving is a step-by-step strategy that may help distressed patients to solve and manage their problems (55).

In general, direct advice should not be offered. Instead, patients should be helped to explore their own solutions (see Box 2).

#### Box 2. Problem-solving technique

1. List problems as solvable (can be influenced or changed) and unsolvable (cannot be influenced or changed).
2. Choose an easier (solvable) problem to start with.
3. Choose the part of the problem for which the solution is practical in nature and in your control.
4. If a problem has many parts, break it down and deal with each part separately.
5. Make a list of possible solutions to the problem. Think of what you can do by yourself and also think of people who can help you to manage parts of the problem.
6. From the list of potential solutions, choose those that have most helpful strategies (those that have very few disadvantages and are easier to carry out).
7. Develop a detailed plan (step by step) of how and when you will carry out the solution.
8. After trying to solve the problem, review to see what has been solved and what the next step should be.

### 4.5.4 Provide support to the caregivers

It is important to realize how stressful it can be to care for people with TB and how important the caregiver is in helping the patient to recover completely from TB. Caregivers need to be respected even if they find it difficult to support the patient with TB; if the patient allows, the caregiver should be involved in making decisions about treatment. Providing support to the caregivers is an important psychosocial element of treatment for chronic conditions (45).

Some areas that may help assess the stress in caregivers are:

- worries and anxiety around caring for the person with TB;
- practical challenges (e.g. burden on the caregivers' time, freedom, money);
- ability to carry out other daily activities, such as work or participation in community events;
- physical fatigue;
- social support available to the caregivers;
- psychological well-being.

Once their needs have been assessed, the health-care provider can help by:

- providing information;
- linking the caregiver with community services and supports;
- discussing respite care, which is when another family member or appropriate person can take over the care of the patient temporarily while the main caregiver takes a rest or does other things they need to do;
- offering problem-solving or stress management counselling;
- referring the caregiver to mental health services, if needed.

### 4.5.5 Refer to mental health services

If a mental health condition is suspected or identified, refer the patient to appropriate mental health services.

## 4.6. Counselling on nutritional care and support

In view of a strong bidirectional causal link between TB and undernutrition, WHO recommends that all persons with active TB should receive appropriate counselling based on their nutritional status at diagnosis and throughout treatment (27).

Undernutrition can present in children, adolescents or adults, including pregnant women. In case of young children (under the age of 10), their parents need to be part of counselling and support. In case of adolescents (ages 10–19), the healthcare providers should make an effort to develop a therapeutic alliance with the young person as well as his/her parents (section 4.2.1.).

### 4.6.1 Treat the underlying cause

An assessment of the cause of undernutrition is essential. If the cause is primarily poverty or food insecurity related, these socioeconomic issues will need to be addressed. If underlying medical causes are suspected, then an appropriate medical referral should be considered. In cases of co-morbid medical (e.g., diabetes) or psychiatric conditions (e.g., alcohol use), again the individual should be referred appropriately.

Irrespective of these causes, the person should be offered the counselling techniques already described: basic psychological support (4.5.1), strengthen social support (4.5.2), Problem solving technique (4.5.3), and provide support to the family/caregivers (4.5.4).

### 4.6.2 Educate the person

In cases where the healthcare providers feel that the person does not understand the nature of undernutrition, potential harm and need for diet modification or nutritional supplements, the healthcare providers should follow the principles of 'health education and counselling' described in chapter 3 to educate the person.

### 4.6.3 Assess 'readiness' of the person to change diet/lifestyle

The basic principle of a health behaviour change is that people hold a range of beliefs about their problems and behaviours. They range between those who do not acknowledge that there is a problem, those who acknowledge that there is a problem but are not ready to act and those who understand and make efforts to act but are unable to persist with desired actions. A careful assessment of an individual's readiness or preparedness to change can help a healthcare provider plan further intervention.

### 4.6.4 Motivate the person

Healthcare providers are trained to 'advise' and have an inherent desire to set things right for their patients. This rarely helps to bring a change in behaviour. Instead, the aim should be to explore people's difficulties about changing their behaviour and help them find their own solutions. A therapeutic alliance (section 4.2.1) is important to understand the person's point of view and identify the conflicts between how the person behaves and what he/she aims to achieve. The healthcare providers should encourage the person with whatever efforts he/she is able to make towards a desired change in diet/taking supplements, without any confrontation or external pressures.

### 4.6.5 Rewarding desired behaviour (in children)

It can be very helpful if children are rewarded for implementing a desired behaviour (e.g. eating nutritious food or taking supplements) to reinforce those habits. The most effective reward is attention from the parents.

## 4.7. Counselling at the end of TB treatment and on palliative care

### 4.7.1 Counselling at the end of TB treatment and post-TB treatment

After completing TB treatment, some people have to deal with the possibility of post-TB symptoms or sometimes respiratory disability or sequelae. TB recurrence may happen in a small proportion of patients including those successfully treated. Counselling at the end of TB treatment is necessary to provide people with necessary information on the possibilities of post-TB symptoms, disability or sequelae, or the recurrence of TB; they need to access health care services for follow-up examinations when necessary. The process of counselling should continue to support people to adjust to their health challenges until they are emotionally stable. Counselling aims to provide a safe and trusted space to help people to work through their inner fears and apprehensions.

Patients and family members often need emotional support to face the losses associated with post-TB disability. People who suffer from post-treatment debilitating complications may also experience adverse psychological, social and financial impacts. It is extremely important to monitor their adjustment to compromised health status. It may take up to several months before they are able to completely recover their emotional health. During this period, counselling and other forms of social and occupational support can be of tremendous help.

### 4.7.2 Counselling on palliative care

As discussed in Chapter 6, assessment and relief of psychological, social and spiritual distress of patients and family caregivers are critical parts of palliative care for people affected by TB.

When patients learn that they are likely to die from their illness, they may experience any or all of the following emotions or thoughts in no particular order (56, 57):

- Denial: inability to believe, understand or accept the terminal prognosis.
- Anger: blaming others or God for the situation.
- Bargaining: desperately searching for a way out of the terminal situation.
- Depression: feelings of despair, worthlessness, guilt or shame.
- Acceptance: finding peace.

In addition to the counselling techniques already described – providing basic psychological support (section 4.5.1), strengthening social supports (section 4.5.2), problem-solving (section 4.5.3), supporting the family/caregivers (section 4.5.4) – health-care providers can do the following (57):

1. Allow the patient to express strong emotions such as sadness, tearfulness or anger without interrupting or judging.
2. Express the wish that there were some means to treat the illness.
3. Assure patients that they will continue to be cared for, that they will be accompanied throughout the illness and that any discomforts will be treated.
4. Ask whether the patient would like spiritual support and arrange for an appropriately trained spiritual supporter if requested by the patient.
5. Assess the patient for symptoms of anxiety or depression. If these symptoms are in excess of what would normally be expected in this situation, consider treating. Refer for mental health services only if such services are easily and quickly accessible by the patient.
6. Prior to the patient's death, assess family members for bereavement risk (e.g. history of mental illness, difficult and emotionally charged relationship with the patient) (58).
7. Make bereavement support available to the family via the palliative care team, a community-based bereavement support group, or a social worker (59).
8. In the course of bereavement support, watch for signs and symptoms of prolonged grief disorder (e.g. more than 12 months of difficulty in accepting the death and clinically significant impairment in social or occupational functioning). Refer to a mental health specialist if suspected (58).
9. Implement resilience-promoting programs within palliative care or DR-TB teams such as regular sharing of difficult cases, memorial ceremonies for deceased patients, regular social activities.

Provide information and education to patients, as follows:

1. Educate the patient about common reactions to disability or terminal conditions. The following statements are some examples:

*People in similar situations may react in different ways. Some people show strong emotions while others do not.*

*It is alright to feel sad and even cry; it does not mean you are weak.*

*People who do not cry may feel the emotional pain just as deeply as others but have different ways of expressing it.*

*There are no right or wrong feelings. Sometimes you might feel very sad, and at other times you might feel better.*

2. People who suffer from debilitating complications after treatment may also experience adverse psychosocial and financial impacts. It is extremely important to monitor their adjustment to compromised health status; it may take up to six months before they are able to recover their emotional health completely. During this period, other forms of social and occupational support can be of tremendous help.

3. Health-care providers also need to be mindful of patients' cultural and religious beliefs. Spiritual distress and existential concerns should be treated with the same level of priority as psychosocial distress and physical pain. Support may involve a spiritual caregiver.
4. If a person presents with severe symptoms of distress, or is unable to sleep or eat, or there are signs of mental disorders (e.g. substance use disorders or depressive disorders) he/she should be referred to mental health services.
5. Patients and family members often need emotional support to face the losses associated with disability, dying and bereavement. In cases where a patient dies, the family may need to be supported through the bereavement periods. Some bereaved family members may develop complicated grief requiring specialist treatment. Community support can also be mobilized to sustain bereaved family members.
6. Providing support to people facing disability or death can be extremely distressing for health-care providers themselves. They also need to be supervised and supported within their teams. National TB programmes should encourage self-care and staff support strategies, such as regular sharing of difficult cases, memorial ceremonies for patients who have died, regular social activities for palliative care team members, regular exercise and other supports.



# 5. Models of care for TB services

## 5.1. Models of care for all TB patients

Although traditionally patients with DR-TB were hospitalized for portions of, and sometimes all of, their treatment, recommendations on this have changed. With the increasing use of all oral DR-TB treatment, patients with DR-TB should be treated whenever possible in an outpatient-based treatment programme similar to patients with DS-TB (60–62). Additionally, for both patients with DR-TB and those with DS-TB, treatment should move towards a decentralized, ambulatory care setting in order to make it easier for all patients to access medications and treatment support and for TB treatment to be less disruptive to their lives.

The following recommendations from WHO's guidelines (15) apply to patients with DR-TB.

### Recommendations:

- 2.1. **Patients with multidrug-resistant TB (MDR-TB) should be treated using mainly ambulatory care rather than models of care based principally on hospitalization**  
*(conditional recommendation, very low quality of evidence).*
- 2.2. **A decentralized model of care is recommended over a centralized model for patients on MDR-TB treatment**  
*(conditional recommendation, very low certainty of evidence).*

However, sometimes patients do require treatment in the hospital (inpatient). These may be patients with DR-TB, but they may also be patients with DS-TB with severe disease or treatment complications. The following discussion addresses some of the concerns regarding strategies for decentralized (outpatient/ambulatory) care models – which apply to majority of TB patients – and inpatient or hospital-based treatment for patients who need special treatment and care.

### 5.1.1 Outpatient model of TB treatment: decentralized care

Decentralized care means care that is provided in smaller, ambulatory, non-specialized health-care centres closer to where a patient lives, often by community health workers or nurses, non-specialized doctors, community volunteers or TB treatment supporters. Care could occur at local centres (e.g. community centres), or at the patient's home or workplace. Having treatment and care provided in decentralized health-care centres is a good way to improve access to treatment and increase the number of patients who receive regular, community-based treatment and support. Decentralized care is often less disruptive to patients' lives, allowing them to access treatment, care and counselling more easily and with less cost. It may also allow them to continue to work (therefore lessening the financial burden of TB disease) and to remain with their families. Decentralized care can be used for patients with either DS-TB or DR-TB. According to the WHO guidelines, all oral regimens are preferred for TB treatment (61–63); however, if the patient must receive injectable medication, it should be investigated whether the injectable can be given at a decentralized location (60–62).

Decentralized care may not be best for all patients. Of particular concern would be patients with severe TB disease or severe comorbidities or very infectious forms of TB. However, studies have shown higher rates of treatment success and fewer patients lost to follow-up when patients were treated with decentralized care versus hospital-based care (64). There were no higher risks of death or treatment failure among patients who were treated with decentralized care. Before a patient begins decentralized care, the health-care provider needs to make sure that all required safety monitoring (e.g. laboratory tests, ECG) can still be done in the decentralized system or that, when needed, a patient can travel to a clinic or hospital with a higher level of care that can do this monitoring. There should always be a plan to get patients to a hospital if they need inpatient treatment. This may be necessary in certain patient groups at particular risk, such as children with severe forms of TB or people who also have advanced HIV. These patients may need close monitoring in a hospital for a certain period of time.

The backbone of community-based TB care is often a community TB treatment supporter, who may belong to the neighbourhood where the patient lives (53). Community TB treatment supporters, like all health-care workers, must respect and preserve patient confidentiality at all times. They can also play an important role in educating the community about TB and can help reduce stigma around the disease. Community-based TB providers need to be properly trained and supervised by qualified health-care workers (65). In some settings, and where there are no other alternatives, a community-based TB treatment supporter can even be a family member who has undergone proper training and is supervised by a health-care worker or qualified community member. However, family relationships can be complex, and so the nature of family relations should be evaluated beforehand to ensure that the patient receives fully supportive care.

Decentralized care requires staff at the clinics to receive extra training and for the clinics to be able to support TB patients. This is likely to require additional help from the NTP. Clinic staff must be aware of the early detection and management of adverse drug reactions and should be familiar with social support services. When patients are on good medical treatment, the bacterial load rapidly falls and the risk of transmission of TB drops. Nevertheless, infection control measures need to be put in place at the clinic. The patients also need to be educated on infection control measures they can do at home, particularly if they live with someone who is at a particular risk from TB infection, such as a young child or someone living with HIV. These infection control measures will decrease the risk of transmission in households, the community and clinics. In the case of a patient with DR-TB, it may be illegal in some countries to treat DR-TB patients in a decentralized setting, especially when the treatment involves injections. Such legal concerns need to be considered when making plans for decentralized versus hospital-based care (see Box 3).

This decentralized model of care may require the patient to travel from home and receive medicines under person-centred treatment support at the clinic. Long daily travel times or cost of travel could lead to loss to follow-up. Patients may need financial support to help with their travel costs.



### Box 3. Basic conditions to be met by an optimum community-based model of decentralized TB care

- The public health legal framework should allow community members to deliver the required health-care functions.
- The patient has no medical indication for receiving long-term care in hospital.
- The patient's household/living situation can allow for basic standards for respiratory infection control.
- All health-care workers and community TB treatment supporters are trained, follow the rules of TB infection control and have access to masks and respirators at all times.
- There are sufficient community TB treatment supporters to provide person-centred treatment support to all patients as needed and required by NTPs.
- A team consisting of a physician, a nurse, a pharmacist and a social worker supervises, monitors and supports community-based TB treatment supporters and can provide rapid care to patients if needed.
- Plans are in place for good and rapid communication with laboratories providing the tests in order to monitor the response to treatment and detect adverse drug reactions.
- All community-based TB treatment supporters are trained in patient confidentiality and in methods to decrease stigma.
- All community-based TB treatment supporters are fully covered for all out-of-pocket costs associated with their work. The TB treatment supporters also receive fair compensation for the services being provided to the patients (Note: compensation is more than just reimbursement of the out-of-pocket costs of doing the job and needs to be included in the budget of all TB programmes that use community-based TB treatment supporters).

## 5.1.2 Inpatient model of TB treatment and care

Some patients may need to stay in hospital to receive treatment for TB. This is the case, for instance, if a patient has a severe form of DS-TB or DR-TB disease (e.g. meningitis, vertebral bone infection, pericarditis, miliary TB or severe TB lung disease with signs of respiratory distress/failure or sepsis), has serious comorbidities (e.g. severe malnutrition, untreated HIV, uncontrolled diabetes mellitus), is either very young or quite old, or has serious adverse reactions to medication (66). In these cases, the patients may need to be hospitalized until these conditions stabilize. In the past, patients with DR-TB, were routinely kept in hospital until the end of the intensive phase of treatment or until conversion to smear/culture-negative status. Long hospitalization should not be routinely required for patients on DR-TB treatment unless it is absolutely medically necessary. The treatment regimen should rarely require a patient with DR-TB to be hospitalized because every attempt should be made to put the patient on an all-oral regimen that they can receive as an outpatient. Additionally, a patient should be kept in isolation while hospitalized only when no other options remain.

Box 4 lists things to consider when a patient must be hospitalized. Hospitalized patients should have access to all the social support services they need (see section 3.1). Patients should be hospitalized for the shortest amount of time that is medically safe, and this duration of time should regularly be

reassessed by the health-care providers. Every effort should be made to transfer the patient's care to outpatient clinics as soon as it possible.

Good communication and coordination need to be in place between the hospital(s) and outpatient care providers. This should include: 1) notification to appropriate outpatient teams several days ahead of the planned discharge of the patient from the hospital; and 2) supplying all clinical information about the patient, including all prescribed drugs needed for the first 2–4 weeks of treatment as an outpatient.

An assessment of the risks for a patient who is not able to take his/her medicines and a plan to reduce the risks with social support should be discussed with patient and the outpatient care providers well ahead of the patient's discharge from hospital.

#### **Box 4. Basic conditions to be considered when a TB patient needs hospital care (inpatient)**

- Basic standards for respiratory infection control are in place.
- Respiratory isolation rooms are available for all patients who remain smear- or culture-positive.
- All staff are properly trained in TB infection control.
- Treatment support teams are available to provide all recommended and necessary services to all patients.
- An open and safe space is available for patients to socialize and conduct occupational therapy activities.
- Friendly administrative procedures are in place to allow family members to visit patients regularly.
- There is good communication with the laboratories providing services during treatment, and with the health-care centres that will take over the patient's care after discharge from hospital.
- Social support should be provided to patients to pay for hospital-related costs, which may include transport to and from the hospital of relatives or family caregivers living close by.

### **5.1.3 Deciding on the best-suited model for a situation**

It is important to remember that: 1) decisions on the model of care for a particular situation should not be made in the belief that only one model serves the needs of all patients in a particular setting; and 2) in some settings, allowing community health-care workers to do more and different types of jobs to relieve staff shortages and to encourage more meaningful community participation may be important to allow services to be available to all patients. Therefore, in real-life circumstances, multiple models of care may be used depending on the needs of the patient and the resources of the health-care system.

Some patients may need hospital-based care (inpatient model) either while receiving complicated treatment or when on end-of-life care. This is because hospitals play a very important role in the clinical management of severe TB disease and DR-TB. This includes: treatment of TB comorbidities (such as HIV or noncommunicable diseases (e.g. diabetes, severe mental health disorders); surgical treatment

of selected TB patients; management of severe adverse drug reactions (particularly to second-line anti-TB drugs); treatment of pulmonary complications in patients with severe TB disease; medical support during palliative and end-of-life care; and the initial care of patients who are homeless, have difficult family situations, or who live in remote areas where TB care is difficult or DR-TB care is not yet available.

However, in some settings, depending only on an inpatient model of care may result in problems, namely: it may slow down or even make it impossible to get all patients into treatment due to the high costs of hospital care; create long patient waiting lists due to the lack of hospital beds; cause longer than necessary suffering of patients with TB; and create catastrophic costs for patients. An outpatient system must be in place to support patients upon discharge even in settings that rely mainly on a hospital-based model. Thus, the ability to provide ambulatory TB care has to be built into whatever model is used.

When comparing different treatment models, a number of issues have to be considered (see Box 5) and ethical concerns need to be respected. While outpatient care is often socially more acceptable to patients and reduces health system costs, the creation of outpatient person-centred treatment support is challenging. It requires access to a primary health care network, strong social support and community-based care. However, in some settings, the community-based decentralized model of care is the only way to achieve universal access to treatment.

Whichever model is chosen to provide treatment for TB, a multidisciplinary team of providers – including physicians, nurses, psychologists, social workers and community health workers or volunteers – should be involved in care. The roles and responsibilities of each of these groups of providers will vary depending on the needs and resources available in specific settings.

Adherence to TB treatment – particularly DR-TB treatment – is challenging and therefore social support and social protection measures to improve adherence should be used, whichever model is chosen (see Section 3.1).

The risk of TB (with particular concern for DR-TB) transmission when proper infection control measures are not being used occurs in all models of care whenever the patient remains sputum smear-/culture-positive. However, the risk is particularly serious in the hospital-based model where the adverse effects of transmission could be higher (hospitals are crowded so it is easier to infect more people, and those people are likely to have other serious illnesses as well). This is a critical factor to consider when selecting a model of care for a DR-TB patient.

Person-centred treatment support is the method recommended to deliver treatment and support patients in each of the models of care. New ways to deliver person-centred treatment include VST, which can also be considered in any of the models of care presented above. More specific and detailed WHO guidance on how to implement VST and other digital based technologies to monitor adherence to treatment are presented elsewhere (25).

### Box 5. Factors to consider when selecting the model of care for TB patients

- Patients' needs, values and preferred options for treatment.
- Attitudes of caregivers, patients and their families to the different options of care.
- Local laws and ethical standards.
- The availability of care (of particular concern for DR-TB care).
- Quality of infection control measures used in the hospital or clinic.
- The ability to teach patients and family about hygiene and infection control measures at the household level.
- Comorbidities (e.g. HIV, mental health illnesses, diabetes mellitus, liver disease, kidney disease, malnutrition and substance use disorders (particularly alcohol and opioids)).
- Funding to support health-care workforce delivery of person-centred treatment support.
- Availability of private sector and public hospitals to provide DR-TB management.
- Training requirements for the different models.
- Capacity to train and supervise TB treatment supporters, with special attention to the more complex DR-TB treatment.
- Social support networks to assist person-centred treatment support.
- Costs of a specific model of care.
- Political commitment from the government to implement and sustain the model of care most convenient to the needs of the patient and health system.

## 5.2. Decentralized and integrated family-centred models of TB care for children and adolescents

In high TB burden countries, the capacity to manage TB in children and adolescents is often centralized at the tertiary or secondary level of health care rather than being decentralized at the primary health care level where children and adolescents with TB or TB exposure commonly seek care (67, 68). Care at higher levels in the health system is often managed in a vertical, non-integrated way. Children and adolescents with TB may go undetected because of missed opportunities for contact investigation, TB prevention, detection and care, and as a result of weak integration of child and adolescent TB services with other programmes and services – especially the integrated management of childhood illness (IMCI), malnutrition and HIV services. If not addressed, such access challenges contribute to preventable delays in diagnosis and treatment, which may lead to increased disease severity, suffering and mortality (69).

An important step towards improving access to TB prevention and the management of TB in children and adolescents is the provision of decentralized, family-centred integrated care (67). Integrated, person-centred care and prevention is a key pillar of WHO's End TB Strategy and aims to ensure that all people with TB have access to affordable high-quality services according to their needs and preferences (5). This is further underpinned in the 2018 WHO roadmap towards ending TB in children

and adolescents (67), which calls for the implementation of integrated family- and community-centred strategies.

This section focuses on models of care to increase access to TB services for children and adolescents through family-centred, integrated care. Family-centred models of care refer to interventions selected on the basis of the needs, values and preferences of the child or adolescent and their family or caregiver. This can include health education, communication and material or psychological support. Integrated services refer to approaches to strengthen collaboration, coordination, integration and harmonization of child and adolescent TB services with other child health-related programmes and services. This can include integration of models of care for TB screening, prevention, diagnosis and treatment with other service delivery platforms for maternal and child health (e.g. antenatal care, integrated community case management, IMCI) and other related services (e.g. HIV, nutrition, immunization). Other examples include the evaluation of children and adolescents with common comorbidities (e.g. meningitis, malnutrition, pneumonia, chronic lung disease, diabetes, HIV) for TB and community health strategies that integrate child and adolescent TB awareness, education, screening, prevention and case-finding into training and service delivery activities.

The following are the WHO recommendations on decentralized and integrated family-centred models of care for TB services for children and adolescents (70).

### Recommendations:

- 3.1. **In TB high burden settings, decentralized TB services may be used in children and adolescents with signs and symptoms of TB and/or those exposed to TB**  
*(conditional recommendation, very low certainty of evidence).*
- 3.2. **Family-centred, integrated services in addition to standard TB services may be used in children and adolescents with signs and symptoms of TB and/or those exposed to TB**  
*(conditional recommendation; very low certainty of evidence).*

Comments:

- These recommendations are applicable to children and adolescents with signs and symptoms of TB in terms of the impact on case detection. They also apply to children and adolescents who are exposed to TB (TB contacts) and who are eligible for TB preventive treatment (TPT) in terms of the impact on provision of TPT. Children and adolescents with signs and symptoms who need evaluation for TB disease may also have a history of exposure to TB (TB contacts). Children and adolescents who are TB contacts who do not have signs and symptoms need to be evaluated for TPT eligibility.
- The recommendation on decentralized services refers to enhancing child and adolescent TB services at peripheral levels of the health system that are closer to the community, and not to replacing specialized paediatric TB services at higher levels of the health system.
- Decentralization should be prioritized for settings and populations with poor access to existing services and/or in areas of high TB prevalence.
- Family-centred, integrated approaches are recommended as an additional option to standard TB services (e.g. alongside specialized services that may have a limited level of integration with other programmes or linkages to general health services).
- Family-centred care is a cross-cutting principle of childcare at all levels of the health system.

These approaches on decentralization and family-centred integrated care aim to bring TB services closer to where children, adolescents and families live. As the recommendations were published in 2022 (70), evidence on the best ways to implement these recommendations is emerging, and national programmes are encouraged to document examples of best practice in this area.

Decentralization includes the provision of access to or capacity for child and adolescent TB services at a lower level of the health system than the lowest level where it is currently routinely provided. In most settings, decentralization applies to the district hospital level (first referral level), the primary health care level or the community level. Interventions to facilitate decentralization include capacity-building of various cadres of health-care workers, access to diagnostic services, availability of TB medicines for children and adolescents, and follow-up of children and adolescents with TB or on TPT.

Since children and adolescents who are unwell commonly seek care at the primary health care level, where TB services are not always available, decentralization and integration of such services using a family-centred approach has the potential to improve access to care, especially for children and adolescents who do not need referral to a higher-level facility. The objectives of decentralization are closely linked to the aspirations of universal health coverage (all people have access to the health services they need, when and where they need them, without financial hardship), which is a strategic priority for Sustainable Development Goal (SDG) target 3.8 (71).

Decentralization of care at the community level has the following advantages:

- increased equity via improved access to health services;
- provision of TB care at the same time and in the same place for all family members;
- savings in time and money when care is provided closer to home;
- continuity of care between the person's home, community and local health centre;
- increased community support, which may lead to better adherence to treatment and can be instrumental in overcoming barriers to long-term care, including treatment adherence, transportation costs, missing school, and loss of wages during sickness and clinic visits.

Other potential benefits of decentralization in the context of TB include increased treatment coverage in children and adolescents, reduced time to diagnosis and time to treatment, improved treatment success among children and adolescents started on TB treatment and TPT initiation, and reduced transmission (72–75).

Regarding family-centred integrated care, many opportunities exist for the integration of TB services. For instance, opportunities for the integration of TB services at the health facility level exist in outpatient departments; nutrition, HIV, maternal and child health clinics (e.g. prevention of mother-to-child transmission, antenatal care, immunization clinics); general paediatric, adult TB and chest clinics; and inpatient departments. If resources are available, the NTP may consider implementing provider-initiated TB screening in relevant child health entry points, and linkages to diagnosis or treatment. If resources are limited, entry points or services designed to care for sick children could be prioritized.

The WHO policy on collaborative TB/HIV activities recommends the delivery of integrated TB/HIV services, preferably at the same time and location (76). The policy further recommends that HIV programmes and NTPs should collaborate with other programmes to ensure access to integrated and quality-assured services, including for children and adolescents. Quality statement 1.8 of the *Standards for improving the quality of care for children and young adolescents in health facilities* recommends that all children at risk for TB or HIV are correctly assessed and investigated and receive appropriate management according to WHO guidelines (77).

Many health-care providers at the primary health care level in high TB burden countries have been comprehensively trained on assessing and caring for children with pneumonia, diarrhoea and malnutrition using IMCI and integrated service delivery packages on community case management. These packages are centred on the most common childhood illnesses, such as pneumonia and malnutrition, which have a clinical presentation similar to TB (78, 79). Therefore, they offer an opportunity to strengthen integrated symptom-based screening for TB in sick children aged under 5 years. Specifically, the 2014 *WHO IMCI chart booklet* (79) caters for referral of children with a cough for more than 14 days, assessment of TB infection among children with acute malnutrition, and TB assessment and TPT among children living with HIV (78, 79).

Several considerations for the implementation of decentralized and integrated family-centred models of care for children and adolescents are included in the *WHO operational handbook on tuberculosis. Module 5: management of tuberculosis in children and adolescents* (69).

### **Treatment support**

Implementation of the recommendations related to treatment support should enable the provision of people-centred TB services. Treatment adherence interventions that may be offered for people on TB treatment may include material support (e.g. food, financial incentives, transport fees), psychological support, tracers such as home visits or digital health communication (e.g. SMS, telephone) and medicine monitoring (75, 76). Interventions should be selected on the basis of assessment of the individual's needs and preferences as well as available resources. It is important to involve local schools, including educating teachers and other staff about TB and providing accurate information about infectiousness, the needs of children and adolescents with TB or TB/HIV coinfection, the necessity for frequent visits to clinics, and the importance of taking medicines regularly. This may help to reduce stigma in schools and minimize time out of education. Faith-based organizations and other community groups can also be involved in supporting children and adolescents with TB and their families.

### **Socioeconomic impact of TB on children, adolescents and families**

TB commonly affects people of lower socioeconomic status and worsens poverty through high costs related to treatment and reduced household income. Most children with TB develop it after contact with an adult family member with active infectious pulmonary TB (PTB). A high number of TB notifications in children indicates an ongoing adult epidemic (80). TB in the family threatens household income and financial security.

Some examples of the impact of TB on children include dropping out of school following parental bereavement from TB or leaving school to go to work to maintain household income (81). TB in childhood or adolescence may also disrupt or delay schooling and impair growth (82). A recent scoping review reported that time spent caring for a child with TB had impacts on family spending, nutrition and education, and overall reduced household income – all of which were associated with lowered family well-being.<sup>8</sup> In addition, perceived and enacted stigma had practical implications for TB diagnosis, clinic attendance and treatment, and other psychosocial impacts beyond stigma, including breakdown of parental relationships. School disruption, food insecurity and a lack of social protection have also been reported for children and adolescents with TB based on an analysis of national TB patient cost surveys.<sup>9</sup>

## **5.3. Models of service delivery for people with TB, HIV and comorbidities**

Models of service delivery for people with TB and comorbidities range from the least integrated, where stand-alone disease-specific providers refer patients to the relevant specialist services for comorbidities, to the most integrated, where all services across the cascade of care for TB and key comorbidities are provided in a “one-stop-shop” by one health-care worker (83, 84).<sup>10</sup> Services may be provided at different levels of the health system, depending on the availability of comprehensive primary care and the degree of decentralization of the respective services. In some settings, TB services may be decentralized to the primary care level, while services for comorbidities such as diabetes and mental disorders may be available only at the secondary care level. In this situation, the degree

<sup>8</sup> Atkins S et al., unpublished, 2022.

<sup>9</sup> Nishikiori N et al., unpublished, 2022.

<sup>10</sup> The models of care described here are categorized according to where a person first seeks care, and according to the degree of integration. They are not prescriptive; national programmes should define the models that best enable the provision of quality-assured comprehensive services as close as possible to the end-user.

of integration can be increased only if diabetes and mental health services are also decentralized closer to the end-user (22). The provision of integrated care and comprehensive services for people with HIV-associated TB as close as possible to where they live has long been a focus of WHO policy documents. Such efforts should include integrating services for the prevention, diagnosis, treatment and care of TB and HIV into maternal and child health services, including the prevention of parent-to-child transmission of HIV, and treatment centres for drug dependency where applicable (76).

Within these models, care may be provided by separate specialist health-care workers who refer patients to different services according to established pathways. Alternatively, multidisciplinary teams comprising professionals with a mix of skills, including medical and nonmedical, that are required to meet the needs of the end-user, may provide coordinated care (85). Care can also be provided by one health-care worker for both TB and comorbidities, where the expertise is available (e.g. for TB and HIV) (84). All models of care may be strengthened by the engagement of community health-care workers, outreach teams and peer supporters.

## 5.4. Private-sector involvement in TB care

In many high TB burden countries, the majority of people seek treatment from private providers not linked to the public health-care system (86). Private health-care providers are an entry point to TB care and treatment (86–88). However, people with TB may not have good-quality TB services if the NTP does not cooperate with the private sector. Health-care providers in the private sector may not be provided with information about TB or trained in the up-to-date guidance on TB diagnosis and treatment, including the use of child-friendly formulations. Additionally, patients managed in private health facilities and services are often not notified to the NTP. A wide range of private health-care providers exist in different settings, and the services they provide vary. It is important for NTPs to recognize the different private health-care providers in the community and work with them to improve the services TB patients are receiving. Private health-care providers should particularly be educated on TB – including TB prevention, screening, diagnosis, treatment and care – and should understand the importance of mandatory reporting (67). Working with professional organizations and nongovernmental organizations who also work with the private sector may help to build relationships with the private sector in providing TB care.

## 5.5. TB and health emergencies

Health emergencies, such as the COVID-19 pandemic, are associated with a disruption in health service delivery, either directly due to the focused attention given to the emergency or indirectly due to the actions taken to control the emergency.

The COVID-19 pandemic has reversed years of progress in providing essential TB services and reducing the disease burden of TB. There has been a large global drop in the number of people newly diagnosed with TB. Reduced access to TB diagnosis and treatment has resulted in an increase in the number of TB-related deaths.

Indirect impacts of health emergencies, such as reduced household income, increased poverty, food insecurity, malnutrition, missed health checks, missed vaccinations and missed work or schooling, may affect TB diagnosis and care.

In May 2021, WHO updated its information note on *COVID-19 – considerations for tuberculosis (TB) care* to guide countries on approaches to maintaining TB services (89). For instance, both COVID-19 and TB have respiratory symptoms, which provides an opportunity to diagnose both COVID-19 and TB (90).

Programmes should make sure that there are enough stocks of TB preventive therapy for the predicted increased need for this therapy resulting from people with undiagnosed TB and increased associated



exposure because of COVID-19-related lockdowns. NTPs should ensure that supplies of TB medicines are not interrupted and that people with TB are provided with adequate refills to enhance treatment completion and minimize frequent trips to health facilities, where there may be an increased risk of infection from COVID-19. This may be achieved via multi-month dispensing or community delivery of TB medicines. Efforts should be made to ensure that neonatal and infant Bacillus Calmette–Guérin (BCG) vaccination continues uninterrupted.



# 6. Palliative care

Palliative care is the preventing and relieving of the suffering of people affected by TB during and after treatment and at the end-of-life.

Many people with TB, and most with DR-TB, suffer in multiple ways: from physical symptoms such as pain or dyspnoea, from psychological symptoms such as anxiety or depression, and from social problems such as discrimination or homelessness. This suffering may be due to the disease, its treatment, physical or psychological comorbidities such as HIV/AIDS, diabetes, or mental health/substance use disorders, stigma and discrimination, or extreme poverty (91, 92). People continue to die from both DR-TB and DS-TB (93), and their family members may suffer from the stress of caregiving, financial challenges, further stigma and grief (91).

## 6.1 What is palliative care?

Palliative care is the prevention and relief of the physical, psychological, social and spiritual suffering of adults and children with serious illnesses and psychosocial support for their families (94, 95). The prevalence, types and severity of suffering of people with TB vary by geopolitical situation, socioeconomic conditions, culture, accessibility of primary and specialized health care, and the susceptibility of their TB to anti-TB medicines. Attention to local needs is necessary for palliative care services to be person-centred: tailored to local needs and to the needs of individual patients and families (94, 96).

### 6.1.1 Why is palliative care an essential part of comprehensive TB care?

WHO's End TB Strategy has a vision of zero suffering (73). Based on this vision alone, palliative care is an essential part of comprehensive care for people with TB (73, 91, 94, 97). In addition, World Health Assembly Resolution WHA67.19 from 2014 and the WHO Ethics Guidance for the implementation of the End TB Strategy state that palliative care is "an ethical responsibility of health systems and that it is the ethical duty of health-care professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured." (76). They also state explicitly that palliative care is a core component of the human right to health, and of comprehensive care for people with DR-TB (76, 94). Palliative care not only can alleviate the suffering of patients with TB but also may improve treatment outcomes and protect the community by helping patients adhere fully to treatment (91, 92).

### 6.1.2 When and where should palliative care be provided for people with TB?

An initial assessment for suffering related to TB should be done at the time of diagnosis. Palliative care should be initiated immediately as needed and should be combined with TB treatment to relieve any suffering due to the disease, to the adverse effects of treatment, to comorbidities, or to social problems. It is especially important for people with DR-TB (98). Tailored to the patient's needs, palliative

care should continue regardless of whether the cure is expected or whether treatment fails. It should be available at all levels of the health-care system (94–96), namely:

- TB and lung disease hospitals and general hospitals with TB units;
- district hospitals;
- TB clinics in the community;
- patients' homes.

Even when a patient recovers from TB disease, all the medical effects of TB may not be resolved. People that survive TB may have long-term impairment from TB disease (99–102). People who had bone or neurological infections may continue to have problems related to bone damage or neurological issues. It is also becoming more and more recognized that even people who had pulmonary TB may have serious long-term medical problems resulting from lung damage resulting from TB. Studies find that a majority of patients report respiratory symptoms after completing TB treatment. Patients may have continued shortness of breath, cough, decreased lung function, bronchiectasis and recurrent bacterial pneumonia. They may also develop heart failure due to lung damage. These symptoms often continue to affect their daily lives. Although many people improve with time, a significant number continue to have symptoms, and their symptoms may even worsen with time.

It is important to continue to monitor the health of TB patients even after they have finished their medications for TB disease. They may need to be followed by a lung or heart doctor to help treat ongoing symptoms. They may benefit from palliative care which can offer treatments to help with their symptoms such as shortness of breath, swelling from heart disease, pain, and psychiatric care to help patients who are facing long-term health problems.

### 6.1.3 Who should provide palliative care for people with TB?

Most palliative care can and should be provided by TB and lung disease specialists, primary care doctors and nurses with at least basic palliative care training (30–40 hours of training), TB treatment supporters and community health workers trained to recognize and report uncontrolled suffering, and by social workers and psychologists (91, 92, 94–96). Ideally, specialist palliative care doctors should be available to treat patients with refractory or complex suffering and also as supervisors, consultants and teachers.

### 6.1.4 What is end-of-life care for people with TB?

End-of-life care is palliative care for patients whose curative treatment options have been completely exhausted. When failure of all curative options is suspected, it is imperative that careful plans be made both:

- to suspend all non-beneficial anti-TB therapy, and
- to commence end-of-life care combined with infection control.

These plans are crucial to maximize the patient's comfort and quality of life, help prevent transmission, and protect public health.

## 6.2. Planning and implementing palliative care for people affected by TB

### 6.2.1 Integration of palliative care into national tuberculosis programmes

Most people with DR-TB, and many with DS-TB, have palliative care needs. Yet palliative care is in general not widely accessible in high TB burden countries (103). Wherever palliative care services are not yet accessible, the NTP may need to take the lead in planning and implementing them (16). If possible, official collaboration should be established between an existing palliative care programme and the NTP (104). Plans for TB palliative care should include the following:

- a list of palliative care interventions (Table 5);
- an essential package of palliative care (medicines, equipment, social supports, human resources) (Table 6);
- the estimated number of patients to be served;
- models of care that are responsive to the needs of patients;
- regulations to assure access to essential medicines for palliative care;
- monitoring and evaluation; and
- sustained funding to cover the costs of the operation (91).

**Table 5. Palliative care interventions needed for people with TB**

General intervention	Specific examples
Physical suffering relief	<ul style="list-style-type: none"> <li>• Assessment and treatment of pain, dyspnoea and other physical symptoms due to TB.</li> <li>• Assessment and treatment of pain and other physical symptoms due to comorbidities, adverse drug reactions or adverse events.</li> </ul>
Psychological suffering relief/psychological support	<ul style="list-style-type: none"> <li>• Assessment and treatment of psychological symptoms or mental illnesses such as anxiety, depression, delirium or hallucinations.</li> <li>• Assessment and treatment of substance use disorders such as alcohol use disorders.</li> <li>• Counselling to promote coping and treatment adherence.</li> <li>• Counselling to assist patients to prepare for death when appropriate.</li> <li>• Bereavement counselling as needed for family members.</li> </ul>
Social suffering relief/social support	<ul style="list-style-type: none"> <li>• Counselling to mitigate stigma and discrimination.</li> <li>• Specific supports for patients or family caregivers living in extreme poverty (Table 6).</li> <li>• Referral for legal counselling as needed.</li> </ul>
Spiritual suffering relief/spiritual support	<ul style="list-style-type: none"> <li>• Enable access to local volunteer spiritual supporters.</li> </ul>

## 6.2.2 Essential package of palliative care for people affected by TB

The essential package of palliative care for people affected by TB consists of a set of medicines, simple equipment, social supports and human resources (Table 6). Adapted from the WHO essential package of palliative care for primary care (95), it is designed to be safe and effective for preventing and relieving all types of suffering associated with TB (Box 6). The package includes only inexpensive and readily available medicines and equipment, and its use requires only basic palliative care training (30–40 hours). Consequently, this package can and should be made accessible everywhere, including for the rural poor. The medicines include: at least one non-opioid analgesic, opioid analgesic, anti-pyretic, anti-emetic, anxiolytic, antidepressant, antihistamine, anticholinergic, antifungal, and anti-diarrhoeal agent; as well as a bronchodilator, corticosteroid, diuretic, expectorant, laxative, neuroleptic and proton pump inhibitor.

**Table 6. Essential package of palliative care for people affected by TB (91, 105)**

<b>Medicines*</b>
Albuterol metered-dose inhaler
Amitriptyline, oral
Bisacodyl (Senna), oral
Dexamethasone, oral and injectable
Diazepam, oral and injectable
Diphenhydramine (chlorpheniramine, cyclizine or dimenhydrinate) oral and injectable
Fluconazole, oral
Fluoxetine (sertraline and citalopram), oral
Furosemide, oral and injectable
Guaifenesin, oral
Haloperidol, oral and injectable
Hyoscine butylbromide, oral and injectable
Ibuprofen (naproxen, diclofenac or meloxicam), oral
Lactulose (sorbitol or polyethylene glycol), oral
Loperamide, oral
Metoclopramide, oral and injectable
Metronidazole, oral – to be crushed for topical use
Morphine, oral fast-acting and injectable
Naloxone, injectable
Omeprazole oral
Oxygen

Paracetamol, oral
Petroleum jelly
<b>Equipment</b>
N-95 respirator masks
Surgical masks
Antimicrobial hand wash
Spacers for metered-dose inhalers
Pressure-reducing mattress
Nasogastric drainage & feeding tube
Urinary catheters
Opioid lock box, only for hospitals & clinics
Flashlight with rechargeable battery (if no access to electricity)
Adult diapers/cotton and plastic
<b>Social supports**</b>
Cash payment monthly for housing or school tuition
Food package monthly
In-kind support once per patient or caregiver, including blanket, sleeping mat, shoes, soap, toothbrush, toothpaste
Transportation costs to receive health care
Funeral costs, once, only if patient & caregiver in extreme poverty
<b>Human resources for palliative care***</b>
Doctor with at least basic training in palliative care (specialist or general practitioner)
Nurse with at least basic training in palliative care (specialist or general)
Social worker, psychologist or counsellor
Pharmacist
Community health workers/TB treatment supporters

\* Based on *WHO Model List of Essential Medicines, 2019*. In parentheses () are acceptable substitutes where the primary recommended medication is not available or is expensive.

\*\* For patients who qualify on the basis of financial need.

\*\*\* Staffing will vary depending on the level of the health-care system (referral hospital, provincial hospital, district hospital, community health centre, or home). Staff members of palliative care centres or wards may provide palliative care full-time. Others may provide relief of suffering combined with TB treatment most of the time and may provide end-of-life care only when needed. All staff members should be trained to practise and teach infection control.

### 6.2.3 Oxygen for relief of mild dyspnoea

Oxygen therapy may provide relief from mild dyspnoea and sometimes at least partial relief from moderate dyspnoea. It should be accessible at least in TB hospitals and wards. Whenever possible, it also should be accessible in the home.

### 6.2.4 Morphine for safe relief of chronic or refractory dyspnoea

Strong opioids such as morphine have been proven to relieve safely and effectively not only pain but also dyspnoea that is refractory to oxygen therapy and treatment of the underlying cause (106–112). Morphine is the most studied and least expensive strong opioid and is widely available on the world market. Consequently, morphine, in both oral fast-acting and injectable preparations, is the most essential of the essential palliative medicines for people with TB (106, 107). Misconceptions about the use of opioids held by health-care workers and caregivers result in unnecessary suffering from pain and chronic or refractory dyspnoea and perpetuate unethical medical practices (108). NTPs should work with the officer responsible for controlled medicines at the health ministry to ensure that these morphine preparations are accessible for TB palliative care at least in TB hospitals and wards, and ideally also at TB clinics, according to international standards (91, 94, 106, 107, 109–112).

### 6.2.5 Palliative care teamwork

Palliative care is best provided by a multidisciplinary team whenever possible (104). The ideal palliative care team includes a physician, nurse and psychologist or social worker. TB treatment supporters, community health workers or volunteers can be trained and supervised to visit patients at home, to provide emotional support, to recognize and report inadequately controlled suffering or inappropriate use of opioids, and to practise and teach strict infection control (91).

### 6.2.6 Management of substance use disorders and other comorbidities

People affected by TB are often also affected by other medical conditions such as HIV/AIDS, diabetes, hepatitis, chronic lung disease, neurological disease, substance use disorders and other mental health problems. Some of these illnesses and disabilities may by themselves contribute to an increased risk of death among people with TB while on treatment and afterwards. When creating TB palliative care services, the prevalence of serious comorbidities in the target population and the associated types of suffering should be estimated and preparations should be made to address them. Mental health disorders may worsen when TB patients learn of a poor prognosis. Therefore, all TB patients in need of palliative care should undergo an assessment for mental health disorders.

Alcohol use disorder and injection drug use are risk factors for poor DS-TB and DR-TB treatment outcomes and many other problems (113–115). Treatment of alcohol use disorder and opioid use disorder can and should be integrated with comprehensive TB care and treatment (116, 117). WHO guidance on task-shifting, training and supervision of human resources for palliative care is provided elsewhere (104). Task-shifting to enable effective community-based treatment of alcohol use disorder has also been demonstrated (118, 119).



## 6.2.7 Monitoring and evaluation of palliative care for people affected by TB

Palliative care for people affected by TB should be monitored and evaluated to help assure its accessibility and quality (104, 120, 121). The following two outcome indicators are recommended:

- Number of patients with TB in the previous reporting period/year for whom all attempts at curative treatment were deemed to have failed.
- Number of patients with TB in the previous reporting period who received morphine (oral fast-acting or injectable) for symptom relief.

The following process indicators are optional but also suggested:

- Is there a national TB policy strategic plan that includes palliative care? (Yes / No / NA)
- Is morphine (oral fast-acting or injectable) available in public TB hospitals or wards (Yes / No / Unknown) (available in over 50% of TB hospitals or wards)?

## 6.2.8 Cost savings from palliative care integration into TB programmes

The essential palliative care package need not increase the cost of the routine TB care and treatment significantly, if at all. There is growing evidence that palliative care integrated into health-care systems and including home care can save money for these systems by reducing hospital admissions near the end of life and the length of stay in hospitals (92, 105, 122–125). For patients not expected to survive, a one-time expense may be necessary to refurbish rooms either in institutions or in the home to ensure infection control. Palliative care has also been shown to provide financial risk protection for patients and families (92, 126, 127).

## 6.3. End-of-life care for people with TB

### 6.3.1 When should suspension of TB treatment be considered?

TB treatment often consists of an initial treatment cycle and, if no response is seen, it is necessary to reassess the regimen and treatment plan as well as to formulate a new plan of action. Suspension of drug therapy is recommended in cases where the medical personnel involved are confident that the patient has been adherent to the prescribed regimen, the patient is on the correct regimen with respect to drug sensitivities (e.g. the patient is not on a DS-TB regimen if they may have DR-TB) and there is no possibility of offering another effective therapy (61). In patients who have no therapeutic options, there is a medical, moral and public health obligation to continue providing care to the end of life with proper infection control (91, 103).

### 6.3.2 Important considerations in suspending TB treatment

There are at least three important considerations in suspending anti-TB therapy:

- **Doing no harm:** The medicines used to treat TB, and especially DR-TB, have significant adverse effects. Continuing them while the treatment is failing may cause additional unnecessary suffering and create false expectations in patients and families.
- **Public health:** Patients in whom DR-TB regimens fail are likely already to have highly resistant strains, and ongoing therapy can result in resistance to even more medications. The resultant highly resistant strains could subsequently infect others and be extremely difficult to treat. In addition to the creation of further resistance, continued treatment in this situation also uses resources that may

be very scarce. Thus, in general, treatment should be discontinued in this situation. However, if there is no clinical deterioration and the clinician prefers to continue the regimen, strict respiratory infection control is critical.

- **Non-abandonment:** Provision of palliative and end-of-life care is imperative to optimize the quality of life with proper TB infection control (16, 91).

### 6.3.3 Decision-making about suspension of TB treatment

If suspension of DR-TB therapy is considered, there should be discussion with the entire clinical team – including the patient and all physicians, nurses and health workers or TB treatment supporters involved in the patient's care. If the clinical team decides together that treatment should be suspended, a clear plan should be prepared for approaching the patient and the family. This process usually requires personal interaction with patient and family, ideally including home visits, and may take several weeks. It is not recommended to suspend therapy before the patient understands and accepts the reasons to do so, agrees with a change in goals of care to optimizing quality of life and comfort, and accepts palliative care. It is crucial that care continues and that the patient not be abandoned.

#### Box 6. Checklist of essential palliative and end-of-life care

- **Is relief from dyspnoea offered?** Oxygen may be used to alleviate shortness of breath in some cases, but there is no significant evidence to generalize its practice. Bronchospasm can be controlled with a metered-dose inhaler with a spacer or mask. Morphine and other strong opioids provide effective relief from chronic or refractory dyspnoea and should be offered according to established clinical protocols available in the medical literature (106–111). Morphine also relieves cough refractory to bronchodilators, guaifenesin or non-opioid cough suppressants.
- **Is relief from pain and other symptoms offered?** Paracetamol typically gives relief from mild pain. A strong opioid such as morphine should be used to treat moderate or severe pain (110–112). Antiemetics and antipyretics may be needed.
- **Is psychological support being offered?** Psychological counselling for the patient and family caregivers is critical for providing emotional support and assisting patients with end-of-life decision-making. Patients should be assessed for anxiety or depression and treated whenever the assessment is positive. Any doctor with basic palliative care training should be able to diagnose and treat uncomplicated anxiety disorders, depression, and delirium (91, 95). Patients with complex mental health problems should have virtual or in-person psychiatric evaluation.
- **Are infection control measures being applied thoroughly?** A patient who is taken off anti-TB treatment because of failure often remains infectious. Infection control measures should be continued with reinforcement of environmental and personal measures, including N95 mask use for caregivers and surgical masks for patients.
- **Is there respect for patient's beliefs and values?** Every patient is different, and an acceptable quality of life for one patient would not be acceptable to another. As much as possible, the patient's wishes for the location and type of care should be respected (10, 16, 91). Also, it is common for patients and family caregivers to develop or increase their interest in spirituality or religion once they perceive that the end of life is approaching. Health-care providers should respect those beliefs and not impose personal values and practices.

- **Has the patient received nutritional assessment and support?** Small and frequent meals are often best for a person at the end of life. Nausea and vomiting should be treated, but it should be accepted that appetite and intake will decline as the patient's condition deteriorates and during end-of-life care. Artificial nutrition, either enteral via gastric tube or parenteral, typically provides no longevity benefit and often worsens suffering from dyspnoea or oedema.
- **Is the patient being visited regularly by the TB programme?** When TB treatment stops, regular visits by health care providers and the support team should continue in order to address medical needs and to ensure that infection control practices are being followed.
- **Are all basic hygiene and preventive measures being given?** Oral care, prevention of bedsores, bathing and prevention of muscle contractures are indicated in all patients. Regular scheduled movement of the bedridden patient is very important except in the last hours of life. Encourage patients to move their bodies in bed if able to do so. Keeping beds dry and clean is also important.

### 6.3.4 Providing end-of-life care for people with TB

End-of-life care can be provided either in an inpatient setting (hospital or hospice) or in the home depending on: the preference of the patient; the willingness of the relatives and community to provide home care; the presence of a medical need for inpatient care; and the existing capacity for proper infection control in each setting (91, 122). Palliative home care combined with strict infection control may be preferred by many patients and may be less expensive than institutional care for health-care systems. Patients could be with family and friends rather than isolated in an institution that may be far from home. Those who are well enough may be able to engage with family in income-earning activities such as crafts or Internet-based businesses. However, adherence to infection control measures should be a prerequisite for remaining at home. TB programmes should explore opportunities to collaborate with local palliative care programmes to provide palliative home care for people with TB. In addition, TB programmes should build basic capacity for the estimated number of patients in need of institutionally-based end-of-life care either for medical reasons or because of the lack of relatives or community members willing to provide home care.



# References

1. International Standards for Tuberculosis Care. The Hague: Tuberculosis Coalition for Technical Assistance; 2014.
2. Health systems strengthening glossary [website]. Geneva: World Health Organization; 2016.
3. A people-centred model of TB care. A blueprint for eastern European and central Asian countries, first edition. Copenhagen: World Health Organization Regional Office for Europe; 2017 ([https://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0004/342373/TB\\_Content\\_WHO\\_PRO\\_eng\\_final.pdf](https://www.euro.who.int/__data/assets/pdf_file/0004/342373/TB_Content_WHO_PRO_eng_final.pdf), accessed 22 June 2022).
4. Horter S, Daftary A, Keam T, Bernays S, Bhanushali K, Chavan D et al. Person-centred care in TB. *Int J Tuberc Lung Dis.* 2021;25(10):784–7 (<http://www.ncbi.nlm.nih.gov/pubmed/34615573>, accessed 18 June 2022).
5. End TB Strategy. Global strategy and targets for tuberculosis prevention, care and control after 2015. Geneva: World Health Organization; 2014 (<https://www.who.int/publications/i/item/WHO-HTM-TB-2015.19>, accessed 23 June 2022).
6. Moving to people-centred care: achieving better TB outcomes. TB Europe Coalition. 2017 (<https://www.tbcoalition.eu/wp-content/uploads/2020/02/Moving-to-People-centred-Care-Achieving-Better-TB-Outcomes.pdf>, accessed 18 June 2022).
7. Ethics guidance for the implementation of the End TB strategy. Geneva, Switzerland, World Health Organization. 2017 (<https://apps.who.int/iris/handle/10665/254820>, accessed 18 June 2022).
8. Sah S, Craig G, Mandelbaum M. Psychosocial counselling and treatment adherence support for people with tuberculosis. Paris: International Union Against Tuberculosis and Lung Disease; 2021 ([https://theunion.org/sites/default/files/2021-04/TheUnion\\_TBAlert\\_PsychosocialCounselling\\_April2021\\_webversion.pdf](https://theunion.org/sites/default/files/2021-04/TheUnion_TBAlert_PsychosocialCounselling_April2021_webversion.pdf), accessed 18 June 2022).
9. Declaration of the Rights of People affected by TB. Geneva: Stop TB Partnership; 2019 (<https://stoptb.org/assets/documents/communities/FINAL%20Declaration%20on%20the%20Right%20of%20People%20Affected%20by%20TB%2013.05.2019.pdf>, accessed 18 June 2022).
10. The Patients' Charter for Tuberculosis Care. San Francisco (CA): World Care Council; 2006.
11. Companion handbook to the WHO guidelines for the programmatic management of drug-resistant tuberculosis. Geneva: World Health Organization; 2014 ([https://apps.who.int/iris/bitstream/handle/10665/130918/9789241548809\\_eng.pdf](https://apps.who.int/iris/bitstream/handle/10665/130918/9789241548809_eng.pdf), accessed 18 June 2022).
12. A patient-centred approach to TB care. Geneva: World Health Organization; 2018 (<https://apps.who.int/iris/bitstream/handle/10665/272467/WHO-CDS-TB-2018.13-eng.pdf>, accessed 18 June 2022).
13. Implementing the end TB strategy: the essentials. Geneva: World Health Organization; 2015 (<https://www.who.int/publications/i/item/9789241509930>, accessed 18 June 2022).
14. Best practice for the care of patients with tuberculosis: a guide for low-income countries. Paris: International Union Against Tuberculosis and Lung Disease; 2017 (<https://theunion.org/technical-publications/best-practice-for-the-care-of-patients-with-tuberculosis-a-guide-for-low-income-countries>, accessed 18 June 2022).
15. Consolidated guidelines on tuberculosis. Module 4: Treatment. Tuberculosis care and support. Geneva: World Health Organization; 2022.
16. Guidelines for treatment of drug-susceptible tuberculosis and patient care – 2017 update. Geneva: World Health Organization; 2017 (<https://apps.who.int/iris/handle/10665/255052>, accessed 18 June 2022).

17. Hayward SE, Deal A, Rustage K, Nellums LB, Sweetland AC, Boccia D et al. The relationship between mental health and risk of active tuberculosis: a systematic review. *BMJ Open*. 2022;12(1). doi: (12(1):e048945).
18. Li H, Ji Y, Chen T. The roles of different sources of social support on emotional well-being among Chinese elderly. *PloS one*. 2014;9(3):e90051-e (https://pubmed.ncbi.nlm.nih.gov/24594546, accessed 18 June 2022).
19. Standardized package of community-based support services to improve TB outcomes. Copenhagen: World Health Organization Regional Office for Europe & TB Europe Coalition; 2021 (https://www.tbcoalition.eu/wp-content/uploads/2021/10/Standardized-package-of-community-based-supportive-services-to-improve-TB-outcomes-27\_Oct\_21.pdf, accessed 18 June 2022).
20. United To End TB. Every word counts: suggested language and usage for tuberculosis communication. First edition. Geneva, Stop TB Partnership. 2013 (https://stoptb.org/assets/documents/resources/publications/acsm/LanguageGuide\_ForWeb20131110.pdf, accessed 18 June 2022).
21. Guideline: nutritional care and support for patients with tuberculosis. Geneva: World Health Organization; 2013 (https://apps.who.int/iris/handle/10665/94836, accessed 18 June 2022).
22. WHO framework for collaborative action on tuberculosis and comorbidities. Geneva: World Health Organization; 2022.
23. Alipanah N, Jarlsberg L, Miller C, Linh NN, Falzon D, Jaramillo E et al. Adherence interventions and outcomes of tuberculosis treatment: a systematic review and meta-analysis of trials and observational studies. *PLoS Med*. 2018;15(7):e1002595 (http://www.ncbi.nlm.nih.gov/pubmed/29969463, accessed 18 June 2022).
24. Digital health for the End TB Strategy: an agenda for action. Geneva: World Health Organization; 2015 (https://apps.who.int/iris/handle/10665/205222, accessed 18 June 2022).
25. Handbook for the use of digital technologies to support tuberculosis medication adherence. Geneva: World Health Organization; 2017 (https://apps.who.int/iris/handle/10665/259832, accessed 18 June 2022).
26. Ngwatu BK, Nsengiyumva NP, Oxlade O, Mappin-Kasirer B, Nguyen NL, Jaramillo E et al. The impact of digital health technologies on tuberculosis treatment: a systematic review. *Eur Respir J*. 2018;51(1):1701596. doi: 10.1183/13993003.01596-2017.
27. Nsengiyumva NP, Mappin-Kasirer B, Oxlade O, Bastos M, Trajman A, Falzon D et al. Evaluating the potential costs and impact of digital health technologies for tuberculosis treatment support. *Eur Respir J*. 2018;52(5):1801363. doi:10.1183/13993003.01363-2018.
28. Liu XQ, Lewis JJ, Zhang H, Lu W, Zhang S, Zheng GL et al. Effectiveness of electronic reminders to improve medication adherence in tuberculosis patients: a cluster-randomised trial. *PloS Med*. 2015;12(9):e1001876.
29. 99DOTS [website] (https://www.99dots.org/, accessed 18 June 2022).
30. Cattamanchi A, Crowder R, Kityamuwesi A, Kiwanuka N, Lamunu M, Namale C et al. Digital adherence technology for tuberculosis treatment supervision: a stepped-wedge cluster-randomized trial in Uganda. *PLoS Med*. 2021;18(5): e1003628.
31. Thomas BE, Kumar JV, Chiranjeevi M, Shah D, Khandewale A, Thiruvengadam K et al. Evaluation of the accuracy of 99DOTS, a novel cellphone-based strategy for monitoring adherence to tuberculosis medications: comparison of digital adherence data with urine Isoniazid testing. *Clin Infect Dis*. 2020;71(9):e513-6.
32. Chuck C, Robinson E, Macaraig M, Alexander M, Burzynski J. Enhancing management of tuberculosis treatment with video directly observed therapy in New York City. *Int J Tuberc Lung Dis*. 2016;20(5):588-93. doi:10.5588/ijtld.15.0738.
33. Wade VA, Karnon J, Elliott JA, Hiller JE. Home videophones improve direct observation in tuberculosis treatment: a mixed methods evaluation. *PLoS One*. 2012;7(11):e50155 (http://www.ncbi.nlm.nih.gov/pubmed/23226243, accessed 18 June 2022).

34. Story A, Aldridge RW, Smith CM, Garber E, Hall J, Ferenando G et al. Smartphone-enabled video-observed versus directly observed treatment for tuberculosis: a multicentre, analyst-blinded, randomised, controlled superiority trial. *Lancet*. 2019;393(10177):1216–24 (<http://www.ncbi.nlm.nih.gov/pubmed/30799062>, accessed 18 June 2022).
35. Ravenscroft L, Kettle S, Persian R, Ruda S, Severin L, Doltu S et al. Video-observed therapy and medication adherence for tuberculosis patients: randomised controlled trial in Moldova. *Eur Respir J*. 2020;56(2):2000493 (<http://www.ncbi.nlm.nih.gov/pubmed/32381495>, accessed 18 June 2022).
36. Dick J, Lombard C. Shared vision--a health education project designed to enhance adherence to anti-tuberculosis treatment. *Int J Tuberc Lung Dis*. 1997;1(2):181–6 (<http://www.ncbi.nlm.nih.gov/pubmed/9441085>, accessed 18 June 2022).
37. Clark PM, Karagoz T, Apikoglu-Rabus S, Izzettin FV. Effect of pharmacist-led patient education on adherence to tuberculosis treatment. *Am J Health Syst Pharm*. 2007;64(5):497–505 (<http://www.ncbi.nlm.nih.gov/pubmed/17322163>, accessed 18 June 2022).
38. Datiko DG, Lindtjorn B. Health extension workers improve tuberculosis case detection and treatment success in southern Ethiopia: a community randomized trial. *PLoS One*. 2009;4(5):e5443 (<http://www.ncbi.nlm.nih.gov/pubmed/19424460>, accessed 18 June 2022).
39. Kigozi NG, Heunis JC, Engelbrecht MC, Janse van Rensburg AP, van Rensburg HCJD. Tuberculosis knowledge, attitudes and practices of patients at primary health care facilities in a South African metropolitan: research towards improved health education. *BMC public health*. 2017;17(1):795- (<https://pubmed.ncbi.nlm.nih.gov/29017526>, accessed 18 June 2022).
40. Idris NA, Zakaria R, Muhamad R, Nik Husain NR, Ishak A, Wan Mohammad WMZ. The effectiveness of tuberculosis education programme in Kelantan, Malaysia on knowledge, attitude, practice and stigma towards tuberculosis among adolescents. *Malays J Med Sci*. 2020;27(6):102–14.
41. Yousif K, Ei Maki M, Babikir RK, Abuaisa H. The effect of an educational intervention on awareness of various aspects of pulmonary tuberculosis in patients with the disease. *East Mediterr Health J*. 2021;27(3):287–92.
42. Koech BA, Nyamgoba EN. The role of communication in the management of tuberculosis disease. *IOSR Journal of Humanities and Social Science*. 2017;22(5):62–6.
43. Lief H, Fox R. Training for “detached concern” in medical students. In: Lief H, editor. *The psychological basis of medical practice*. New York (NY): Harper & Row; 1963:12–35.
44. Zachariah R, Harries AD, Srinath S, Ram S, Viney K, Singogo E 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(6):714–7 (<https://www.ncbi.nlm.nih.gov/pubmed/22613683>, accessed 18 June 2022).
45. mhGAP Intervention Guide – Version 2.0. Geneva, World Health Organization 2019 (<https://www.who.int/publications/i/item/9789241549790>, accessed 18 June 2022).
46. Nursing guide for managing side effects to drug-resistant TB treatment. Geneva: International Council of Nurses and Curry International Tuberculosis Center; 2018 ([https://www.icn.ch/system/files/documents/2020-11/CITC\\_NursingGuide\\_English\\_v14\\_WEB\\_pages.pdf](https://www.icn.ch/system/files/documents/2020-11/CITC_NursingGuide_English_v14_WEB_pages.pdf), accessed 18 June 2022).
47. Njie GJ, Khan A. Prevalence of tuberculosis and mental disorders comorbidity: a systematic review and meta-analysis. *J Immigr Minor Health*. 2021 (<https://www.ncbi.nlm.nih.gov/pubmed/34796457>, accessed 18 June 2022).
48. de Araujo GS, Pereira SM, dos Santos DN, Marinho JM, Rodrigues LC, Barreto ML. Common mental disorders associated with tuberculosis: a matched case-control study. *PLoS One*. 2014;9(6):e99551 (<https://www.ncbi.nlm.nih.gov/pubmed/24937319>, accessed 18 June 2022).
49. Harling G, Castro MC. A spatial analysis of social and economic determinants of tuberculosis in Brazil. *Health Place*. 2014;25:56–67 (<https://www.ncbi.nlm.nih.gov/pubmed/24269879>, accessed 18 June 2022).

50. Fonseca M, Guimarães M, Vasconcelos E. Sofrimento difuso e transtornos mentais comuns: uma revisão bibliográfica. (Diffuse distress and common mental disorders: a bibliographic review). *Rev. APS.* 2008;11(3):285–94.
51. Janse Van Rensburg A, Dube A, Curran R, Ambaw F, Murdoch J, Bachmann M et al. Comorbidities between tuberculosis and common mental disorders: a scoping review of epidemiological patterns and person-centred care interventions from low-to-middle income and BRICS countries. *Infect Dis Poverty.* 2020;9(1):4 (<https://www.ncbi.nlm.nih.gov/pubmed/31941551>, accessed 18 June 2022).
52. Pachi A, Bratis D, Moussas G, Tselebis A. Psychiatric morbidity and other factors affecting treatment adherence in pulmonary tuberculosis patients. *Tuberc Res Treat.* 2013;2013:489865 (<https://www.ncbi.nlm.nih.gov/pubmed/23691305>, accessed 18 June 2022).
53. Wai PP, Shewade HD, Kyaw NTT, Thein S, Si Thu A, Kyaw KKY et al. Community-based MDR-TB care project improves treatment initiation in patients diagnosed with MDR-TB in Myanmar. *PLoS One.* 2018;13(3):e0194087 (<https://www.ncbi.nlm.nih.gov/pubmed/29596434>, accessed 18 June 2022).
54. World Health Organization (WHO). Doing what matters in times of stress. An illustrated guide [website]. Geneva: World Health Organization (WHO); 2020 (<https://www.who.int/publications/i/item/9789240003927>, accessed 18 June 2022).
55. World Health Organization (WHO). Problem management plus (PM+): individual psychological help for adults impaired by distress in communities exposed to adversity [website]. Geneva: World Health Organization 2016 (<https://www.who.int/publications/i/item/WHO-MSD-MER-16.2>, accessed 18 June 2022).
56. Kübler-Ross E. On death and dying. London: Routledge; 1969.
57. Block SD. Psychological issues in end-of-life care. *J Palliat Med.* 2006;9(3):751–72.
58. Simon NM. Treating complicated grief. *JAMA.* 2013;310(4):416–23 (<https://pubmed.ncbi.nlm.nih.gov/23917292>, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4530627>, both accessed 18 June 2022).
59. Hudson P, Remedios C, Zordan R, Thomas K, Clifton D, Crewdson M et al. Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. *J Palliat Med.* 2012;15(6):696–702.
60. Rapid communication: key changes to the treatment of drug-resistant tuberculosis. Information note. Geneva: World Health Organization; 2022 (<https://www.who.int/publications/i/item/WHO-UCN-TB-2022-2>, accessed 18 June 2022).
61. WHO consolidated guidelines on tuberculosis. Module 4: Treatment – drug-resistant tuberculosis treatment. Geneva: World Health Organization; 2020 (<https://www.who.int/publications/i/item/9789240007048>, accessed 18 June 2022).
62. WHO operational handbook on tuberculosis. Module 4: Treatment – drug-resistant tuberculosis treatment. Geneva: World Health Organization; 2020 (<https://www.who.int/publications/i/item/9789240006997>, accessed 18 June 2022).
63. WHO consolidated guidelines on tuberculosis, Module 4: Treatment – drug-susceptible tuberculosis treatment. Geneva: World Health Organization; 2022 (<https://www.who.int/publications/i/item/9789240048126>, accessed 18 June 2022).
64. Ho J, Byrne AL, Linh NN, Jaramillo E, Fox GJ. Decentralized care for multidrug-resistant tuberculosis: a systematic review and meta-analysis. *Bulletin of the World Health Organization.* 2017;95(8):584–93 (<https://pubmed.ncbi.nlm.nih.gov/28804170>, accessed 18 June 2022).
65. TB Care II. Community-based care for drug-resistant tuberculosis: a guide for implementers [website]. North Carolina: USAID; 2017 (<https://www.tbdia.org/resources/publications/community-based-care-for-drug-resistant-tuberculosis-a-guide-for-implementers/>, accessed 18 June 2022).
66. Bhargava A, Bhargava M. Tuberculosis deaths are predictable and preventable: comprehensive assessment and clinical care is the key. *J Clin Tuberc Other Mycobact Dis.* 2020;19:100155.



67. Roadmap towards ending TB in children and adolescents. Geneva: World Health Organization; 2018 (<https://apps.who.int/iris/handle/10665/275422>, accessed 18 June 2022).
68. Graham SM, Sekadde MP. Case detection and diagnosis of tuberculosis in primary-care settings. *Paediatr Int Child Health*. 2019;39(2):84–7 (<http://www.ncbi.nlm.nih.gov/pubmed/30957711>, accessed 18 June 2022).
69. WHO operational handbook on tuberculosis. Module 5: Management of tuberculosis in children and adolescents. Geneva: World Health Organization; 2022 (<https://www.who.int/publications/i/item/9789240046832>, accessed 18 June 2022).
70. WHO consolidated guidelines on tuberculosis. Module 5: Management of tuberculosis in children and adolescents. Geneva: World Health Organization; 2022 (<https://www.who.int/publications/i/item/9789240046764>, accessed 18 June 2022).
71. The Sustainable Development Agenda [website]. New York (NY): United Nations; 2021 (<https://www.un.org/sustainabledevelopment/development-agenda/>, accessed 18 June 2022).
72. Talukder K, Salim MAH, Jerin I, Sharmin F, Talukder MQK, Marais BJ et al. Intervention to increase detection of childhood tuberculosis in Bangladesh. *Int J Tuberc Lung Dis*. 2012;16(1):70–5. doi: 10.5588/ijtld.11.0060.
73. Ketema L, Dememew ZG, Assefa D, Gudina T, Kassa A, Letta T et al. Evaluating the integration of tuberculosis screening and contact investigation in tuberculosis clinics in Ethiopia: a mixed method study. *PLoS One*. 2020;15(11):e0241977.
74. Dongo JP, Graham SM, Nsonga J, Wabwire-Mangen F, Maleche-Obimbo E, Mupere E et al. Implementation of an effective decentralised programme for detection, treatment and prevention of tuberculosis in children. *Trop Med Infect Dis*. 2021;6(3):131.
75. Maha A, Majumdar SS, Main S, Phillip W, Witari K, Schulz J et al. The effects of decentralisation of tuberculosis services in the East New Britain Province, Papua New Guinea. *Public Health Action*. 2019;9:S43–9.
76. WHO policy on collaborative TB/HIV activities: guidelines for national programmes and other stakeholders. Geneva: World Health Organization; 2012 (<https://apps.who.int/iris/handle/10665/44789>, accessed 18 June 2022).
77. Standards for improving the quality of care for children and young adolescents in health facilities. Geneva: World Health Organization; 2018 (<https://apps.who.int/iris/handle/10665/272346>, accessed 18 June 2022).
78. Young M, Wolffieim C, Marsh DR, Hammamy D. World Health Organization/United Nations Children’s Fund Joint Statement on Integrated Community Case Management: An equity-focused strategy to improve access to essential treatment services for children. *Am J Trop Med Hyg*. 2012;87(5):6–10.
79. Integrated Management of Childhood Illness: chart booklet. Geneva: World Health Organization; 2014 (<https://apps.who.int/iris/handle/10665/104772>, accessed 18 June 2022).
80. Marais BJ, Obihara CC, Warren RM, Schaaf HS, Gie RP, Donald PR. The burden of childhood tuberculosis: a public health perspective. *Int J Tuberc Lung Dis*. 2005;9(12):1305–13 (<http://www.ncbi.nlm.nih.gov/pubmed/16466051>, accessed 18 June 2022).
81. Onazi O, Gidado M, Onazi M, Daniel O, Kuye J, Obasanya O et al. Estimating the cost of TB and its social impact on TB patients and their households. *Public Health Action*. 2015;5(2):127–31 (<http://www.ncbi.nlm.nih.gov/pubmed/26400384>, accessed 18 June 2022).
82. Goyal-Honavar A, Markose AP, Chhakchuakk L, John SM, Joy S, Kumar SD et al. Unmasking the human face of TB. The impact of tuberculosis on the families of patients. *J Family Med Prim Care*. 2020;9(10):5345–50.
83. Foo C, Shrestha P, Wang L, Du Q, Garcia-Basteiro AL, Abdullah AS et al. Integrating tuberculosis and noncommunicable diseases care in low- and middle-income countries (LMICs): a systematic review. *PLoS Med*. 2022;19(1):e1003899 (<http://www.ncbi.nlm.nih.gov/pubmed/35041654>, accessed 18 June 2022).

84. Legido-Quigley H, Montgomery CM, Khan P, Atun R, Fakoya A, Getahun H et al. Integrating tuberculosis and HIV services in low- and middle-income countries: a systematic review. *Trop Med Int Health*. 2013;18(2):199–211 (<http://www.ncbi.nlm.nih.gov/pubmed/23217030>, accessed 18 June 2022).
85. China: multidisciplinary teams and integrated service delivery across levels of care. Country case studies on primary health care. Geneva: World Health Organization; 2018 (<https://apps.who.int/iris/handle/10665/326085>, accessed 18 June 2022).
86. Public–private mix for TB prevention and care: a roadmap. Geneva: World Health Organization; 2018 (<https://apps.who.int/iris/handle/10665/333885>, accessed 18 June 2022).
87. Stallworthy G, Dias HM, Pai M. Quality of tuberculosis care in the private health sector. *J Clin Tuberc Other Mycobact Dis*. 2020;20:100171 (<https://www.ncbi.nlm.nih.gov/pubmed/32642560>, accessed 18 June 2022).
88. Uplekar M, Juvekar S, Morankar S, Rangan S, Nunn P. Tuberculosis patients and practitioners in private clinics in India. *Int J Tuberc Lung Dis*. 1998;2(4):324–9 (<https://www.ncbi.nlm.nih.gov/pubmed/9559404>, accessed 18 June 2022).
89. COVID-19 – considerations for tuberculosis (TB) care. Information note. Geneva: World Health Organization; 2021 (<https://apps.who.int/iris/handle/10665/341126>, accessed 18 June 2022).
90. Briefing note: testing for both tuberculosis and SARS-CoV-2. Geneva: Global Fund to Fight AIDS, Tuberculosis and Malaria; 2021 (<https://www.theglobalfund.org/en/covid-19/news/2021-11-03-briefing-note-testing-for-both-tuberculosis-and-sars-cov-2/>, accessed 18 June 2022).
91. Krakauer EL, Dheda K, Kalsdorf B, Kuksa L, Nadkarni A, Nhung NV et al. Palliative care and symptom relief for people affected by multidrug-resistant tuberculosis. *Int J Tuberc Lung Dis*. 2019;23(8):881–90 (<https://www.ncbi.nlm.nih.gov/pubmed/31533877>, accessed 18 June 2022).
92. Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Jiang Kwete X et al. Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage: the Lancet Commission report. *Lancet*. 2018;391(10128):1391–454 (<https://www.ncbi.nlm.nih.gov/pubmed/29032993>, accessed 18 June 2022).
93. Beaumont A-L, Doumbia A, Chateau N, Meynard J-L, Pacanowski J, Valin N et al. Why are people still dying of drug-susceptible TB in Paris in the 21(st) century? *Int J Tuberc Lung Dis*. 2022;26(2):142–9 (<https://www.ncbi.nlm.nih.gov/pubmed/35086626>, accessed 18 June 2022).
94. Resolution WHA67.19. Strengthening of palliative care as a component of comprehensive care throughout the life course. Sixty-seventh World Health Assembly, Geneva, 19–24 May 2014. Geneva: World Health Organization; 2014 (<https://apps.who.int/iris/handle/10665/162863>, accessed 18 June 2022).
95. Integrating palliative care and symptom relief into primary health care: a WHO guide for planners, implementers and managers. Geneva: World Health Organization; 2018 (<https://apps.who.int/iris/handle/10665/274559>, accessed 18 June 2022).
96. Resolution 69.24. Strengthening integrated, people-centred health services. World Health Assembly, Geneva Sixty-ninth World Health Assembly; Geneva, 23–28 May 2016. Geneva: World Health Organization; 2016 ([https://apps.who.int/gb/ebwha/pdf\\_files/WHA69/A69\\_R24-en.pdf](https://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_R24-en.pdf), accessed 18 June 2022).
97. Connor SR. Palliative care for tuberculosis. *J Pain Symptom Manag*. 2018;55(2):S178–80.
98. Connor S, Foley K, Harding R, Jaramillo E. Declaration on palliative care and MDR/XDR-TB. *Int J Tuberc Lung Dis*. 2012;16(6):712–3. doi:10.5588/ijtld.12.0267.
99. Meghji J, Lesosky M, Joekes E, Banda P, Rylance J, Gordon S et al. Patient outcomes associated with post-tuberculosis lung damage in Malawi: a prospective cohort study. *Thorax*. 2020;75(3):269–78.
100. Manji M, Shayo G, Mamuya S, Mpembeni R, Jusabani A, Mugusi F. Lung functions among patients with pulmonary tuberculosis in Dar es Salaam – a cross-sectional study. *BMC Pulm Med*. 2016;16(1):58.

101. Maguire GP, Anstey NM, Ardian M, Waramori G, Tjitra E, Kenangalem E et al. Pulmonary tuberculosis, impaired lung function, disability and quality of life in a high-burden setting. *Int J Tuberc Lung Dis*. 2009;13(12):1500–6.
102. Vashakidze SA, Kempker JA, Jakobia NA, Gogishvili SG, Nikolaishvili KA, Goginashvili LM et al. Pulmonary function and respiratory health after successful treatment of drug-resistant tuberculosis. *Int J Infect Dis*. 2019;82:66–72.
103. Connor S, editor. *Global atlas of palliative care*, second edition. London: Worldwide Palliative Care Alliance; 2020.
104. *Planning and implementing palliative care services: a guide for programme managers*. Geneva: World Health Organization; 2016 (<https://apps.who.int/iris/handle/10665/250584>, accessed 18 June 2022).
105. Krakauer EL, Kwete X, Verguet S, Arreola-Ornelas H, Bhadelia A, Mendez O et al. Palliative care and pain control. In: Jamison DT, Gelband H, Horton S, Jha P, Laxminarayan R, Mock CD et al., editors. *Disease control priorities: improving health and reducing poverty*, Washington (DC); The World Bank; 2017 (<http://www.ncbi.nlm.nih.gov/pubmed/30212149>, accessed 18 June 2022).
106. Jennings AL, Davies AN, Higgins JP, Gibbs JS, Broadley KE. A systematic review of the use of opioids in the management of dyspnoea. *Thorax*. 2002;57(11):939–44 (<https://www.ncbi.nlm.nih.gov/pubmed/12403875>, accessed 18 June 2022).
107. Bausewein C, Currow D, Johnson M, editors. *Palliative care in respiratory disease*. Sheffield: European Respiratory Society; 2016.
108. Fine RL. Ethical and practical issues with opioids in life-limiting illness. *Proc (Bayl Univ Med Cent)*. 2007;20(1):5–12 (<https://www.ncbi.nlm.nih.gov/pubmed/17256034>, accessed 18 June 2022).
109. Mahler DA, Selecky PA, Harrod CG, Benditt JO, Carrieri-Kohlman V, Curtis JR et al. American College of Chest Physicians consensus statement on the management of dyspnea in patients with advanced lung or heart disease. *Chest*. 2010;137(3):674–91 (<https://www.ncbi.nlm.nih.gov/pubmed/20202949>, accessed 18 June 2022).
110. Qaseem A, Snow V, Shekelle P, Casey DE Jr, Cross JT Jr, Owens DK et al. Evidence-based interventions to improve the palliative care of pain, dyspnea, and depression at the end of life: a clinical practice guideline from the American College of Physicians. *Ann Intern Med*. 2008;148(2):141–6 (<https://www.ncbi.nlm.nih.gov/pubmed/18195338>, accessed 18 June 2022).
111. *Palliative care for the patient with incurable cancer or advanced disease, Part 2: Pain and symptom management – dyspnea*. Guidelines & Protocols Advisory Committee. New Westminster: BC Centre for Palliative Care; 2017 ([http://www2.gov.bc.ca/assets/gov/health/practitioner-pro/bc-guidelines/palliative2\\_dyspnea.pdf](http://www2.gov.bc.ca/assets/gov/health/practitioner-pro/bc-guidelines/palliative2_dyspnea.pdf), accessed 18 June 2022).
112. *Opioids in palliative care: safe and effective prescribing of strong opioids for pain in palliative care of adults*. NICE clinical guideline 140. Manchester: National Collaborating Centre for Cancer; 2012 ([www.nice.org.uk/nicemedia/live/13745/59287/59287.pdf](http://www.nice.org.uk/nicemedia/live/13745/59287/59287.pdf), accessed 18 June 2022).
113. Ragan EJ, Kleinman MB, Sweigart B, Gnatienco N, Parry CD, Horsburgh CR et al. The impact of alcohol use on tuberculosis treatment outcomes: a systematic review and meta-analysis. *Int J Tuberc Lung Dis*. 2020;24(1):73–82 (<https://www.ncbi.nlm.nih.gov/pubmed/32005309>, accessed 18 June 2022).
114. Deiss RG, Rodwell TC, Garfein RS. Tuberculosis and illicit drug use: review and update. *Clin Infect Dis*. 2009;48(1):72–82 (<https://www.ncbi.nlm.nih.gov/pubmed/19046064>, accessed 18 June 2022).
115. Getahun H, Gunneberg C, Sculier D, Verster A, Raviglione M. Tuberculosis and HIV in people who inject drugs: evidence for action for tuberculosis, HIV, prison and harm reduction services. *Curr Opin HIV AIDS*. 2012;7(4):345–53 (<https://www.ncbi.nlm.nih.gov/pubmed/22678489>, accessed 18 June 2022).

116. Shin S, Livchits V, Connery HS, Shields A, Yanov S, Yanova G et al. Effectiveness of alcohol treatment interventions integrated into routine tuberculosis care in Tomsk, Russia. *Addiction*. 2013;108(8):1387–96 (<https://www.ncbi.nlm.nih.gov/pubmed/23490304>, accessed 18 June 2022).
117. Bruce RD, Lambdin B, Chang O, Masao F, Mbwambo J, Mteza I et al. Lessons from Tanzania on the integration of HIV and tuberculosis treatments into methadone assisted treatment. *Int J Drug Policy*. 2014;25(1):22–5 (<https://www.ncbi.nlm.nih.gov/pubmed/24210295>, accessed 18 June 2022).
118. Nadkarni A, Weiss HA, Weobong B, McDaid D, Singla DR, Park AL et al. Sustained effectiveness and cost-effectiveness of Counselling for Alcohol Problems, a brief psychological treatment for harmful drinking in men, delivered by lay counsellors in primary care: 12-month follow-up of a randomised controlled trial. *PLoS Med*. 2017;14(9):e1002386 (<https://www.ncbi.nlm.nih.gov/pubmed/28898239>, accessed 18 June 2022).
119. Nadkarni A, Weobong B, Weiss HA, McCambridge J, Bhat B, Katti B et al. Counselling for Alcohol Problems (CAP), a lay counsellor-delivered brief psychological treatment for harmful drinking in men, in primary care in India: a randomised controlled trial. *Lancet*. 2017;389(10065):186–95 (<https://www.ncbi.nlm.nih.gov/pubmed/27988144>, accessed 18 June 2022).
120. Sharkey L, Loring B, Cowan M, Riley L, Krakauer EL. National palliative care capacities around the world: results from the World Health Organization Noncommunicable Disease Country Capacity Survey. *Palliat Med*. 2018;32(1):106–13 (<https://www.ncbi.nlm.nih.gov/pubmed/28677988>, accessed 18 June 2022).
121. Assessing the development of palliative care worldwide: a set of actionable indicators. Geneva: World Health Organization; 2021 (<https://apps.who.int/iris/handle/10665/345532>, accessed 18 June 2022).
122. Davis MP, Temel JS, Balboni T, Glare P. A review of the trials which examine early integration of outpatient and home palliative care for patients with serious illnesses. *Ann Palliat Med*. 2015;4(3):99–121 (<https://www.ncbi.nlm.nih.gov/pubmed/26231807>, accessed 18 June 2022).
123. Desrosiers T, Cupido C, Pitout E, van Niekerk L, Badri M, Gwyther L et al. A hospital-based palliative care service for patients with advanced organ failure in sub-Saharan Africa reduces admissions and increases home death rates. *J Pain Symptom Manage*. 2014;47(4):786–92 (<https://www.ncbi.nlm.nih.gov/pubmed/23969328>, accessed 18 June 2022).
124. Hongoro C, Dinat N. A cost analysis of a hospital-based palliative care outreach program: implications for expanding public sector palliative care in South Africa. *J Pain Symptom Manage*. 2011;41(6):1015–24 (<https://www.ncbi.nlm.nih.gov/pubmed/21330096>, accessed 18 June 2022).
125. Mosoiu D, Dumitrescu M, Connor SR. Developing a costing framework for palliative care services. *J Pain Symptom Manage*. 2014;48(4):719–29 (<https://www.ncbi.nlm.nih.gov/pubmed/24709365>, accessed 18 June 2022).
126. Ramsey SD, Bansal A, Fedorenko CR, Blough DK, Overstreet KA, Shankaran V et al. Financial insolvency as a risk factor for early mortality among patients with cancer. *J Clin Oncol*. 2016;34(9):980–6 (<https://www.ncbi.nlm.nih.gov/pubmed/26811521>, accessed 18 June 2022).
127. Postier A, Chrastek J, Nugent S, Osenga K, Friedrichsdorf SJ. Exposure to home-based pediatric palliative and hospice care and its impact on hospital and emergency care charges at a single institution. *J Palliat Med*. 2014;17(2):183–8 (<https://www.ncbi.nlm.nih.gov/pubmed/24380448>, accessed 18 June 2022).





For further information, please contact:

**Global Tuberculosis Programme**  
**World Health Organization**

20, Avenue Appia CH-1211 Geneva 27 Switzerland

Web site: [www.who.int/tb](http://www.who.int/tb)

