The Union

International Union Against
Tuberculosis and Lung Disease

PSYCHOSOCIAL COUNSELLING AND TREATMENT ADHERENCE SUPPORT FOR PEOPLE WITH TUBERCULOSIS

First Edition
2021

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Stop TB Partnership

TB alert

S Sah, G Craig & M Mandelbaum

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Reference group

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Glossary

Term	Definition
Psychosocial support	Addressing psychological, social and economic factors that can prevent people from accessing diagnosis, adhering to care plans and successfully completing a course of treatment.
People affected by TB	People with TB disease or who previously had TB disease, as well as their caregivers and immediate family members.
Key populations	People who are vulnerable, under-served or at risk of TB infection and illness.
People-centred care	An approach to care that consciously adopts individuals', carers', families' and communities' perspectives as participants in, and beneficiaries of, trusted health systems that are organised around the comprehensive needs of people rather than individual diseases, and that respect social preferences. People-centred care also requires that patients have the education and support they need to make decisions and participate in their own care and that carers are able to attain maximal function within a supportive working environment. People-centred care is broader than patient-centred and person-centred care, encompassing not only clinical encounters, but also including attention to the health of people in their communities and their crucial role in shaping health policy and health services.[1]
Civil society organisation	A non-state, not for profit entity. Some CSOs are small and led by the community, while others employ paid staff.
Healthcare worker	People engaged in actions whose primary intent is to enhance health.

Glossary (continued)

Tuberculosis infection	Also knows as Latent TB or Latent TB Infection (LTBI), the person has infection with *MTB* but the infection is dormant, the bacteria cannot be detected by culture-based or any other direct method and the person is asymptomatic and does not transmit the infection to others. There is no perfect way to directly diagnose tuberculosis infection. The diagnosis is made by measuring the immunological response to *MTB* antigens using a tuberculin skin test (TST) or an interferon gamma release assay (IGRA).
Digital Health Technologies (DHTs)	The use of computers, internet, mobile devices (smartphones), software applications (apps) to improve health care delivery, promote and monitor health and psychological wellbeing.
Tuberculosis disease	Tuberculosis disease means that the infection is active, the organisms are usually detectable by culture-based or other molecular methods and the person usually has symptoms and can transmit the infection to others. When we say a person has TB, it is taken to mean that the person has active tuberculosis disease.

List of abbreviations

AIDS	Acquired immunodeficiency syndrome
CRG	Communities, rights, and gender
CLM	Community-led monitoring
COVID-19	Coronavirus disease
CSNAT	Carer Support Needs Assessment Tool
CSO	Civil society organisation
DDU	Drug dependency unit

DM	Diabetes Mellitus
DOT	Direct observation of treatment
DR-TB	Drug-resistant tuberculosis
DST	Drug susceptibility testing
ECG	Electrocardiogram
EPTB	Extra-pulmonary tuberculosis
HCV	Hepatitis C Virus
HCW	Healthcare worker
HIV	Human immunodeficiency virus
IBSR	Inquiry-based stress reduction
IGRA	Interferon gamma release assay
LMIC	Low and middle-income countries
MDR-TB	Multidrug-resistant tuberculosis
MTB	Mycobacterium tuberculosis
NGO	Non-governmental organisation
NSAID	Non-steroidal anti-inflammatory drug
PHQ	Patient health questionnaire
PLWHA	People living with HIV/AIDS
PSS	Psychosocial support
PTB	Pulmonary tuberculosis
PTSD	Post-traumatic stress disorder
PWUID	People who use and inject drugs
Rif	Rifampicin
SCW	Social care worker
TB	Tuberculosis
TPT	Tuberculosis preventive treatment
UNAIDS	United Nations Programme on HIV/AIDS
UNHLM	United Nations High Level Meeting
VOT	Video observed treatment
WHO	World Health Organization
XDR-TB	Extensively drug-resistant tuberculosis

About the authors

Sameer Sah is International Programme Director at TB Alert where he leads on the development and implementation of projects and the provision of technical advisory and support services to national and international civil society organisations working on TB. He was a member of the first WHO Global Civil Society Taskforce on Tuberculosis and participates in the WHO Europe Regional Coordinating Committee on TB, HIV and Viral Hepatitis. Sameer has over 30 years' experience in international development, especially in capacity building and participatory methodologies, gained in over 30 countries in Asia, Africa and Latin America. He has experience of working on TB and TB-HIV co-infection in the Sub-Saharan context and in India and Laos. He has been an external subject specialist adviser and guest lecturer at Westminster University and has presented various papers on TB screening and patient finding at international conferences. He has previously produced a training programme and a manual for outreach health staff for CSOs working in the TB in the Mining Sector in Southern Africa (TIMS) programme and has conducted numerous trainings on TB for civil society organisations (CSOs) in Southern Africa and SE Asia.

Gill Craig is a Chartered Psychologist (Education and Research) and an Associate Fellow of the British Psychological Society. She specialises in social science and public health research, with a specific interest in social diversity, inclusion health and under-served populations. She has developed and evaluated models of psychosocial care for homeless and migrant populations with TB in London, UK. She has been involved in the education and training of TB and public health community nurses and is a Fellow of the Higher Education Academy. She has co-authored several chapters in the Tuberculosis Stigma Measurement Guidance developed by the USAID funded, KNCV-led Challenge TB project. Gill obtained her PhD at University College London, UK, which researched the psychosocial support needs of parents of nutritionally compromised children with neurodisability and was awarded a prize for her work by the British Psychological Society. She was the Chief Investigator of a National Institute for Health Research grant scoping models of psychosocial support for this group of children and their families. She is an independent consultant and holds an Honorary Senior Lectureship at City, University of London, UK.

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Foreword

"Being treated for multidrug-resistant TB (MDR-TB) was the hardest and loneliest time of my life. I am a registered nurse and was expected to know everything about this terrible disease and its management. I received no education about the disease or the medication that I was to take. I was shunned when I went to the clinic for check-ups, maybe because I was a health worker. I was terrified about the lack of infection control measures at the health facilities - there was no proper ventilation, and in the box marked "take a mask if you are coughing" there were never any masks available. I felt so ill on the medication, I had no energy, I felt nauseated most of the time and I could not sleep at night. I became deaf with the injections. This was ten years ago. At that time there was no manual available to assist healthcare workers to usefully care for the psychosocial needs of those affected with tuberculosis. I wish there had been as my journey from diagnosis to successful treatment of this terrible disease might have been a lot easier".

This quote from Trisha Bond, a registered nurse who needed a partial lung resection after falling ill with MDR-TB in South Africa, speaks volumes.

Tuberculosis can be traced in humans back to 6000 BC. In classical times, in the medieval ages and the pre-industrial revolution the disease was known under various names "phthisis", "scrofula" and "consumption". During the Industrial Revolution and in Europe particularly, TB rates reached staggering levels. The disease became known as the White Plague.

Then we began to get progress. Between 1880 and 1970, we learnt what causes TB, we developed appropriate tests to diagnose it and we discovered and produced the drugs to successfully treat it. As a result of these discoveries, in the late 1970s and 1980s many experts came to regard TB as a disease of the past, to be confined to the history books. How complacent and mistaken we were.

TB remains a global public health threat and the top infectious disease killer worldwide. Every year, 10 million people become ill with TB – half a million of whom develop difficult-to-treat drug-resistant disease – and nearly 1.5 million people die as a result. We desperately want to end the scourge of TB and have pledged to do so by the year 2030. And as a result, we have become obsessed with targets, interim milestones and large numbers. The UN General Assembly high-level meeting on TB, held in September 2018, committed countries to successfully diagnose and treat 40 million people with TB and give TB preventive therapy to

30 million people between 2018 and 2022. These are laudable aspirations, but we will only succeed in our goals if each individual person with TB can take daily uninterrupted medication until the end of their course of treatment. And herein lies the challenge. A course of treatment for drug-susceptible TB lasts for six months while for drug-resistant TB the course can last from nine to 24 months. The medications are unpleasant to take. The journey ahead for the affected individual, already weakened by disease, is daunting and is likely to only be completed if there is good support at hand.

So here is where this new manual on psychosocial counselling and treatment adherence support comes in. The manual focuses on the needs of people affected by TB, and their families – providing sound guidance on delivering social and economic assistance and psychological support. It does this through narrative, illustrative tables and figures, case examples and using consolidated learning activities at the end of each chapter. It is comprehensive in its scope covering issues such as stress, stigma, discrimination, barriers to diagnosis and barriers to treatment, and it addresses many of the common co-morbidities that are associated with TB. The manual helps to strengthen health and care workers' interactions with affected people through guided conversations and it places people affected by TB at the centre of their care. One of the centrepieces is a presentation and discussion of the collaborative multidisciplinary approach and the important role of CSOs in supporting people before and after the diagnosis of TB and during treatment.

This manual is primarily for trained health workers, social workers and care workers who can use its contents as a self-study tool and incorporate its guidance into practice. The manual can also be used to provide training and guidance to both lay and professional TB treatment adherence workers and it can serve as a reference tool for TB clinicians, activists, programme managers and policy makers so that they can understand the sort of challenges that are faced by individuals affected by TB and can appreciate the support that can make a difference.

I commend TB Alert for having the vision to write this much-needed manual. I strongly recommend that it is widely read and its contents digested, so that people with TB can feel and embrace a strong ring of support as they embark on their difficult yet life-saving treatment regimens.

Anthony D Harries

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1 Introduction

In Tajikistan, Safar Naimov was finally diagnosed with drug-resistant tuberculosis after enduring eight months on standard therapy. Once he began taking appropriate medication, Safar began to feel the unwelcome effects of the more toxic regimen. "It starts affecting your soul and your morale" says Safar when he talks about his treatment. Safar had already lost one brother to MDR-TB whilst another still required MDR-TB treatment many years after diagnosis. Safar did not have the heart to tell his parents about his own MDR-TB diagnosis and so stopped visiting them, making up stories about work related travel and meetings. Close relatives abandoned him and his self-stigma prevented him from telling his friends about his illness. Lacking their support, feelings of hopelessness and depression compounded his symptoms of sensitivity to light, nausea, body aches, and severe headaches. Though his TB medication was free, the tests and treatment to manage the side effects were expensive. Safar's wife needed to end her studies to bring in much needed income for the family. "There was absolutely no psychosocial support available. The only information I had with regard to my treatment was one brochure which I would read again and again", remembers Safar. Meanwhile, Safar's brother was faring even worse, as he struggled with psychosis and suicidal thoughts caused by his medication. Tragically, the month Safar was finally cured, his brother died from his illness.

Safar now leads 'Stop TB Partnership Tajikistan'. He wishes to devote his life to support other people who are undergoing TB treatment, so that they do not have to go through the same suffering and pain that he and his family endured. His story demonstrates the real and urgent need for psychosocial support for people on TB treatment.

Purpose and scope of the manual

Worldwide, TB is one of the top 10 causes of death and the leading cause of death from a single infectious agent; even above HIV/AIDS. An estimated 10 million people fell ill with TB in 2019 of whom only 7.1 million were detected and notified to health authorities. It is estimated that 1.5 million people died from TB in 2019 (including 208,000 deaths among HIV positive people). This high level of death and suffering is compounded by drug resistance among people on

TB treatment. Treatment success rates for people with drug-sensitive TB and drug-resistant TB remain low globally at 85% and 57% respectively.[2]

Ensuring that people affected by TB are supported to complete their treatment is key to achieving global targets, improving TB prevention and treatment coverage, and achieving TB treatment success – especially in light of the toxicity of the medication used for MDR-TB. However, the existing guidance available for health and care workers largely focuses on systematic screening and on treatment adherence, with less attention paid to the psychosocial needs of people affected by TB.

Psychosocial support addresses the psychological, social and economic factors that can prevent people from accessing diagnosis, adhering to care plans and successfully completing a course of treatment. For example, people who have TB symptoms may refuse screening for TB or avoid going for diagnostic tests due to stigma, discrimination and fear. COVID-19 is creating additional barriers by increasing people's fear of visiting healthcare facilities and by worsening inequalities which further limit people's ability to access health and social protection services. Similarly, people who do not have adequate shelter or finance, those with no identification documents or those who experience mental health issues are less likely to complete tuberculosis treatment without appropriate PSS.

Several key populations are particularly affected because they have increased exposure to TB bacteria, they have limited access to health services, and/or they are at increased risk of developing TB due to compromised immune systems. These populations include children, miners, mobile populations, prisoners, and people who use drugs. People who support such key populations will be aware of common needs within a population but will also know that each individual has their own specific needs. While this manual provides approaches which broadly apply to all people with TB, the person providing support will need to consider how to 'tailor' the approach to each individual.

In this manual the term "people with tuberculosis" refers to people who currently have tuberculosis disease; "people affected by tuberculosis" refers to any person with tuberculosis disease or who previously had tuberculosis disease, as well as their caregivers and immediate family members.

The right to health establishes entitlements and freedoms to promote the highest attainable standard of physical and mental health for all. This means national TB programmes should make provision for psychosocial care and make services available and accessible to people affected by TB who need them during treatment. Compassionate care that drives communication between health and social care workers and people and families affected by TB, is central to effective PSS. This manual aims to strengthen workers' interactions with affected people through guided conversations and provides illustrated examples on how to do this.

Effective provision also includes social protection measures such as nutritional support, cash assistance and housing. This may require new ways of working which place people affected by TB at the centre of their care, enabling them to communicate to workers about their lived experiences and how these experiences impact on their treatment and their need for support. It might also involve scaling up investment in community systems that can provide these services.

The manual is underpinned by values and principles of rights-based, people-centred and compassionate care which aim to empower people to become active participants in their treatment. This represents a shift away from direct observation of treatment (DOT) as the mainstay of care. The manual aims to encourage health and social care workers to reflect on their practice and their relationships with people affected by TB. The manual aims to encourage and empower people affected by TB, including TB survivors, to become active and capable supporters of their peers.

In particular, we examine the role of unconscious bias, which is a driver of stigma and a barrier to rights-based, people-centred care, in the context of diversity and social difference. We provide examples of practical tools, including guided conversational assessment, to facilitate people-centred relationships, and frameworks for reflective practice. We also signpost to other useful resources.

Audiences for this manual

This manual is written for audiences that have some knowledge about TB. They may be involved in developing policy guidelines, providing systematic screening, actively finding people with TB, or providing treatment adherence support.

There are four key audiences for this manual:

- trained health workers, social workers and care workers who can use this manual as a self-study tool and incorporate its guidance into their practice
- governmental and non-governmental employers of lay and professional TB treatment adherence workers, including civil society organisations and community leaders, who can provide training and guidance to their staff using the guidance in this manual
- TB clinicians, activists, programme managers, policy makers and other leaders, to make them aware of the full range of interventions required by a person with TB to complete their treatment and thus help them to understand the gaps that often exists in the support provided to patients
- people who, with enhanced capacity and support, can act as peer counsellors and supporters for people affected by TB. This can include family members who, in most contexts, play an important role in offering support to people with TB.

Further reading

Global Tuberculosis Report 2020. Geneva: World Health Organisation; 2020. Available at: *www.who.int/tb/publications/global_report/en/*

The Paradigm Shift: Global Plan to End TB 2018-2022, 2019. Geneva: Stop TB Partnership; 2019. Available at: *www.stoptb.org/assets/documents/global/plan/GPR_2018-2022_Digital.pdf*

A people-centred model of TB care: Blueprint for EECA countries, first edition, 2017. Copenhagen: WHO Regional Office for Europe; 2017. Available at: *www.euro.who.int/en/health-topics/Health-systems/pages/publications/2017/a-people-centred-model-of-tb-care-2017*

Psychosocial support for people with TB, HIV and viral hepatitis in the continuum of care in the WHO European Region, 2020. Copenhagen: WHO Regional Office for Europe; 2020. Available at: *https://www.euro.who.int/en/health-topics/communicable-diseases/hivaids/publications/2020/psychosocial-support-for-people-with-tb,-hiv-and-viral-hepatitis-in-the-continuum-of-care-in-the-who-european-region.-report-july-2020*

Activating a Human Rights-Based Tuberculosis Response: A Technical Brief for Policymakers and Program Implementers, 2020. Amsterdam: Global Coalition of TB Activists; Geneva: Stop TB Partnership; Chicago: Northwestern Pritzker School of Law Center for International Human Rights; July 2020. Available at: *www.stoptb.org/assets/documents/communities/Activating%20A%20Human%20Rights%20Based%20Tuberculosis%20Response_Policy%20Brief%20(2020).pdf*

The Impact of COVID-19 on the TB Response: A Community Perspective, 2020. Washington DC: ACTION; Amsterdam: GCTA; London: Global TB Caucus; Nairobi: KANCO; Montreal: McGill International TB Center; London: RESULTS; Geneva: Stop TB Partnership; Community and NGO Delegations; Kyviv: TBpeople; Montreal: TB PPM; Smyrna, GA: We Are TB; 2020. Available at: *www.stoptb.org/assets/documents/resources/publications/acsm/Civil%20Society%20Report%20on%20TB%20and%20COVID.pdf*

United to End TB: Every word counts - suggested language and usage for tuberculosis communications, 2013. Geneva: Stop TB Partnership; 2013. Available at: *www.stoptb.org/assets/documents/resources/publications/acsm/LanguageGuide_ForWeb20131110.pdf*

2 Principles of psychosocial support

Learning objectives

- to understand the PSS needs of people affected by TB, including key populations, and how these needs can be met by TB and community services and partners in the broader care landscape
- to appreciate the role of PSS as an integral component of high quality, rights-based, people-centred care, enabling people to complete TB treatment and achieve positive health outcomes
- to understand how self-stigma impacts on the psychosocial health of people affected by TB and their healthcare workers and apply measures to mitigate the impact of self-stigma on individuals, care workers and health systems
- to appreciate wider mental health issues in the care of people affected by TB and how to facilitate rights-based people-centred care through appropriate referrals to specialist services and use of digital health technologies
- to engage and empower TB survivors and people affected by TB to be effective advocates and peer supporters.

Box 1: The role of NGOs in supporting refugees with complex psychosocial support needs in the UK, a low TB incidence country

Faduma, who fled her home in Somalia, was seeking asylum in the UK at the time of her TB diagnosis. With the help of an interpreter, Faduma's TB nurse identified that the 63-year-old had a number of PSS needs. Faduma needed help with her immigration status and was worried about the threat of deportation. Because of this she found it difficult to prioritise her health. Faduma also feared TB stigma in the Somali community. She worried that she would be evicted by the family who allowed her to sleep on the floor in a shared living area, and that she would lose social status and the valuable social and economic support that came with it, if the wider community found out about her diagnosis. She had no private space to store her TB medication and took her pills in secret when the family had gone to sleep. She had very little money and was unable to afford "good quality halal food", which made it difficult to manage her diabetes. Faduma's TB nurse involved a social worker, part of a multidisciplinary TB team, to provide enhanced support. This included a jointly agreed care plan and outreach to community-based organisations. A local refugee support NGO provided Faduma with legal assistance for her Visa; invited her to drop-in sessions and sewing classes that protected her from social isolation; and provided the hot meals and encouragement she needed to manage her treatment. Eventually, Faduma's application for refugee status was accepted, with legal support, which entitled her to housing and social welfare assistance. Psychosocial support interventions enabled Faduma to successfully complete her TB treatment and she was later discharged from the TB service.

Introduction

In this chapter we discuss the principles of PSS. We discuss the rationale for psychosocial interventions, the type of interventions that are necessary and the range of organisations that can provide support using the stepped psychosocial pyramid. We expand on the concept of stigma, how this is internalised by people affected by TB *and* their healthcare workers (self-stigma), and highlight ways in which stigma can inadvertently be perpetuated in health systems. We provide examples of interventions that can be used to address stigma. We also discuss broader undiagnosed mental health issues and make recommendations to screen for mental health in collaboration with experts and develop protocols for referrals and management.

Why provide psychosocial support?

In the introductory chapter we defined psychosocial support as any form of support which aims to address the barriers (physical, economic, psychological or social) to accessing TB care and successfully completing a course of treatment. Providing PSS to people affected by TB is an integral aspect of rights-based, people-centred TB care[1] and fulfils the right to health as defined by the International Covenant on Economic, Social, and Cultural Rights[3] (UN General Assembly, 1966). The Covenant recognises: "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health" (article 12), supports a "whole person" approach to the integration of physical and mental healthcare and firmly places PSS as an essential aspect of TB care, rather than an option. The Declaration of the Rights of People affected by TB also affirms the right to PSS as "a legal, ethical, and moral imperative".[4]

The importance of PSS has been further recognised and committed to by countries in their endorsement of the UN High Level Meeting (UNHLM) on the TB Political Declaration, paragraph 14, as part of a TB response that promotes equity, ethics, gender equality and human rights.[5]

The provision of PSS interventions will empower people to gain control over decisions affecting them and enable them to better cope with their illness. People can be empowered through services that provide a facilitating environment where people and communities have a clear understanding of their roles and

responsibilities, and where people are provided with sufficient information to be involved as active participants in their treatment.[6]

Appropriate support will improve people's quality of life and enable them to adhere to, and complete, a course of treatment. Services are then more likely to retain people in their care, reduce the number of people lost to follow up, and achieve higher treatment success rates.[7] If people are only able to adhere to their treatment intermittently, perhaps because of costs or the side effects of treatment, this can lead to more serious and difficult to treat forms of drug-resistant TB, worse quality of life, and worse treatment outcomes with consequences for the health of individuals, their families and communities.

Appropriate assessment, ongoing monitoring and provision of psychosocial support is necessary because:

- there are significant structural barriers (see chapters 5 and 6) to people accessing care, and delays in seeking treatment may result in significant morbidity for individuals and increased risk of community transmission. Mechanisms are needed for people affected by TB to report these barriers and to overcome them
- stigma and self-stigma surrounding TB can prevent people accessing care and impact their ability to adhere to a course of treatment, particularly if they are afraid to disclose their diagnosis to others. Support mechanisms are needed to identify, report and overcome stigma
- the prolonged length of TB treatment means people may stop taking their medication once they begin to feel better, if they feel there is no improvement, as a result of the costs or burden of treatment, or because they experience adverse effects. Support is needed to overcome other barriers that might prevent people from adhering to, and completing treatment
- people may have to cope with the psychological and financial aspects of other complex comorbidities (e.g. diabetes, HIV/AIDS) which often have consequences for psychological and financial health. Support is necessary to address co-morbidities (see chapter 7)
- people's circumstances can change over time; for example, people may experience financial hardship and malnutrition over the course of their treatment, factors which can impact psychological health and adherence. Proactive support that responds to these changes and that match people's current needs is necessary

- TB affects key populations who often represent the poorest and most marginalised communities that are also most likely to experience significant health and economic disparities. PSS is necessary to address these inequalities through equitable access to care and treatment, free from stigma and discrimination. Support is needed to address social marginalisation
- poor quality care can add to the psychological burden of illness and treatment. Support is needed to ensure high-quality, rights-based, people-centred care.

Ultimately, it is a goal of a rights-based and people-centred TB response for people affected by TB to provide informed and qualified counselling and support for their peers – as communities are best placed to provide this function. Also, it is important to know that PSS (and broader TB) services are available, accessible, acceptable, of appropriate quality, free from discrimination and confidential, which can be monitored and reported on by people experiencing treatment through community-led monitoring (CLM) activities.

What type of psychosocial support is needed?

For the purpose of this manual it can help to think about people's support needs as those requiring:

- social and economic assistance (e.g. livelihood support such as access to benefits, and documentation (see Table 1 on p26)
- psychological support

Social and economic assistance aim to address people's livelihood needs (e.g. food, shelter, transport, diagnostic and treatment costs) in order that they can prioritise their health, access care and complete a course of treatment. Psychological support aims to address the mental health issues that may arise as a result of receiving a diagnosis of TB, for example: worry, anxiety, shock, and shame due to the stigma associated with TB. People may not want to accept the diagnosis or engage in self-blame believing their behaviour may have contributed in some way. Similarly the label of "TB patient", commonly used in healthcare settings, may result in identity and self-esteem issues, fear of stigma and discrimination. Box 2 describes the psychological support needs of people affected by TB.

It should be noted that people may not experience their health in terms of 'psychological', 'social' and 'economic' impacts; rather people may present with more generalised feelings of anxiety about their financial circumstances and concerns about their health. Health and social care workers will need to tease out the root causes of people's concerns through guided conversational assessment (discussed in chapter 3).

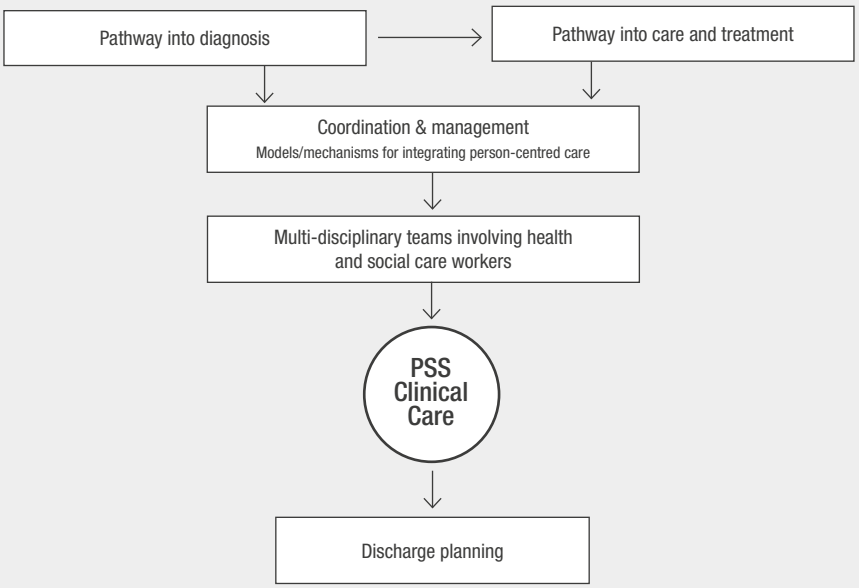
Box 2: Factors that may impact psychological health, health seeking behaviour and adherence:

- psychological effort in keeping illness a secret due to stigma and fears of discrimination
- feelings of failure or self-blame for having contracted TB, particularly drug-resistant TB, as care workers may (wrongly) assume people did not take their medication
- the impact on self-esteem and identity as a result of a TB diagnosis
- social isolation as a result of illness or rejection due to stigma and infection control policies
- psychological impact of coping with other comorbidities (e.g. HIV, diabetes)
- pre-existing mental health issues
- the side effects of treatment
- feelings of hopelessness and loss when treatment doesn't work
- lack of actual or perceived support from services, friends and family
- poor quality services including a lack of rights-based, people-centred and respectful care adding to the distress a person may feel
- the burden of caring responsibilities when feeling unwell
- limitations on participation in everyday activities due to illness
- financial and other worries associated with illness (e.g. time off work) and its treatment (e.g. diagnostic and treatment costs, transport costs)
- worries about legal status and entitlements impacting people's ability to prioritise their health needs.

When is psychosocial support offered?

Psychosocial support is needed to support people into diagnosis and for those with a confirmed diagnosis, until the completion of treatment[7] and discharge from the service. PSS should be made available as part of in-patient, or out-patient care; this includes family or community-based treatment adherence, peer support and TB affected community empowerment programmes. The need for PSS should be assessed for people with both presumptive TB and confirmed TB at first contact. The psychosocial care pathway is illustrated in Figure 1.

Figure 1: The psychosocial care pathway



Who provides psychosocial support: The stepped psychosocial support pyramid

Psychosocial support can be offered using a stepped approach illustrated in the Psychosocial Support Pyramid Model (see Figure 2). The model demonstrates that for most people affected with TB, their needs can be met by the TB services working with families and community-based organisations to provide social and economic assistance (level 1) to meet livelihood needs, adherence support (see box 2) and emotional and spiritual support (level 2). Low intensity psychological support is provided where there are additional needs at level 3 (e.g. drug and alcohol services). At level 4 a smaller proportion of affected people will require intervention from specialised health/mental health and trauma teams where this cannot be provided at level 3. In terms of a rights-based and people-centred response to TB, TB survivors and affected communities should have their expertise recognised and be involved in providing support at every level of the support pyramid.

Figure 2: The Psychosocial Support Pyramid Model

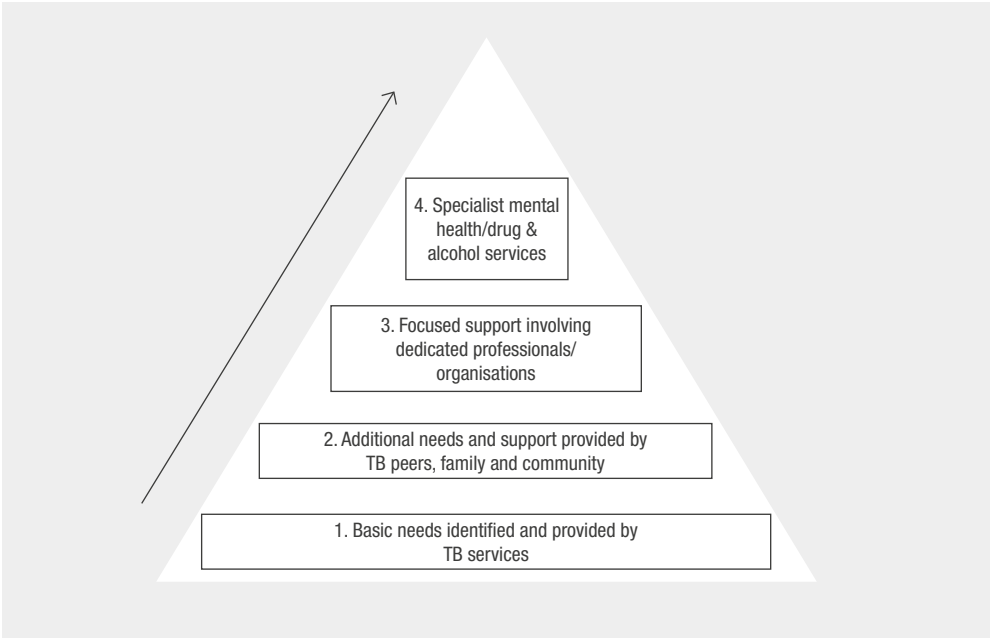


Table 1, on the next page, illustrates a range of psychological and livelihood support needs that can be met by different service providers although this may differ according to country, context and resources. A study mapping the provision of mental health services reported that people who were staying in hospital as in-patients accessed PSS as part of hospital care. The care provided was more likely to be structured and aimed at coping with the acceptance of a diagnosis of TB and the side effects of treatment. Those receiving care as an out-patient, however, were more likely to access psychological and social and economic assistance through multidisciplinary approaches involving community-based organisations[7] (see chapter 4). It is essential that local services identify other organisations in the community that can provide care and support and develop collaborative care pathways and service level agreements to provide care as needed.

Table 1: Who can provide support?[8]

Level	*Description of Support*	*People Involved*
Level 1	Social and economic assistance to ensure livelihood support needs are met to stabilise a person's environment and enable treatment (e.g. TB diagnostic and treatment costs, shelter, nutrition, legal assistance for documentation or visa status, transport subsidies, clothing, incentives, adherence support initiatives).	Assessment by health or social care worker to identify unmet need with input provided by relevant staff (e.g. social workers) and care provided by NGOs, CSOs, para-legal organisations.
Level 2	Emotional and spiritual support resulting from a TB diagnosis and treatment (e.g. guilt, fear, anxiety, self-blame, social isolation, loneliness, identity and self-esteem loss, despair, set-back, discrimination). Stigma reduction initiatives.	Family members, caregivers, friends, or TB survivor peer supporters, trained community volunteers, community health workers and NGOs. Faith-based organisations, religious and spiritual leaders.
Level 3	People may require focused support and require additional input from services. (e.g. alcohol and substance misuse).	Drug and alcohol workers, therapists, involvement of specialist CSO/NGOs
Level 4	People experiencing more severe mental health problems (e.g. depression, substance and alcohol misuse, those experiencing PTSD) that cannot be managed at level 3 will require referrals to specialist services with trained professionals where available.	Psychologists, psychiatrists and mental health workers

Adapted from Save the Children's Resource Centre, Psychosocial Support, The Psychosocial Support Pyramid Model

Box 3: Family-based adherence support in Malawi[9]

Development Aid People to People Malawi, a local CSO, arranges a support system in which the person on TB treatment, along with a family member, and a third person (who could be another family member, a friend or a neighbour) form a treatment support group called a TRIO. They receive training from qualified health outreach workers on how to support the person on TB treatment. A project evaluation identified a range of supportive practices that help with self-care activities, including:

- accompanying the person on TB treatment to the health facility for appointments
- collecting medication from the health facility
- providing direct observation of treatment
- preparing meals for the patient during illness
- providing adherence counselling.

Gender sensitivity

Gender is a social determinant of health. This means that inequalities in people's health, the barriers they face in accessing TB related healthcare and their ability to successfully complete a course of treatment and remain free of TB, are influenced by their gender. Women face particular barriers in accessing TB care, including poverty and the social stigma associated with TB which can result in delayed diagnosis and treatment. Moreover the experience of TB can significantly impact their ability to care for their children, families and other dependents as well as engage in paid work. Stereotypes about gender roles and what constitutes appropriate and acceptable behaviour for men and women may prevent them from prioritising their health, seeking healthcare, accessing support and adhering to treatment. For example, illness and the need for support may be associated with weakness and behaviours considered at odds with dominant constructions of masculinity that privilege the role of men as economic providers and head of household.[10]

Trans people also face significant barriers in accessing healthcare because of fear of discrimination. The way healthcare is organised may also present a barrier to accessing services for example, male and female hospital wards. Gender identity may influence how people engage with healthcare. For example, men who have sex with men, but who do not identify as gay, may fail to access preventative services that are perceived to cater for the gay community.

Men and women also experience different types of risk that expose them to TB-HIV. For example, gender-based violence and being involved in sex work, place women at risk of HIV. Men are more likely to smoke, drink alcohol and use drugs, which are risk factors for TB. Men may work in particular occupations (e.g. mining) or may be overrepresented in prison populations, both considered high risk environments for the transmission of TB.

Services need to understand these different experiences and how gender impacts people's ability to seek healthcare and engage with services and treatment for TB-HIV by embedding gender sensitivity into their services and practice, (see case study at the beginning of chapter 4, Box 7). However, for services to build in a gender perspective they will need to collect data on gender to obtain a better picture of the prevalence of TB-HIV, (see second case study, chapter 4, Box 9).

UNAIDS and the Stop TB Partnership have developed a gender assessment tool for national HIV and TB responses (see section on further reading at the end of the chapter) which allows countries to provide a gender sensitive response to their local HIV and TB pandemics and also provides a rationale for the need for gender sensitivity and a more in-depth discussion of gender in relation to HIV and TB.

Stigma and Discrimination

"Discrimination involves enacting stigma through illegal means or denying a person equal treatment".[11]

TB stigma can be defined as the negative labelling or rejection of people with TB, and often, their families, due to stereotyping or other negative attributes that are associated with TB and affected communities. The devaluation of people with TB can result in discrimination and lead to inequality; for example, people may lose their home or their livelihood because of stigma. Among the 3-4 million people every year who are not diagnosed or reported, stigma plays an important role in people not seeking care.[12] It can affect people's ability to take their medication and because people fear stigma if they tell others they have TB, it can prevent them from accessing other types of community support that might help them to cope better with their illness (see the case study about Faduma in Box 1). People who research the impact of stigma suggest an important distinction exists between anticipated and enacted stigma. Anticipated stigma, the fear of being

stigmatised by others, may encourage people to hide their diagnosis and engage in avoidance behaviour. They may spend a lot of "psychological effort" trying to keep their illness a secret, adding to the burden of coping. Enacted stigma is the actual experience of stigma, for example exclusion or rejection. [13]

Stigma can happen at different levels, including through health, social care, education, legal and policy systems. Different interventions will be required to tackle stigma at these different levels. For the purpose of this manual we will focus on self-stigma in people living with TB and their care workers who may both experience stigma and reproduce stigmatising practices. Given that TB disproportionally impacts key populations who are already marginalised; it can exacerbate existing inequalities and discrimination. People who are homeless, people who use drugs, people living with HIV, people in prison or otherwise deprived of their liberty, indigenous peoples, and undocumented migrants often experience stigma and discrimination in their day-to-day existence and care must be taken to ensure this is not compounded in the context of TB. In addition, a person's gender is a driver of stigma and there is a need for HCWs to understand the impact of stigma on people affected by TB.

Stop TB Partnership, together with partners has developed the TB Stigma Assessment tool (see section on further reading at the end of the chapter). This tool allows countries to measure stigma experienced by people affected by TB in terms of self-stigma, stigma in healthcare settings, stigma in communities and structural stigma. Through this process, targeted and comprehensive interventions are developed to address reported stigma. This tool should be used in all TB high burden countries. The Global Fund has adopted the relevant indicators from the tool into the Modular Framework. Countries can select these indicators to establish levels of TB stigma and to monitor progress of stigma reduction activities funded by the Global Fund over time.

Self-stigma and shame

People experiencing self-stigma (also known as internal stigma) as a result of a diagnosis of TB may experience feelings of shame, self-hatred,[14] guilt or blame which may affect their ability to accept a diagnosis and adhere to their care and treatment plans.

Stigma in healthcare workers and health systems

Healthcare workers may also internalise stigma which can affect their interactions with people with TB. They may engage in behaviour that stigmatises people, either through their individual interactions, the language they use (e.g. 'default on treatment') or everyday clinical practices embedded within health systems. For example, treatment cards that identify those as having TB or HIV through their colour may inadvertently stigmatise people.[15] Care workers may feel undervalued because services often lack resources and because TB care is associated with 'dirty work';[16] that is work that others view as low status or degrading. This devaluation is another driver of stigma and can prevent HCWs delivering high quality care.

Healthcare workers are at increased risk of TB. Fear of infection can also serve as a driver of stigma[11] impacting their relationships with people affected by TB and acting as a barrier to accessing healthcare for themselves, (see section on compassionate care in chapter 3, unconscious bias and the SOCIAL GRACES framework to avoid practices that undermine relationships between care providers and people affected by TB). Mechanisms to report stigma and legal or administrative remedies should be made available to people accessing TB treatment, including providing details of TB survivor networks and legal aid organisations.

Interventions to tackle self-stigma for people with TB

KNCV (the Royal Dutch Tuberculosis Foundation) has developed an evidenced-informed resource with tools designed to tackle TB self-stigma in people with TB and healthcare workers (see appendix). The resource describes four interventions with evidence of effectiveness. These are described in Box 4.

Box 4: Interventions to address self-stigma

Inquiry-based stress reduction

Inquiry-based stress reduction (IBSR) is a community-based, peer to peer, educational program originally developed for people living with HIV in Zimbabwe and adapted to people living with TB experiencing self-stigma and shame. Formal evaluation suggests the course improves self-confidence and reduces concerns about disclosure in relation to HIV. Improvements in self-stigma, depression and daily activities have been reported.

TB clubs

TB clubs in low and middle income countries have proved to be effective in tackling stigma. In some countries, for example Bangladesh, they run as part of government programmes delivered by NGOs. In other countries, such as Zambia, they are run by former TB patients who form committees. In addition to tackling stigma and acceptance of a diagnosis of TB, some TB clubs assist with referrals to services and adherence.

TB Photovoice

TB Photovoice (www.tbphotovoice.org) aims to give people with TB-HIV a voice. Survivors share stories through a project based website using photographs, videos, and narrative. It improves self-esteem through group coaching and uses photo documentary to explore people's feelings and emotions.

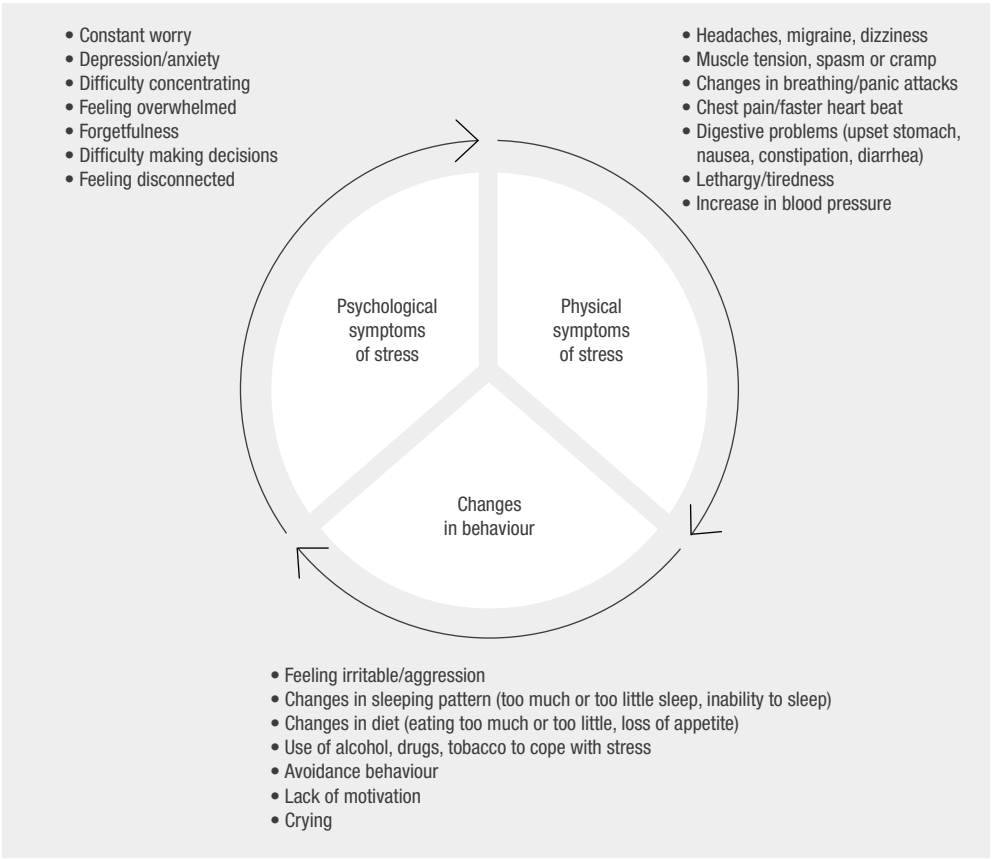
Interventions to tackle self-stigma for care workers and stigma in healthcare systems

KNCV has developed a toolkit with a self-learning module for care workers to understand how their practices may stigmatise people affected by TB. One exercise describes how a nurse challenges stigma in her everyday practice.[11]

TB and broader mental health issues

Figure 3 highlights the stress cycle where psychological symptoms of stress (e.g. depression, anxiety) produce physical symptoms (e.g. chest pain, high blood pressure) which lead to changes in behaviour (e.g. inability to sleep, alcohol use) which in turn trigger symptoms of stress. Worry about TB and the impact on daily routines, employment, income and family and adhering to treatment can trigger a stress response. It is important to break the stress cycle by finding out what people's worries and concerns are and offering appropriate support and referral to services (see guided questions chapter 3 and section on digital health technologies later in this chapter).

Fig 3: The Stress Cycle



Mental health disorders contribute to significant morbidity, disability and mortality among those affected. Additionally, due to the prevailing stigma surrounding mental health disease, these disorders are often hidden by society and consequently, people with poor mental health experience worse quality of life.

The relationship between TB and mental health is complex as people may have undiagnosed mental health issues before they start treatment, or they may develop mental health issues during their care as they try to cope with illness, treatment regimens, the costs of treatment and the stigma and discrimination associated with TB. Women are more likely to experience worse mental health than men as a result of their role as caregivers and the impact of stigma. People from key populations may have very specific mental health issues. Refugees, for

example, have experienced living in countries where war, political and sexual violence, human rights violations and torture are common.

In general, people with undiagnosed mental health issues experience worse treatment outcomes. This was reported in a study in Ethiopia where people with untreated depression at the start of their TB care were less likely to complete their treatment and more likely to die.[15] Similarly, people who engage in substance misuse and alcohol abuse are less likely to adhere to treatment and also experience worse health outcomes without adequate PSS interventions (see case studies in chapter 4, Box 7 and chapter 7, Box 17).[18, 19]

In addition to the social and economic hardship people experience as a result of TB and TB treatment, people with MDR-TB are at greater risk of depression, which may be associated with prolonged treatment regimens and feelings of hopelessness and despair about recovering from TB.[20] Women in particular may suffer poor mental health during treatment for MDR-TB, as well as isolation and financial hardship.

Although estimates of the prevalence of mental health issues in TB populations can be as high as 50% for those with depression, mental health issues are under-recognised in TB care programmes and tend not to be identified as a barrier to treatment success.[21]

Screening for and monitoring mental health issues

It is important to identify and monitor mental health issues at treatment initiation and throughout TB care, including transitions in care; for example when people are discharged from an in-patient setting to out-patient care, and return home. The National TB Program monitoring forms could be adapted and used to record mental health issues or monitoring tools available through OneImpact, a community-led digital health platform (see section on further reading at the end of the chapter). Screening tools for depression or anxiety can be used as a first step to identify those people at risk and who may need more in-depth assessment for a referral to specialist services (e.g. level 3 or 4 in the support pyramid, chapter 2). One screening tool for depression used extensively in primary care with some limited use in LMICs is the Patient Health Questionnaire-2 (PHQ-2) which is used as a first step approach to identifying depression and should be administered to everyone as part of routine care (see section on further reading).

Those people who obtain a positive score should then receive a further assessment with the Patient Health Questionnaire-9 (PHQ-9). Decisions about the use of screening tools and the development of referral protocols should involve affected communities to determine their appropriateness and acceptability, mental HCWs and NGOs with expertise in mental health.

Particular attention is needed when caring for someone coping with the side effects of treatment for MDR-TB, which may require additional PSS including referral to community-based organisations and other specialist services. For example, some drugs can cause depression, anxiety or psychosis.[22] Other drugs have significant life-changing side effects such as hearing loss and peripheral neuropathy. Appropriate monitoring is necessary, as are support services to help people deal with the economic and social consequences. Services should assess family caregivers, usually women, as the burden of caring is also associated with poor mental health and could affect their ability to care for dependents (see chapter 7).

A summary of WHO's evidence-based guidelines for supporting people affected by mental health issues is referenced in the section on further reading.

Digital Health Technologies

In today's digital age, information and communication technology presents considerable scope to make TB care more seamless and integrated for people with TB. There are now over 7.5 billion mobile phone connections globally, and about 40% of the world's population is using the internet.[23]

The COVID-19 pandemic and the ongoing restrictions have brought about fundamental shifts in people's day-to-day life at home and at work, which has had a profound impact on their anxiety and stress levels and overall well-being. In the foreseeable future, it will become a necessity and a new normal to leverage digital health technologies to close the gap in providing PSS to people experiencing high emotional and psychological distress, particularly in TB affected countries.

Digital health technologies can complement and strengthen mental health programs and Digital Adherence Technologies (DATs) can support individuals struggling with mental health to adhere to treatment without having to attend TB clinics in person.

Digital Health Technologies and Mental Health

Digital technologies are available to assist with the management of stress and improve general well-being and can be accessed through the internet or applications on mobile devices. Interventions may include learning exercises, self-monitoring tools, audio sessions and surveys to solicit feedback and ensure the provision of customized support. Over time, the use of such applications can also help in monitoring stress and wellbeing through the creation of dashboards on the user's stress patterns, habits, symptoms, and can recommend personalized plans that help users cope with stress and stigma in a manner that works best for them.

A range of digital technologies are also available for the treatment of depression and anxiety disorder with the majority offering self-help programmes designed for use on their own or with supervised support. However there is great variation in the content of these programmes including the emphasis on education, the tools offered and faithfulness to a prescribed form of therapy.[24]

Digital adherence technologies (DATs)

Digital technologies used to support TB treatment adherence include video observed treatment (VOT), also known as video-based DOT (VDOT), whereby health providers observe people with TB taking their TB medication in-real time, can provide opportunities to embed PSS in similar ways to face-to-face consultations. Pre-recorded videos, which allow people with TB more choice about the scheduling of their TB medication, may result in fewer opportunities to offer support. Consultations where the primary purpose is PSS may help and a blended approach to 'live' and 'recorded' consultations can be offered as needed.

Many health care providers have increased their use of video consultations during the COVID-19 pandemic. However consideration is needed for those groups who do not have access to a smartphone, tablet or computer that allows video calling with a functioning camera, microphone and internet connection or a private space to maintain confidentiality.

People with TB should be given a choice about how they receive their support. DHTs should be assessed for their functionality, content, suitability and acceptability to different users of the technology.

Consolidating learning

- Read the case study at the beginning of this chapter and identify the different types of PSS Faduma received, with reference to the PSS pyramid. If Faduma was in your care, which health facilities/community-based organisation would be involved in providing a similar package of rights-based, people-centred care?
- Read the Declaration of the Rights of People Affected by TB in the section on further reading. There are 23 articles which describe the rights of people affected by TB. Now read the case study about Faduma and identify which rights the multidisciplinary team addressed in providing rights-based, people-centred care.
- Think about the language that is used to describe people affected by TB in health systems. How does the use of this language contribute to the stigmatisation of people with TB? Now read the resource in the further reading section "Every Word Counts" to find alternative, non-stigmatising terminology.
- Identify practices in your service that could stigmatise people with TB, for example colour coded treatment cards to indicate that a person has HIV.
- Discuss with a colleague the ways in which services that are not sensitive to people's gender can affect access to care and treatment completion.
- What measures are in place to identify, support and monitor people with mental health issues, including depression in your service? Which agencies /institutions/healthcare facilities could you work with to ensure people with mental health issues receive appropriate support?

Further reading

Declaration of the Rights of People Affected by TB, 2018. Kyiv: TBpeople; Geneva: Stop TB Partnership; 2018. Available at: *www.stoptb.org/assets/documents/communities/Declaration%20of%20the%20rights%20of%20people%20affected%20by%20TB%20-%20A5%20english%20version.pdf*

Gender sensitivity

Gender assessment tool for national HIV and TB responses, 2016. Geneva: UNAIDS; Geneva: Stop TB Partnership; 2016. Available at: *http://stoptb.org/assets/documents/communities/Gender_Assessment_Tool_TB_HIV_UNAIDS_FINAL_2016%20ENG.pdf*

Human rights and people-centred care

Declaration of the Rights of People Affected by TB, 2018. Kyiv: TBpeople; Geneva: Stop TB Partnership; 2018. Available at: *www.stoptb.org/assets/documents/communities/Declaration%20of%20the%20rights%20of%20people%20affected%20by%20TB%20-%20A5%20english%20version.pdf*

Stigma

TB Stigma Assessment: Implementation Handbook, 2019. Geneva: Stop TB Partnership; 2019. Available at: *www.stoptb.org/assets/documents/communities/STP%20TB%20Stigma%20Assessment%20Implementation%20Handbook.pdf*

KNCV Tuberculosis Foundation. TB Stigma. *www.kncvtbc.org/en/kb/tb-stigma/* KNCV guidance on measuring stigma, toolkits for measuring self-stigma, stigma reduction in healthcare workers and healthcare settings and the photo voice project.

United to End TB: Every word counts - suggested language and usage for tuberculosis communications, 2013. Geneva: Stop TB Partnership; 2013. Available at: *www.stoptb.org/assets/documents/resources/publications/acsm/LanguageGuide_ForWeb20131110.pdf*

A resource on the appropriate use of terminology in TB communication called with recommendations on how to avoid the use of stigmatising language.

Mental Health

Dua, T., Barbui, C., et al. (2011). Evidence-based guidelines for mental, neurological, and substance use disorders in low- and middle-income countries: summary of WHO recommendations. PLoS medicine, 8(11), e1001122. Available at: *https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1001122*

Stop TB Partnership. OneImpact. *https://stoptbpartnershiponeimpact.org*. A mechanism that countries are using to report mental health concerns. This Stop TB Partnership CLM tool allows people affected by TB to report barriers to access, community advocates to monitor human right indicators and national TB programs to take programmatic action to address the needs of people affected by TB.

National HIV Curriculum. Mental Disorders Screening. *www.hiv.uw.edu/page/mental-health-screening/gad-2*. Screening tools for mental health disorders, including the PHQ 2 and 9.

3 Assessing the need for psychosocial support: compassionate care and guided conversational assessment

Learning objectives

- to understand how compassionate care underpins high quality, rights-based, people-centred care
- to provide and promote non-discriminatory, rights-based, people-centred PSS recognising people's values, beliefs, diverse backgrounds, cultural characteristics, race, gender, sexuality, disability, language requirements, needs and preferences
- to appreciate the importance of effective communication in providing people-centred, compassionate care and how unconscious bias serves as a major barrier
- to understand and apply a rights-based, people-centred approach to the assessment of PSS using guided conversational assessment.

Introduction

In this chapter we discuss frameworks for achieving rights-based, people-centred PSS. We argue that central to the provision of support is the relationship between care providers and people affected by TB which is fostered through compassionate care and effective communication. We identify barriers to effective communication, including the role of unconscious bias, in the context of diversity and social difference. We introduce the SOCIAL GRACES as a framework to reflect on unconscious bias and social difference and the impact on the provision of care. Finally, we introduce the concept of guided conversational assessment to understand the lived experiences of people affected by TB. We argue that the best way to assess people's need for PSS is through conversations and active listening which not only situate people at the centre of their care but highlight the impact of TB on their everyday lives.

Theoretical model

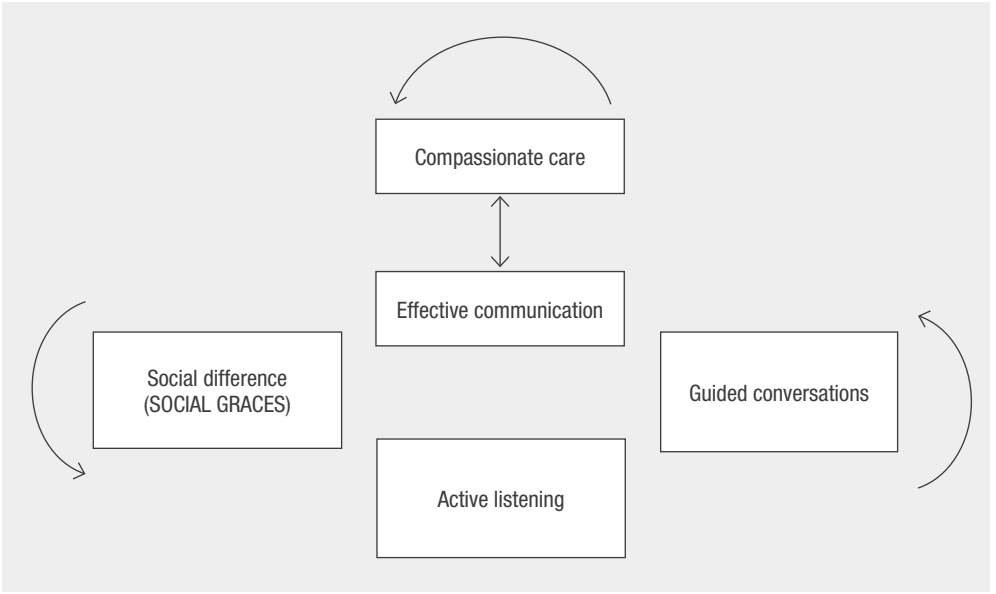
The theoretical model for providing rights-based, people-centred care (see figure 4) involves two main components:

- compassionate care
- effective communication

Effective communication is achieved by reflecting on:

- social difference using the SOCIAL GRACES framework
- guided conversations
- active listening

Figure 4: supporting people: theoretical model



Compassionate care

"Compassion is what drives acknowledgement and action in order to alleviate or eliminate the suffering or pain of another."[25]

TB is often understood as a disease requiring technological solutions that inform how care is delivered; for example: X-rays, sputum smear microscopy and pill taking. This technological approach can result in professionally-led care that people with TB may experience as dehumanising. Particularly if healthcare workers treat them as "sources of infection" rather than people with emotional and social needs, and if the care they receive comes across as a series of medical tasks and interventions.[26] Compassionate care[27] is a values-based approach to providing high-quality, rights-based, people-centred care and involves six components (see Box 5).

Box 5*:* The six Cs of compassionate care

The six Cs of compassionate care

- care that is rights-based, people-centred and attends to diversity and social difference
- compassion in relationships with people based on empathy, respect, dignity and enablement
- competence whereby team members demonstrate the ability to understand, and meet, an individual's need for health and psychosocial care
- courage which enables HCWs to speak out when people's human rights are not respected
- commitment towards improving the experience of care for people affected by TB and their families
- communication that is open and honest and respects dignity and diversity.

Adapted from: Compassion in practice: Nursing, midwifery and care staff. Department of Health; 2012

Effective communication in PSS

"Communication is a process that involves a meaningful exchange between at least two people to convey facts, needs, opinions, thoughts, feelings or other information through both verbal and non-verbal means, including face-to-face exchanges and the written word."[28]

Effective communication is associated with improved treatment outcomes, better quality care and higher rates of patient satisfaction with healthcare.[29] When assessing and planning the provision of care for people with TB, care workers should strive towards providing rights-based, people-centred care. Care is not rights-based and people-centred when professionals dominate and control the flow of communication[26] and make decisions that do not take into consideration the preferences, needs and desires of people with TB. Poor communication can result in poor understanding of TB and its treatment, leading to a lack of engagement with services, and poor adherence.

Social difference

People may be unaware of social difference as a driver of inequality in wider society. It is increasingly recognised that "unconscious bias" (unrecognised bias) amongst healthcare workers can also contribute to health disparities through poor communication and poor quality care because of prejudice towards or stereotyping of particular social groups on the basis of their race, gender, class, age, sexual preference, disability, religion, or other marker of social difference.[30, 31]

HCWs should provide non-discriminatory, rights-based, people-centred care which respects people's values, background, ethnicity, language requirements and needs and preferences.

Unconscious bias and the SOCIAL GRACES framework

The "SOCIAL GRACES"[32] (see box 6) is an evolving framework that can be used to reflect on how unconscious bias can affect interactions between healthcare workers and patients.[33] To illustrate this table 2 provides some examples of how unconscious bias could result in sub-optimal care using the example of a student nurse, Paloma, and conversations with her mentor in practice, Carmen.

Box 6: SOCIAL GRACES

G	**G**ender, **G**ender identity, **G**eography, **G**eneration
R	**R**ace, **R**eligion
A	**A**ge, **A**bility/disability, **A**ppearance
C	**C**ulture, **C**lass, **C**aste
E	**E**thnicity, **E**ducation level, **E**conomics, **E**mployment
S	**S**exuality, **S**exual preference, **S**pirituality

Table 2: Examples of unconscious bias: conversations between Paloma, a student nurse at a TB clinic, and her mentor Carmen

Gender, age and religion	Paloma knows that people with TB should be offered an HIV test. However, when a Bangladeshi Muslim woman attends the TB clinic Paloma tells her mentor that it would be culturally offensive to offer her a test. Paloma argues that the woman is not at risk of HIV as she is older and married. Carmen replies that it is wrong to make healthcare decisions based on assumptions about people's race, age, religion or marital status. Carmen reminds Paloma that failing to offer an HIV test could breach people's rights to healthcare and create disparities in care, and also limit access to treatment for people with undiagnosed HIV.
Gender, sexuality and sexual preference	A man who has been offered an HIV test through the TB clinic asks Paloma if the clinic is offering condoms. He is worried because he has sex with men and has been advised to practise safe sex. Paloma tells him that they do not have any and suggests an organisation that offers sexual health advice for gay and trans people. However, the man says he won't go there as he is not gay. Paloma is confused and talks to Carmen. Carmen explains that some men who have sex with men don't identify as gay and often lose access to public health prevention programmes and other services that they perceive to be for the gay community. Carmen tells Paloma about generic sexual health services that she could recommend. Paloma says she will offer people a choice of venue in future and not make assumptions about their sexuality.
Religion and culture	The TB clinic has received a donation of food to make into parcels for some of the poorer groups attending the clinic. When a Hindu man asks for one, Paloma tells him there is none suitable for him, as she assumes he is a vegetarian. When he says he can eat ham Paloma is surprised. He explains that he eats meat but not beef (meat from a cow). Carmen tells Paloma that it is always better to ask people about their food preferences rather than make assumptions based on cultural and religious stereotypes.

Guided conversational assessment: Using conversations to assess and plan people's care and support

(Adapted from Using Conversations to Assess and Plan People's Care and Support, Skills for Care, 2018)

Guided conversations can be used to assess and plan people's care and support[34] and are the first step in delivering rights-based, people-centred care. The principles of guided conversational assessment include:

- a focus on people's lives where they are encouraged to talk about their lived experiences in their own words
- a recognition that people are experts in their own lives and have skills to enable them to play an active role in their care, including decisions about their care
- an understanding that experiences of illness and care take place within the context of people's life history, their families and communities and other structural determinants such as racism
- an acknowledgment that relationships with care workers are based on honesty and trust.

Whereas some assessments, such as risk assessments, dominate the flow of conversation between care worker and patient and can be described as "form led" communication, conversational assessment allows people-led communication.[34] Consider the examples provided in table 3 which aim to assess the need for support for adherence. Question A provides an example of a closed question which requires a fixed response. It is professionally led and sets up a particular power dynamic in the relationship between care worker and the person receiving care. Question B, however, is more likely to facilitate person-led communication and is presented in a less accusatory way. Additional examples of guided conversations are given in table 4 at the end of this section.

Table 3: Assessing support for adherence

Type of question	*Example*
A) Example of a closed question	How many times have you missed taking your medication in the last week/month?
B) An example of a conversational approach to assessment	**Care worker**: *How have you been getting on with your medication?* *Any problems? Have you managed to take them every day?* *Can you tell me about a time in the last week/month when you weren't able to take your medication?* **Patient may reply, for e.g.**: *I missed my medication on Thursday/market day/the day I worked/the day after I went to the drug dependency unit* **Care worker**: *Can you tell me what happened?* **Patient**: *elaborates on the reasons* **Care worker**: *What would help to support you to take your pills next time this happens?* *Is there anything you could do differently?* *Is there anything we could do to support you to do this?*

Guided conversations are particularly useful when trying to understand people's experiences in the context of culture and diversity. Different cultures have their own understanding and experience of illness. Medical anthropologists have developed eight culturally sensitive assessment questions that are widely used in cross cultural medicine to understand how a person is affected by illness.[35] Allowing people to describe their illness, in their own words, can help care workers understand people's concerns and the psychosocial stresses experienced as a consequence of illness, including the impact of illness on work, family, relationships, and livelihood. The questions are:

1 What do you call this problem (i.e. illness)?
2 What do you believe is the cause of this problem?
3 What course do you expect it to take?
4 How serious do think it is?
5 What do you think this problem does inside your body?
6 How does it affect your body and your mind?
7 What do you most fear about this condition?
8 What do you most fear about the treatment?

These questions can also be used for all people affected by TB, not just those from different cultures, to assess people's knowledge and understanding of TB and their reactions to receiving a diagnosis and following a course of treatment (particularly questions 7 and 8).

Table 4: Guided Conversations - supporting people with TB

Opening the conversation	Hello [*name*]. How are you feeling today?
Identifying issues	*How have you been getting on with your treatment?* *What difficulties are you experiencing managing your symptoms/ medication/work/relationships with family/everyday activities/costs of treatment?*
Exploring emotions and honing down	[Note any changes in mood and ask about these] You seem a little tired/upset/withdrawn/sad/angry today *Is there anything in particular bothering/worrying you?* *Can you tell me if there's anything in particular you are struggling with?* [Alternatively acknowledge a positive change in mood] *You seem a lot better/brighter/happier today. Is there a reason for that? What's changed?*
Identifying co-created solutions	*What are your thoughts about how to manage these issues that are bothering you/ you are struggling with?* *Have you got any ideas about how to change the way you're feeling about* [issues raised]*/managing your illness/managing your medication?* *What can we do to support you to manage [issues raised] better?*
Summarising the discussion	*So let me summarise what we have discussed today to make sure we have covered everything* *So from what you have told me you have been feeling...* *You are worried about...* *You have been finding* [issues raised] *difficult* *You would like to change* [issues raised] *You think* [solutions identified] *would be helpful…* *You would like more support with/ to do* [issues raised] *Could I also suggest…* [other supportive actions/referrals to other services]

Seeking clarification	*Have I understood you correctly? Have I missed anything?* *Is there anything else you would like to add to what we have discussed already?*
Safely closing the conversation, agreeing objectives, goal setting and identifying support mechanisms	*Let's set some goals to help support you* *What would you like to achieve* [set timescale, e.g. in the next two weeks]? *How will you achieve these?* *Are there any barriers to stop you reaching these goals?* *How can you overcome these barriers?* *Who can help you to achieve these goals in your family, community network?* *What support can you expect from them?* *From what you've told me I think these are the things we need to think about* [list them] *Let's agree these objectives* [clarify objectives verbally or in writing]

Active listening

Rights-based, people-centred communication can be achieved through active listening and attending to what people are saying. Table 5 provides a checklist to guide active listening.[36]

Table 5: Active listening checklist - do's and don'ts

Do	✓ check the need for an interpreter or advocate in advance ✓ think about the location of the appointment and issues of safety, accessibility, privacy and confidentiality ✓ try to allow adequate time so the appointment is not rushed ✓ turn off your mobile phone or switch to silent and ensure no other distractions ✓ maintain a neutral, relaxed position, feet on the floor and arms on lap - turn to face the patient to demonstrate interest ✓ encourage open communication by allowing patients time and space to voice their concerns ✓ listen to what the patient is telling you - ask open questions to find out what the patient is thinking or feeling. ✓ maintain an appropriate level of eye contact ✓ demonstrate interest in what the patient is saying with verbal reassurance and non-verbal communication (e.g. moving or nodding of head) ✓ demonstrate you are listening by summarising and paraphrasing what the patient has told you (e.g. so you've told me you're worried about the impact of clinic appointments on your job and taking time off work, what other worries do you have about the treatment?)

Don't	✗ rush to fill pauses or silence ✗ interrupt people, allow them to finish ✗ plan what to say next without listening to what people are telling you now

Consolidating learning

- Discuss with colleagues the values of compassionate care and how these values are, or could be, embedded within your practice and wider service.
- Reflect on your own assumptions and unconscious bias about people from socially diverse backgrounds using the SOCIAL GRACES framework.
- Reflect on a time when communication with a person affected by TB did not go so well. Using the learning from this chapter, think about what you could do differently to communicate more effectively in future.
- Compare and contrast guided conversations as an approach to the assessment of PSS with usual practice.

Further reading

Communication skills

Nursing Times. Assessment Skills – Communication. *www.nursingtimes.net/clinical-archive/assessment-skills/#9*

Advice on effective communication, covering five areas:

Communication skills 1: Benefits of Effective Communication

Communication skills 2: Overcoming the Barriers to Effective Communication

Communication skills 3: Non-verbal communication

Communication skills 4: The influence of appearance and environment

Communication skills 5: Effective listening and observation skills

Culture and diversity

Brathwaite, B. eds, (2020). Diversity and Cultural Awareness in Nursing Practice. London: Sage. Available at: *https://us.sagepub.com/en-us/nam/diversity-and-cultural-awareness-in-nursing-practice/book257607*

4 Multidisciplinary teams and collaborative psychosocial support as an integral part of prevention and care

Learning objectives

- to understand the role of different members of the multidisciplinary team, including TB peer supporters, in providing collaborative, people-centred PSS
- to understand mechanisms for coordinating multidisciplinary support
- to appreciate the role and importance of a rights-based, people-centred approach to the coordination and delivery of multidisciplinary, collaborative PSS for key populations
- to understand the role and importance of rights and gender-based PSS in meeting the needs of people with TB
- to understand how affected communities and different government and non-governmental sectors, including CSOs, work together to provide collaborative PSS for key populations
- to appreciate the role of community-led monitoring in protecting people's human rights to high quality, people-centred care.

Box 7: Case study: Collaborative working to provide rights-based, people-centred psychosocial support to women who misuse substances

Michelle is a vulnerable woman with a history of dependence on opiates. She was living in a homeless shelter when she fell ill with TB. Though Michelle had been losing weight for some time, it was only when she collapsed with chest pains and shortness of breath that it became obvious that something was seriously wrong. Fortunately, staff at the shelter had recently attended a TB awareness training session offered by the local TB service. They realised Michelle's symptoms could be TB and took her to hospital. Michelle was admitted as an in-patient and diagnosed with TB. Whilst still in hospital, she was linked to a community TB nurse and referred to a drug dependency unit (DDU). Staff from the DDU visited Michelle and prescribed a methadone maintenance (opiate substitution) programme. The TB nurse also visited Michelle to establish a relationship and contribute to her discharge plan. She then liaised with the homeless shelter to advise on infection control, arrange TB screening for staff and residents, and ensure Michelle was not evicted when she returned to the shelter.

When Michelle was discharged, her TB medication was provided through DOT, administered by the DDU alongside her methadone programme. Michelle soon began missing her DOT appointments and the DDU alerted her TB nurse. The TB nurse organised a patient care management conference for all the members of the multidisciplinary team involved in Michelle's care – her key worker at the homeless shelter, a TB social worker and the DDU worker – to better understand why she was missing her treatment and to find ways to support her. Michelle was also supported to attend the meeting. Michelle explained that she had missed her appointments because she was feeling unwell. She was breathless and had difficulty walking. She didn't know if her symptoms were due to TB, the TB medication, or drug withdrawal – as she did not think she was on sufficient methadone to prevent symptoms of withdrawal. She also believed the TB medication wasn't working and that the rifampicin was interacting with her methadone. Because the experience of drug withdrawal was so painful and frightening, Michelle had resorted to injecting drugs to cope. She was also feeling stressed about her housing situation and said she had used drugs to cope with that.

The team agreed a care plan that respected Michelle's preferences and choices, detailed the responsibilities of everyone involved in her care and the key action points agreed, and set a date to review progress against the action points. With Michelle's consent, each member of the team received a copy.

As a result, the DDU reviewed Michelle's prescription for methadone and transferred her appointments to a community pharmacist nearer the homeless shelter. The TB nurse contacted the laboratory to find out if they had found any evidence of drug-resistance, given Michelle was feeling so unwell. Michelle was diagnosed with mono-resistant TB and her medication reviewed by a TB doctor. The social worker agreed housing was a priority for Michelle. They began working with Michelle's key worker at the homeless shelter to obtain evidence and documentation of her need for housing, and with housing authorities to find suitable accommodation for her. The TB nurse, with Michelle's permission, also involved a TB peer supporter (a survivor of TB). Michelle stipulated that she wanted to be matched with a female peer supporter and disclosed that a family member had sexually abused her when she was a child. The TB nurse offered a referral to a mental health trauma specialist (see chapter 2 and the support pyramid), and the peer supporter agreed to accompany Michelle to her appointments and offered encouragement and support.

Thanks to the collaborative support she received, Michelle successfully completed her treatment 18 months later, whilst living independently in her own home.

Introduction

In this chapter we discuss the role of a rights-based, people-centred approach to providing multidisciplinary, collaborative PSS. We outline the importance of affected communities and CSOs, including peer supporters, working in partnership with TB services to deliver collaborative care packages that enhance support for people with TB. We discuss the role of the care manager as a mechanism for coordinating multidisciplinary PSS, particularly where multiple agencies and professionals are involved. We discuss the role of CLM in promoting and protecting the right to access high quality care. We conclude with

exercises to help consolidate learning. This chapter should be read in conjunction with chapters 2 and 3 for advice on how to assess the PSS needs of people and their families, and chapter 7 which focuses on the support needs of people with complex comorbidities, and their caregivers.

Care coordination and management

Care coordination and management is a collaborative, multidisciplinary approach to supporting people with presumptive TB to access health services, achieve a diagnosis and, following a confirmed diagnosis, successfully complete their TB treatment. It involves specific treatment goals, interventions and outcomes achieved within a specified timeframe.[37] The coordination of care is usually the role of a named care coordinator or manager who may be a nurse or trained non-clinical member of the multidisciplinary team. Care coordination and management should begin when a person first presents with, or is identified as having, symptoms suggestive of TB. Integral to the approach are the principles of rights-based and people-centred care which would include appropriate PSS based on a person's needs.

Figure 2 in chapter 2 illustrates a care management model with PSS integrated into people's clinical care and accorded equal importance. Given that people can have complex health and social needs (see chapter 7), care may be provided by different types of health and care workers and different services or organisations. This is illustrated in the case study at the beginning of this chapter where we introduced Michelle, a homeless woman living in a shelter. Collaborative working between different services and sectors enabled Michelle to complete her TB treatment. In the example provided, the TB nurse was Michelle's care coordinator. She worked closely with the DDU and the TB social worker who liaised with the staff at the homeless shelter where Michelle lived. The shelter staff acted as "eyes on the ground" and helped motivate Michelle, whilst a TB peer supporter accompanied Michelle to appointments and provided encouragement and support. Together the peer supporter and involved services were able to provide a package of support "wrapped around" Michelle and "held together" by the care coordinator. The care coordinator plays a pivotal role in linking people with complex needs to other services and agencies for enhanced support where this is needed. Addressing complex needs may require the support of skilled outreach or advocacy workers who can effectively engage with allied services to

address needs such as HIV testing and counselling (see case study below) and livelihood support needs (see chapter 2).[38]

When a person like Michelle has very complex health and social care needs that affect her ability to adhere to treatment, the care coordinator can schedule a patient management conference or review to agree an action plan and enhanced support as required. This should involve the person affected by TB; their family members, chosen advocates or a peer supporter; and key professionals from the multidisciplinary team.

Rights-based, people-centred care

WHO defines people-centred care as: 'care that is focused and organised around the health needs and expectations of people and communities rather than on diseases.'[39] It is an approach to care that sees the person as a whole, with many different needs and goals and personal circumstances of the person, not just the immediate need for medical treatment.[39] This is clearly illustrated in the case studies of collaborative care involving Michelle (at the beginning of this chapter) and Faduma (see chapter 2).

Principles of people-centred care include the following aspects:[40]

- the rights of people affected by TB
- access to care
- respect for people's values, preferences and expressed needs
- the coordination and integration of care
- information, communication and education
- physical comfort
- emotional support and alleviation of fear and anxiety
- involvement of family and friends
- continuity and transition.

These principles are further supported by the rights of people affected by tuberculosis as enshrined in the 'Declaration of the rights of people affected by tuberculosis':[4] for example, article 4, the right to the highest standards of physical

and mental health; article 11, the right to information; article 12 the right to informed consent and article 14, the right to freedom from discrimination (see the consolidating learning activity to see how the support provided to Faduma, introduced in chapter 2, was provided with regard to the principles enshrined in the human rights declaration).

From a human rights perspective, National TB programs must also ensure psychosocial services are made available and accessible to people with TB, including nutritional support, cash assistance, and counselling. Ensuring TB services and facilities are of good quality and are available and accessible to people affected by TB also means governments and national TB programs must identify and remove all barriers to services (see chapters 5 and 6) and facilities and provide people-centred TB care.[41]

Multidisciplinary team working

Multidisciplinary teams are mechanisms for organising, coordinating and delivering rights-based, people-centred, integrated care and such teams involve practitioners, professionals and key workers from health and social care services. Family members are also included in the multidisciplinary team because of their roles as carers. The composition of teams, and number of team members involved, may vary depending on the resource settings and healthcare systems, the needs of people affected by TB and national guidance. In the UK, for example, national guidance recommends a team of professionals with an appropriate skill mix to care for key populations including their PSS needs. Members of the team could include TB peer supporters and workers from NGOs who can address people's legal rights to health and social care[7] (see the case study at the beginning of this chapter for information about the roles of different members of the multidisciplinary team).

Collaborative working is where different professionals and services work together to assess the care needs of people affected with TB and their families and jointly agree a care plan. The care plan will usually detail jointly agreed goals and packages of care that include clinical, psychological and social support for patients and their families, as appropriate. The care plan usually details who will be responsible for delivering different aspects of care and the name of the care coordinator or patient manager and main point of contact (see case study about Michelle).

Health and social care workers

Healthcare workers protect and improve the health of individuals and communities. HCWs are: "those people engaged in actions whose primary intent is to enhance health" [39], including mental health. They usually include paid workers, or trained volunteers, and may work in the public or private health sectors, or form part of wider civil society sectors. HCWs may also work in industry; for example, a doctor may be employed by a mining company.

Social care workers (SCWs) often provide support on non-clinical aspects of care, including social assistance and psychological and emotional support to people affected by TB to promote well-being, enable patients to prioritise their health, access complementary services and adhere to their care plans and complete a course of tuberculosis treatment. They play a vital role in linking people affected by TB to government and civil society social programmes, for example, access to food programmes. They may be employed by a range of organisations including Social Services and CSOs such as community-based organisations and faith-based groups.

People with TB receive care and support from both HCWs and SCWs. However in lower income and lower middle income settings, especially in remote and rural areas with poor access to services, health and social care is provided by community health workers (CHWs) and family members, especially in relation to treatment adherence. CHWs can be defined as individuals who lack formal medical or nursing education but who have received focused clinical training and are able to reach into under-served or key populations for a variety of health issues. They perform specific diagnostic, preventative, referral, and treatment tasks within, or close to their communities [37] and offer PSS.

The role of affected communities and civil society organisation (CSOs)

The role of affected communities and CSOs in providing PSS will vary according to the local context, capacity, resourcing and the type of intervention.

Their roles may include:

- assessment of need
- stigma measurement and reduction
- provision of livelihood support and social protection
- facilitation of care or provision of medical care
- advocacy of law and policy reform
- supporting people with TB
- training and capacity building of TB affected communities in TB, treatment, research and rights literacy
- community-led monitoring of availability, accessibility, acceptability, and quality of services, their financing and broader issues of accountability (see section on CLM in this chapter)
- assessment of enabling environments and legal, social, gender and other barriers to access.

TB peer supporters

TB peer supporters with lived experience of TB can offer assistance to people receiving TB care to deal with the emotional and physical aspects of diagnosis and treatment. TB peer supporter schemes may have developed as a grassroots or community-based initiative or be professionally led.[43] Everyone providing peer support should understand the legal rights, social and economic barriers that are experienced by people with TB in the context in which they work.

Peer supporters can act as advocates, or provide information, either on a one-to-one basis or in support groups. One scheme in China, called the 57 Zone, involves caretaker buddies, or peer consultants, who support people with TB through an online communication platform, answering any queries and allaying anxieties about treatment. Peer supporters also work off-line accompanying people to

hospital appointments and helping them to navigate healthcare systems to obtain a medical diagnosis, particularly where people have no family support networks (for more information see *https://www.who.int/china/news/feature-stories/detail/the-caretaker-buddy-peer-to-peer-support-for-tb-patients*).

Peer supporters are also a powerful way to reach key populations. In the UK, Find & Treat provides outreach services to vulnerable, homeless people in London who are at high risk of TB, HIV and Hepatitis C. The service uses peers with lived experience of TB and homelessness to offer support. Peer educators have also played a role in raising TB awareness among people living in homeless shelters.[44]

The participation of civil society and affected communities in providing PSS is crucial, especially in resource constrained settings where families of people on TB treatment struggle with costs related to the treatment of TB (e.g. loss of income, transport to clinic etc.) without the social safety net needed to support them to a successful treatment outcome.

The Stop TB Partnership, largely through the Challenge Facility for Civil Society, has led the development of tools and assessments to further enhance the role of TB affected communities and civil society (see Box 8).

Box 8: Stop TB Partnership tools and assessments to enhance the role of affected communities and civil society

1 The OneImpact Platform provides a means to e-monitor the availability, accessibility, acceptability and quality of services and provide real time data on any issues that emerge

2 The TB Community Rights and Gender Assessment (CRG) and TB CRG Action Plan – analyse legal, human rights, gender and key population related barriers to TB services provide recommendations that inform a costed action plan for integration into the National Strategic Plan

3 The TB Stigma Assessment establishes a baseline of stigma experienced by people with TB, including self-stigma, stigma in health facilities and stigma in the community.

Collaborative role of religious leaders and civil society organisations in offering psychosocial support

For both TB and HIV/AIDS, religious leaders can play a role in offering spiritual and pastoral care, encouraging people to get tested (HIV/AIDS), and challenging stigma and discrimination.[41] Faith based organisations also offer safe havens, food, clothing and support and may be better placed to reach out to rural areas if appropriately integrated into health services.

The case study in Box 9 also describes an example of a collaborative partnership between TB services and a faith-based CSO for PLWHA to enable people with TB to get tested for HIV and receive an enhanced PSS package.

Box 9: Case study: Formalising partnership working in Tanzania between TB services and HIV civil society organisations

When Darweshi, in Tanzania, told his TB nurse Aadila about ongoing symptoms she suspected they related to undiagnosed HIV/AIDS. However, she didn't have the confidence in her knowledge and skills to support him, as this care was usually provided in separate programmes at district level. So Aadila contacted a local faith-based CSO that she knew offered support to PLWHA. She learnt that they offered medical care on an out-patient basis, HIV testing and counselling, and PSS. With Darweshi's consent, Aadila referred him for testing and he was diagnosed with HIV and started on anti-retroviral treatment. He was also put in touch with a peer support group to help him come to terms with his HIV status.

Aadila and the CSO discussed the need for HIV testing to be delivered at a specialist clinic reserved for people with TB. They agreed it would require clear criteria, protocols and a referral pathway so that they could evaluate the collaboration and, in particular, the role of peer support. To establish an evidence base of need, they recorded the age and gender of people who attended the clinic and received peer support, and their views on the care they received. Members of the peer support group were trained to interview them to gather this data, which will be used to lobby for more financial support for the peer support group and to further integrate the services.

Under the combined care of the CSO and TB service and with the help of the peer support group, Darweshi began to feel the health benefits of the ART therapy and managed to complete his TB treatment successfully. Aadila is also happy, she knows that she is delivering better care for people with TB and crucial peer support for people with TB-HIV coinfection.

Community-led monitoring of health services

Community-led monitoring (CLM) recognises that communities affected by TB should have a stake in how services are designed, implemented and monitored in order to improve access to high quality care. CLM has gained traction in HIV programmes, in response to variations in the quality of HIV services (CLM, white paper). The foundational principles of CLM are therefore the protection and promotion of human rights, including the right to high quality, people-centred care.

CLM aims to provide an evidence-based approach to highlighting gaps in care and holding decision makers to account for variations in care. It aims to inform evidence-based advocacy through the systematic collection of routine data that identify gaps in services, or poor quality care, that can be presented to funders of services to advocate for changes in policy and practice. (For an example of the methods and cycles of monitoring see the guide to CLM in the section on further reading).

CLM can highlight reasons for poor access to services and retention of people receiving TB treatment. It differs from an audit of health services, which is professionally led, by investing power in communities to own the process of monitoring and help create healthcare services that meet their needs (CLM, white paper). CLM should be used to identify gaps, or examples of best practice, to ensure access to high quality, people-centred, PSS.

Consolidating learning

- Identify the different members of the multidisciplinary team and their roles in your TB service.
- Read the case study about Michelle's care and identify the roles of the different professionals, sectors and agencies involved. How did they contribute to Michelle's care? In what way was the care provided rights-based and people-centred? Now refer to the case study in chapter 2 about Faduma's care and repeat the exercise.
- Discuss the role/potential role of TB peer supporters and peer support groups in supporting people with TB.
- Read the case study and discuss with a colleague how transitions in Michelle's care were managed to provide continuity in the care provided.
- Reflect on the benefits of developing collaborative care pathways with CSOs and different members of the multidisciplinary team in your service, with reference to the case studies described in this chapter.
- Identify the different CSOs in the community that your service works with. Is there a formal arrangement and clear pathway for referral to these organisations or does your service have a more informal arrangement for referrals? Consider which arrangements work best for your service and people with TB.
- Read the white paper on CLM in the section on further reading and reflect on how your services could be enhanced and improved with CLM.

Further reading

WHO (2020) WHO Civil Society Task Force on TB Statement. Meaningful engagement of communities and civil society: World Health Organisation. Geneva Available at: *www.who.int/publications/i/item/who-civil-society-task-force-on-tb*

Community-led monitoring
Community-led Monitoring of Health Services: Building Accountability for HIV Service Quality White Paper. Washington DC: O'Neill Institute; Cape Town: Treatment Action Campaign (TAC); Brooklyn, NY: Health Gap; Johannesburg: The International Treatment Preparedness Coalition (ITPC); Kampala: International Community of Women living with HIV Eastern Africa (ICWEA); Kampala: Sexual Minorities Uganda (SMUG); Kampala: Coalition for Health promotion and Social Development (HEPS– Uganda); 2020. Available at: *https://healthgap.org/wp-content/uploads/2020/02/Community-Led-Monitoring-of_Health-Services.pdf*

Collaborative working with organisations in the community
ENGAGE-TB: Training of community health workers and community volunteers, 2015. Geneva: WHO; 2015. Available at: *www.who.int/tb/publications/2015/engage_tb_training/en/*

Information on integrating community-based tuberculosis activities into the work of nongovernmental and other civil society organizations.

Community-led monitoring
Stop TB Partnership. OneImpact. *https://stoptbpartnershiponeimpact.org*

A mechanism that countries are using to report mental health concerns. This Stop TB Partnership community-led monitoring tool allows people affected by TB to report barriers to access, community advocates to monitor human right indicators and national TB programs to take programmatic action to address the needs of people affected by TB.

Key populations

TB Key Population Briefs published by the Stop TB Partnership, Geneva. Click on the link to access. Available at: *www.stoptb.org/resources/publications*

Population brief 1: Indigenous people:

Population brief 2: Health Care Workers

Population brief 3: People Living with HIV AIDS

Population brief 4: Children

Population brief 5: Miners

Population brief 6: Mobile populations

Population brief 7: Prisoners

Population brief 8: Rural Populations

Population brief 9: Urban Populations

Population brief 10: People who use drugs

TB Key Populations and the Global Fund's Sixth Replenishment. Ottawa: GFAN. Available at: *www.globalfundadvocatesnetwork.org/wp-content/uploads/2018/09/TB-Key-Populations-and-the-Global-Fund%e2%80%99s-Sixth-Replenishment-Full-Report-FINAL.pdf.* Explains the challenges faced by key populations.

Tackling Tuberculosis in Under-Served Populations: A Resource for TB Control Boards and their partners, January 2019. London: Public Health England. Available at: *https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/773730/Tackling_TB_in_Under-Served_Populations_-_a_Resource_for_TBCBs_and_partners.pdf.* A resource for addressing tuberculosis in key and under-served populations in low TB incidence countries, including homeless people, those who misuse substances and alcohol.

5 Barriers in diagnosis

Learning objectives

- to understand the socioeconomic barriers facing people seeking healthcare and receiving a diagnosis of TB
- to appreciate the role of cultural factors within the family, community and at the clinic and how these may influence access to TB diagnostic services by persons with TB symptoms
- to provide information on specific challenges faced by TB key populations and how to overcome these so that they can access TB diagnostic services.

Box 10: Case study: overcoming cultural and structural barriers in Zimbabwe

In the Chimanimani province of Zimbabwe, Zororai had been ill for over three months with stomach pain, fever and weight loss. He did not know anything about TB. As the pains got worse, he decided to seek help from a local religious group. He was told that his pains were due to witchcraft and the solution was for him to vomit. He was given a substance that made him vomit and caused a skin rash. Zororai's symptoms continued. A community caregiver suggested he visit a nearby clinic where Zororai was prescribed painkillers, but still he did not feel better. He then decided to try another religious group further from home, in Mutare, where he was given 'traditional' water. This only gave him diarrhoea, probably because the water was contaminated.

Meanwhile, Zororai had started coughing. A relative advised him to seek help from a private mission hospital, but he returned home without seeing a doctor as he could not afford the US$6 consultation fee. Fortunately, a community volunteer trained under a UKAID funded tuberculosis project visited Zororai's household as a part of a door-to-door screening approach. The volunteer collected a sputum sample and transported it to the nearest TB diagnostic centre. Zororai was found to have active tuberculosis and was referred to the project's clinic where he was treated and cured of TB. It took over half a year for Zororai to be diagnosed, during which time he is likely to have transmitted TB to other people in his family and community.

Introduction

People have the right to the highest attainable standard of physical and mental health. For people affected by TB, this includes a number of related rights, such as: the right to freedom from stigma and discrimination; the right to privacy; the right to confidentiality; the right to access scientific progress; the right to move/liberty; the right to mobilise; and the right to free, prior and informed consent; among others.

In this chapter we discuss barriers that people with TB symptoms may face in accessing TB diagnostic services. These barriers can be geographic, economic or socio-cultural; include stigma and barriers within the health system; and are often higher for key and vulnerable populations. Examples include being unable to recognise symptoms due to a lack of awareness of or information about TB. People with TB symptoms that do not ever obtain a TB diagnosis are categorised as "a person with pre-diagnostic lost to follow-up".[41] There can also be challenges in accessing diagnostic services to identify drug-sensitivity or drug-resistance in the strain of TB bacteria someone is infected with, to determine the best treatment combination. The chapter further helps understand the specific challenges for TB key populations that make it more difficult for them to access diagnostic services.

Barriers to diagnosis

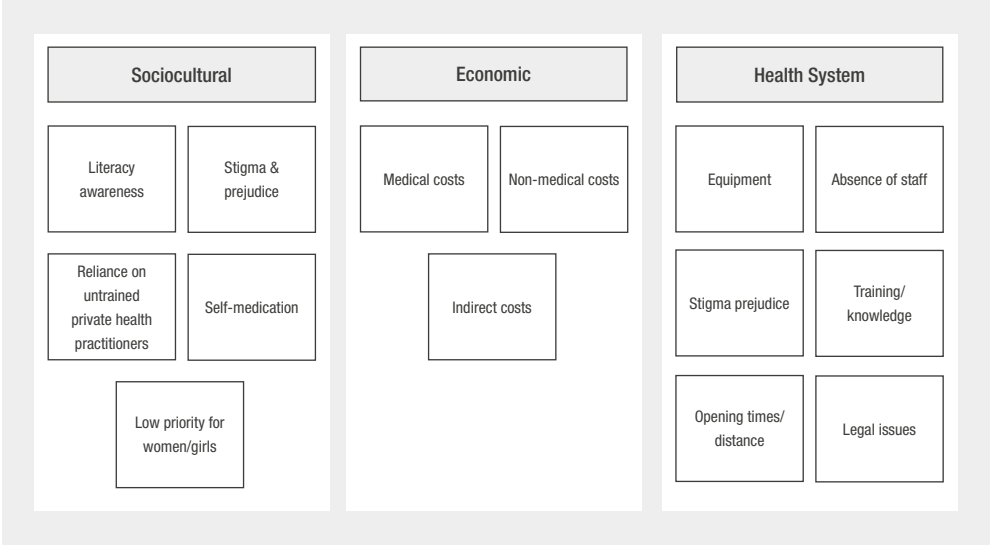
In 2018, an estimated 10 million people fell ill with tuberculosis but only seven million were detected and officially notified to health authorities.[2] The missing three million cases are undetected for reasons including a personal lack of awareness of TB, stigma, insufficient healthcare resources for systematic screening and active case finding, missed opportunities to diagnose in clinics or hospitals, faulty or incomplete diagnosis, lack of follow up after a negative test or receiving care outside national programmes. Unidentified people with TB present one of the biggest and deadliest barriers to TB treatment and control.[46]

Delays in diagnosing TB can result in greater morbidity and mortality, and increases disease burden in the community.[47] It also increases the likelihood of long-term organ damage. People with active TB can infect 10–15 other people through close contact over the course of a year.[48] Therefore, early detection of tuberculosis is essential in improving treatment outcomes and reducing onward transmission.

Many people with TB symptoms self-present at health facilities: this is referred to as passive case-finding. Passive case-finding requires that individuals recognise the need to have their symptoms assessed, have access to health facilities, and are properly evaluated by trained staff who recognise the symptoms of TB and who have access to a reliable laboratory. People with TB can also be detected though active case-finding which requires systematic screening and clinical evaluation of persons who are at high risk of developing TB, such as people who are contacts of someone who was diagnosed with TB or PLWHA.[49]

Despite efforts by national TB programmes as well as CSOs, many people presumed to have TB are unable to access diagnostic services due to barriers that can be classified as socio-cultural, economic or health system related. These barriers occur alone or in combination to preclude patients from accessing TB services, including diagnosis (see figure 5).

Figure 5: Barriers to accessing diagnostic services



Note: Economic costs are adapted from '*Protocol for survey to determine direct and indirect costs due to TB and to estimate proportion of TB-affected households experiencing catastrophic total costs due to TB. Geneva:WHO; 2015*'.

Socio-cultural barriers to TB diagnosis

Low literacy levels and lack of awareness of TB infection and its symptoms

Communities, especially in remote and rural areas, may recognise TB as an illness but do not fully understand TB symptoms and how the infection can be transmitted, prevented, diagnosed and treated. This may be due to low literacy levels, poor understanding of a person's own health, or a lack of TB information –including information available in a language or format that is understood by the local population. Even if people are aware of TB, they may not know the location of the nearest clinic where TB services are provided. The fact that TB symptoms are non-specific, can be attributed to other causes, and are often not recognised as early symptoms of tuberculosis can make the situation more complicated. For example, someone with a cough may attribute it to the changing weather and not seek healthcare. In countries where quarantine is enforced for people with COVID-19, people with TB symptoms may not go for a TB test due to the similarity of COVID-19 and TB symptoms and their wish to avoid being quarantined if they have COVID-19.

TB is stigmatised

People may not want to go for TB diagnosis for the very fear of being diagnosed with TB. People with TB may be shunned by neighbours, lose their friends, lose their jobs because of discrimination or have self-stigma. Women suffer even more. Marriages break down and women with TB are often left to support themselves and their children alone. In countries with high HIV prevalence and high rates of TB-HIV co-infection, the community might assume that a person with TB is also HIV positive – a double stigma. In some settings, TB may be associated with prison and/or injecting drug users.

Reliance on untrained private health practitioners (PHPs)

Many remote and rural communities are unable to access diagnostic clinics due to the large distances involved, poor road conditions and a lack of transport. There may also be distrust of government health services. People thus resort to local, private health practitioners such as traditional healers, faith healers or untrained/semi-trained personnel. While there are good examples of untrained private health providers having their capacity built to work in effective partnership with CSOs and public healthcare services, private health providers are most often unaware of TB, or do not want to refer their patients onward to official health facilities due to the potential loss of face and depletion of income.

Self-medication

People who are ill might self-medicate, particularly if they have low health literacy or misconceptions about their symptoms, if they cannot easily access health facilities, or if they face economic barriers such as insecure employment or a lack of sick pay. This is complicated by the fact that in many countries antibiotics are available over the counter without any need for prescription, even specific TB antibiotics. On occasions, untrained private health providers with no medical qualifications prescribe such medication to their patients. People with TB may also use antibiotics which do not cure TB, until their health deteriorates to the extent that they are forced to seek professional care. This is a big challenge, especially in countries with large and growing middle class populations who perceive TB as a poor person's disease. This can lead to late diagnosis as well as antimicrobial resistance.

Low prioritisation of the health of girl children and women

In certain communities there are cultural or economic factors that place more importance or economic value on men. This may lead to spending on healthcare being prioritised for sons or male adults at the expense of women, and especially girls. When poor women in developing countries are ill, they tend to delay seeking modern treatment until their symptoms are too severe to ignore, often choosing to visit a traditional healer or local pharmacy instead. This means they often remain unwell for longer and return to work whilst still recovering.[50] In addition to the low priority of their health, women and girls also carry household responsibilities that delay health seeking behaviour and make travelling to a distant clinic difficult. Women may have childcare responsibilities, which also often fall to girl children, whilst a working woman may not be able to lose income – especially in a woman led household. A study also found that there is a widespread gender bias towards men in terms of the amount of family support they can expect to receive when ill, which helps them respond better to their illness. Women were far less likely to receive support, leading to less positive coping.[51]

Box 11: Case study: The impact of tuberculosis on women in India

Kottata was just 18 when she was married and she soon became pregnant. She delivered a son and when he was 15 months old, Kottata developed a cough and went for a TB test at a clinic in the nearby village of Paderu, Andhra Pradesh. When she tested positive for pulmonary TB her husband, a bus driver, left her. In India, this is not an uncommon reaction to a wife's TB diagnosis. Though ill, Kottata started collecting firewood to sell in the market to make a living. Kottata was relatively lucky, however. TB Alert India and Vasavya Mahila Mandali (VMM), two local NGOs, had just launched a programme to train and orient women's groups in the community to support women, like Kottata, who had TB. The group provided Kottata with psychological counselling and encouragement to take her treatment and, with this help, she was cured of the disease.

1. Economic barriers to TB diagnosis

People on TB treatment, especially in resource poor settings, may incur catastrophic costs that prevent them from seeking TB diagnostic and treatment services.[52] The End TB Strategy set a milestone that by 2020 zero families affected by TB would suffer catastrophic costs. The TB-specific indicator of "catastrophic total costs" incorporates direct medical costs, direct non-medical costs and overall indirect costs, and helps to capture the economic burden specific for TB.[53] It is therefore critical to identify the main costs for the TB affected family and monitor their financial hardship so that corrective measures can be taken.

Catastrophic total costs due to TB

'Catastrophic total costs' are a measure of total costs borne by patients in tuberculosis treatment, exceeding a given threshold (e.g. 20%) of the household's annual pre-TB income. The focus is on financial and economic hardship due to direct and indirect costs when accessing healthcare for TB, which may adversely affect living standards and the capacity to pay for basic needs.

Source: Tuberculosis patient cost surveys: a handbook. Geneva: WHO; 2017. www.who.int/tb/publications/patient_cost_surveys/en

Direct medical costs

TB diagnosis is assumed to be free as sputum testing in the public sector is not charged in most countries (treatment is also usually free). However, detecting active tuberculosis often requires supplementary tests that may not be free, particularly x-rays. People with drug-resistant TB generally require additional procedures, such as ECG, audiometry and optometry, which are not free in

many countries. Furthermore, many health facilities also charge a registration fee even if the actual diagnosis and treatment for TB is free.

Direct non-medical costs
Even in situations where TB diagnostic services are free, costs can be incurred for transport and subsistence. Public transport may be infrequent, requiring overnight stays, waiting times for clinics are often lengthy, and many people want or need family or friends to travel with them for support. Furthermore, TB diagnosis alone often requires multiple trips to the clinic.

Other indirect costs
Before anyone can even consider the costs of attending a clinic they may have to face other costs, particularly those relating to employment. If they take time off, self-employed individuals, such as small farmers, face reduced productivity, whilst daily wage labourers and contractual workers may lose a day's income or even their jobs. Despite TB services being free, patients have also reported having to pay for medication and services illegally/unofficially.

2. Health system barriers to TB diagnosis

TB diagnosis in a majority of low and lower middle-income countries happens in a public facility, mostly equipped with microscopes and GeneXpert machines. Many factors within these facilities can serve as barriers to diagnosis, even when the patient is able to attend the facilities.

- **Faulty or non-functional equipment**. Effective diagnosis is reduced or prevented when equipment such as microscopes and x-ray machines have not been serviced or are non-operational. The number of samples that GeneXpert platforms are able to test are limited if some modules are not working, though facilities may simply lack cartridges for the MTB/RIF assays. Many laboratories are also short of consumables like x-ray plates or lack refrigeration due to non-available or erratic power supplies.
- **A lack of technicians**. Many smaller health facilities in hard to reach areas are dependent on a single laboratory technician trained to diagnose TB. If they are unavailable, alternative arrangements often include transporting samples to the next diagnostic centre which may itself have limited capacity and which requires resources to transport the samples under controlled conditions.

- **A lack of trained healthcare personnel**. Healthcare staff may not want to work on TB, particularly if they fear being exposed to the bacteria or if they hold stigmatising attitudes towards the disease. This may be exacerbated by low remuneration for the work and the real risk of infection causing HCWs to fall ill, which leads to high rates of staff turnover.
- **A lack of training**. Health facility personnel, especially laboratory technicians, are often insufficiently trained or do not receive ongoing training as knowledge and technologies evolve. In many settings, health personnel are not trained to interpret chest x-rays. Additionally, a lack of resources in central services may limit the number of quality checks made by supervisory staff.
- **Healthcare worker attitudes**. Staff in clinics sometimes have a poor attitude towards patients and do not treat them with respect. This could be due to various factors including stigma, their busy and poorly resourced working environment, prejudice towards patients from a different class or community such as indigenous tribespeople, or language barriers between communities that speak different dialects or who do not speak the national language. At times, the experience of a single person in a small community can influence the group's overall perception of the care they will receive, particularly communities that bond together due to their cultural differences to others.
- **Clinic times**. It may be difficult for people who are reliant on public transport timetables or sharing taxis to reach clinics during their opening hours. Childcare responsibilities and working hours for those in employment may also conflict with clinic opening times, particularly when waiting times are long.
- **Legal systems**. In certain countries, access to free healthcare including TB diagnosis may require specific documentation. This is not possible for undocumented migrants or even legal residents who lack the knowledge, resources or confidence to obtain official documents. Migrant workers, for example, are afraid a TB diagnosis will result in deportation. Indigenous people who live in remote areas often have little interaction with the majority population of a country or its institutions. Certain vulnerable populations such as sex workers, injecting drug users or Roma, might fear criminal sanctions or discrimination in the legal system.
- **Distance**. Healthcare facilities are often far from communities, especially in resource poor countries. Poor transport connectivity, travel costs and poor road conditions are some factors that further prevent access to healthcare.

Barriers to diagnosis and TB key populations

The people most at risk of TB are often among the most vulnerable and under-served in a society, people who are likely to experience difficulties accessing services. Key populations affected by TB can experience significant marginalisation and human rights violations which may further impact their health seeking behaviour. Barriers to accessing healthcare include:

- state and non-state violence and harassment
- restrictive laws and policies
- criminalisation of behaviours or practices which place people at risk of TB and undermine their access to quality healthcare
- stigma and discrimination.

Table 6 outlines the risk conditions and environments[54, 55] that can predispose key populations to TB including risks of exposure, poor access to services and co-morbidity.

Table 6: TB risk conditions and environments

Increased exposure to TB	*Limited access to TB services*	*Increased risk due to co-morbidities and lifestyle factors*
Close contacts of people with infectious TB, including in environments where TB is in wider circulation: family members, prisoners, sex workers, miners, HCWs, hospital visitors, community health workers, homeless people.	People with limited or insecure rights to access services, such as: migrant workers, women experiencing gender discrimination, children, refugees or/and internally displaced people, illegal miners, undocumented migrants.	People who have health conditions or make lifestyle choices that increase their risk of developing TB, including PLWHA, people with diabetes or silicosis, people undergoing immunosuppressive therapy, under-nourished people, people who use substances such as tobacco, alcohol and illegal drugs especially PWUID.

Adapted from *Global Plan to End TB 2016 - 2020, Stop TB Partnership*

Examples of barriers specific to some of the key populations in accessing TB diagnostic and prevention services are presented below.

1. Migrant populations

In the UK, unauthorised immigrants and asylum seekers often fear a TB diagnosis will affect their ability to remain in the UK. Migrants may work very long hours on poor pay and are often not registered with a general practitioner, placing them at risk of delayed diagnosis.[47] Migrant workers from Tajikistan and other surrounding post-Soviet countries working in Russia cannot access free TB and HIV services and are deported from the country when diagnosed with TB or HIV.

2. People living with HIV/AIDS

PLWHA are 15-22 times more likely to develop TB than people without HIV.[56] People in sub-Saharan Africa accounted for 84% of all deaths from HIV-associated TB in 2018.[56] Despite a high proportion of TB deaths, many PLWHA are unaware of TB-HIV co-infection and this prevents them from seeking TB diagnostic and prevention services.

3. Mineworkers

Mineworkers are at higher risk of both TB and HIV because of their living and working environments, which are most often crowded, poorly ventilated and far from their home communities. They are at increased risk of exposure to lung diseases and also experience high rates of industrial silicosis which weakens their lungs, making them more vulnerable to infection. Miners also experience particularly high rates of TB, because of the relationship between mining and the sex trade. The incidence of TB among migrant miners in Southern Africa is 10 times higher than in the communities from which they originate. A study among Southern African miners showed that poor knowledge and understanding of TB and high levels of stigma and fear about the illness, particularly in relation to its association with HIV, caused miners to deny symptoms and delay care-seeking.[57]

4. Prison populations

The level of TB in prisons is up to 100 times higher than that of the general population, according to the World Health Organization, and cases of TB in prisons may account for up to 25% of a country's TB burden.[58] Prisoners mostly live in overcrowded and poorly ventilated prison cells, which often hold

more prisoners than they were built for. Few are provided a nutritious diet – a recent study in DR Congo found that malnutrition and TB were risk factors in prison deaths.[59] Prisoners also have difficulty in accessing TB services, including diagnostics, due to challenges with prison transport, security issues and the lack of priority given to prisoners' health needs.

5. Homeless people

People experiencing homelessness or insecure housing are among the most vulnerable sections of a population. They often experience extreme poverty, hunger and malnutrition, mental health needs, substance misuse issues,[60] and many are from migrant backgrounds with few rights in their country of residence. A study in India found TB prevalence in homeless adults to be at least five times higher than in the general population.[61] The majority of those with TB in urban homeless populations are malnourished and are exposed to ongoing transmission in crowded night shelters. Homeless people often experience difficulty accessing TB diagnostic and treatment services.

6. People who use and inject drugs

PWUID are at increased risk of TB due to the impact of their lifestyle on their immune systems and the risks of concomitant HIV infection. Additionally, fear of criminalisation and chaotic lifestyles make it harder for them to access services. A study found that among people who inject drugs and develop TB, one in three will develop HIV and two out of three will have HCV antibodies indicating coinfection with hepatitis C.[62]

7. Indigenous and tribal communities

There is little information available about the impact of TB on indigenous peoples, but a literature review in 2013[63] indicated that they do experience a significantly increased burden of TB. While poverty, access to education, racism and discrimination are some factors that create barriers to healthcare for indigenous people, their own perception of health can also be a barrier. Indigenous peoples may connect health and illness to a collective well-being of body and mind, behaviour, relationships with ancestors, community, land and nature.[64] Studies have also shown that indigenous areas experience "...precarious health facilities and a lack of supplies and equipment. This, combined with high provider turnover and logistical complexity in some regions, can have a negative impact on the quality of service delivered within indigenous territories."[65]

Sample questions for a guided conversation

Below are sample questions that you can include in a guided conversation with people who are either invited to be screened for TB or who require a test after experiencing symptoms. These questions do not follow a specific order and are provided only to serve as an example. They need to be adapted to the situation and context. Such conversations should be held in confidence and privacy. It is expected that these questions will open up a conversation and can lead on to issues that may need to be addressed.

Pre-screening

Have you heard of TB?

Do you know how TB is transmitted, prevented and diagnosed?

Do you know that TB is curable?

What kind of problems with your family or community or with your job do you anticipate if you have TB symptoms?

What do you think is the relationship between TB and HIV?

Where do you go if you are ill?

Do you know that getting diagnosed early can prevent yourself and your loved ones from contracting TB?

Post screening when a person has TB symptoms

How will your family react if they know that you have TB symptoms?

Will your neighbours talk to you if they find out you are being tested for TB?

Have you been to the clinic before? Are you aware where the clinic is located?

How was your experience during your last visit to the clinic?

What challenges do you foresee if you have to visit the clinic?

Do you know that testing and treatment of TB is provided for free?

Are you the sole earner in the family?

Do you fear that TB may prevent you from working? How would your colleagues react?

How will you get to the clinic? Would going to the clinic every day be a problem for you? Are you afraid people would notice/comment/ask questions if you go to the clinic every day?

Do you think that paying for transport will be a problem for you?

Would you want to provide a sputum sample in the privacy of your home so that no one knows that you are being tested for TB?

Where would you like to get treatment if you have TB? Do you fear that you will be admitted to the hospital if you have TB?

Important to note

It often requires more than one conversation to understand the barriers and convince a person with TB symptoms to accept a test. In the Global Fund's TB in the Mining Sector programme in Southern Africa, an analysis of data from eight countries (Botswana, Lesotho, Malawi, Mozambique, Namibia, Swaziland, Tanzania and Zambia) revealed that out of 15,587 people with TB symptoms identified in a period of 14 months, only 9185 or 58.9% had actually received a TB test. This data also corroborates the need to understand barriers to diagnosis.

Example of a guided conversation

Patient: "I had a persistent cough last year. The community health worker told me about TB and wanted me to go to the clinic but it was harvest season so I didn't go because it cost me a day's loss of work. I still have a cough and now I also have fever."

Health worker: "Well, I could take a sputum sample for you?"

Patient: "Oh, I didn't know that was possible. But I wouldn't want anyone to think I might have TB."

Health worker: "I can collect sputum now and transport it to the clinic for you. Does that help? I can do it inside your home so that no one knows you are being tested?"

Patient: "That will be good but what if I have TB? I am scared of this disease!"

Health worker: "You do not need to worry if you have TB. TB is curable and the test for TB as well as the treatment is completely free. And I will not tell anyone that you have TB. In fact, if you wish, I will even accompany you to the clinic if you need support."

Patient: "Ok, but if I have TB, will I be able to continue working? Do I have to go to the clinic all the time?"

Health worker: "You may have to get some rest initially but if you have TB and it is not treated, it can kill you. You will not have to go to the clinic all the time as they will provide you with two weeks medication each visit. You may have to go in between if your illness does not show improvement"

Patient: "Ok, so how do I give you a sputum sample?"

Health worker provides sputum mugs and instructions to provide a sputum sample.

While the above is just an example, in real life situations, these conversations tend to be more complex and the patient may have questions or fears that could be very difficult to resolve.

Possible interventions to overcome barriers

Every situation is unique and has to be addressed according to the resources and means available locally. Some examples of interventions that address barriers to diagnosis are presented in table 7. While some of these barriers can be addressed by the health worker, some of them are addressed more at an institutional level by NGOs, community groups, government schemes for the poor and service providers etc.

A key intervention that cuts across barriers is community-led monitoring (CLM). CLM (also described in the previous chapter) is a rights-based, people-centred approach to identify and address barriers at all stages of the clinical pathway. CLM enables people affected by TB to report barriers (including knowing and claiming their rights) and develop CLM indicators that are important for them. Community advocates can then coordinate local responses to overcome these barriers, monitor and use data for advocacy and to provide to national TB programs as evidence of the need for programmatic and policy change.

Table 7: Interventions to overcome barriers

Barrier to diagnosis	*Intervention example*
Sociocultural	• work with NGOs to undertake stigma, legal and gender assessments to understand factors impacting access • create awareness of TB symptoms, prevention, transmission, diagnosis and treatment through use of available visual (posters, leaflets, digital messaging on mobile), audio (radio programmes, audio clips through mobile) and audio-visual (short videos, films) materials • tackle stigma and self-stigma through targeted interventions with affected communities, opinion leaders, faith leaders and elders • develop support groups, especially peer support, within the community • involve existing community structures like women's self-help groups, HIV/AIDS committees and village health committees as agents to create awareness and support diagnosis and referral • develop information education communication (IEC) material in local languages and dialects or in pictorial form where literacy levels are low • field test IEC material locally before use

Barrier to diagnosis (cont...)	*Intervention example (cont...)*
Economic	• community or doorstep sputum collection and transport to testing facilities for people who are unable to attend clinics, especially people with a disability, people who are very ill, homeless people, people who have commitments such as childcare that prevent them from attending clinics, or where transport arrangements make it difficult to visit the diagnostic centre • provide cash transfers for poor families to compensate for transport costs, substitute loss of income or to pay for diagnostic tests • arrange transport for patients and any family members who accompany them. This is especially desirable where there is doubt that a cash transfer will be used for the purpose it is provided. For example, a woman may have to surrender the money to an abusive husband to spend on alcohol or tobacco • link and support patients and their family to available social services in the community, for example by helping them complete forms and submitting/following up for them.
Health system	• use stigma and gender assessments for targeted interventions with health staff • advocate for improvements in health services and geographical access to services, for example by bringing challenges in delivering services to the attention of health authorities • integrate services (particularly TB and HIV and also COVID-19) to ensure people-centred care and to address shortages of HCWs • develop and implement mechanisms to motivate HCWs, especially in remote areas • work in partnership with private health providers, especially traditional healers and faith healers, by training them and providing incentives for referrals • provide information to pharmacists and motivate them to refer people with TB symptoms instead of selling them antibiotics • always work closely with diagnostic and treatment facilities • support unauthorised immigrants and residents without documents to get required documentation.
Legal	• reform of laws and policies based on legal assessments • access to justice for key populations and people affected by TB who have experienced discrimination, for example in workplaces • sensitisation of law enforcement and decision-makers regarding inclusive laws for key and vulnerable populations and the importance of access to TB services • in instances of significant legal barriers or violation of rights, CSOs should take legal action against the state and service providers to seek legal recourse and demand change.

Consolidating learning

- Discuss with a colleague what the specific barriers are for both men and women in accessing diagnostic services in your community. What does your service do to overcome these challenges? What could you do in the future to facilitate access?
- How does your service support people with the costs of obtaining a diagnosis, such as transport? What agencies could you work with to limit the impact of costs associated with accessing diagnostic services?
- In this chapter we highlight the specific barriers vulnerable populations experience. Choose two of these groups (e.g. homeless populations and people who use or inject drugs) and discuss with a colleague what your service does/or could do to ensure people from these groups access services to receive a prompt diagnosis of TB.
- Understand the specific needs of affected families, especially among key populations.
- Read the case study at the beginning of this chapter about Zororai. Identify all the factors that contributed to the delay in Zororai achieving a diagnosis of TB. What could be done to address these types of barriers to prevent delays in diagnosis?

Further reading

Jacobs, B., Ir, P., Bigdeli, M., Leslie Annear, P., Van Damme, W. (2011). Addressing access barriers to health services: an analytical framework for selecting appropriate interventions in low-income Asian countries, Health Policy and Planning 2011, 1–13. Available at: *www.who.int/alliance-hpsr/resources/alliancehpsr_jacobs_ir_barriershealth2011.pdf*

Healthy People. Access to Health Services. *www.healthypeople.gov/2020/topics-objectives/topic/Access-to-Health-Services*

Yang, W., Gounder, C.R., Tokunbo, A., De Neve, J., McIntire, K.N., Chandrasekhar, A., de Lima Pereira, A., Gummadi, N., Samanta, S., Gupta, A. (2014) Barriers and Delays in Tuberculosis Diagnosis and Treatment Services: Does Gender Matter? Hindawi Publishing Corporation. January 2014. Available at: *www.hindawi.com/journals/trt/2014/461935/*

Stop TB Partnership. Community Rights and Gender Assessment Protocol. Available at: *www.stoptb.org/assets/documents/communities/TB%20CRG%20Country-Level%20Assessment%20Protocol%20Template_DRAFT.pdf*

6 Undergoing tuberculosis treatment

Learning objectives

- to understand the barriers that prevent people on TB treatment from being treated successfully
- to understand challenges around provision and successful delivery of TB preventive treatment
- to understand the additional challenges facing people on treatment for drug-resistant TB
- to help undertake a guided conversation to support a person on TB treatment or on TB preventive treatment.

Box 13: Case study: managing treatment among PWUID in Lao PDR

Back in 2009, Mao Yengyang from Bloikham district in Laos developed a persistent cough. Mao was reluctant to use government health services due to stigma and the long distances involved to travel, so he treated himself by injecting ampicillin and smoking opium. However, this only provided short periods of relief and he soon became dependent on the opium. Mao was sent to hospital by health authorities who visited the village as part of a programme with treat people with drug dependencies. Mao was started on an eight month course of TB treatment and discharged from hospital with three months' supply of medication and instructions to take it on a daily basis. After completing the three month supply, Mao did not return to the hospital for a repeat prescription as his cough was gone.

In 2019, Mao developed a persistent cough but again decided not to visit the hospital. In June 2020, nearly one year after his TB symptoms returned, he was visited by health workers from Humana People to People (HPP) Laos, a local NGO, under a Global Fund door-to-door outreach programme. Mao was counselled on TB and screened for symptoms, then the outreach worker collected a sputum sample and arranged for it to be transported for testing. Mao was again diagnosed with TB.

This time Mao's experience was different. The HPP health worker provided the family with complete information on tuberculosis and oriented his wife and son to provide treatment adherence support and collect repeat medication from the clinic. The health worker continued to visit Mao on a near daily basis to provide PSS and encourage him to take his medication.

Due to the support from his family and encouragement from the HPP health worker, Mao has taken his medication regularly and is on the path to be cured.

Introduction

Tuberculosis treatment can be overwhelming. TB treatment lasts for a long time, involves numerous pills, often comes with side effects, and requires various tests throughout the course. Treatment regimens are informed by the type of TB with which an individual presents, with drug-resistant forms and TB involving comorbidities requiring more complex or longer courses of treatment.

Preventive TB treatment, especially for people living with HIV and contacts of infectious TB cases who are under 5 years of age, should be a key part of TB care.

This chapter addresses barriers that people on TB treatment face on a regular basis and which may prevent them from completing treatment. It discusses the apprehensions that people who are recommended preventive treatment without having TB disease may hold. It also provides advice and tips on providing PSS to people on TB treatment through guided conversations.

TB treatment and treatment adherence for people diagnosed with TB

TB treatment is long and difficult, yet strict adherence is essential to avoid onward transmission, reduce treatment failure and prevent drug resistance.

Treatment for drug-sensitive tuberculosis usually takes six months (though it may take longer in certain circumstances, for example if the central nervous system is involved). Treatment for drug-resistant tuberculosis can last anywhere between nine and 24 months, depending on the type of drug-resistance and the treatment regimen in use in a particular country. When treatment continues for long periods of time, or with little perceivable effect, people may develop feelings of despair and frustration.

WHO recommends the following treatment adherence interventions:[66]

1 tracers and/or digital medication monitor

2 material support to persons on TB treatment

3 psychological support to persons on TB treatment

4 staff education.

WHO recommends that the package of treatment adherence interventions above may be offered in conjunction with a suitable treatment administration option that includes one of the following:[66]

1 Community or home-based DOT is recommended over health facility-based DOT or unsupervised treatment

2 DOT administered by trained lay providers or health-care workers is recommended over DOT administered by family members or unsupervised treatment

3 Video observed treatment (VOT) may replace DOT when the video communication technology is available, and it can be appropriately organized and operated by health-care providers and patients.

It is important to note that COVID-19 has encouraged many countries to take up VOT that were previously slow to do so.

Box 14: Case study: Administering VOT in Kazakhstan

Treatment adherence is a critical obstacle to successful TB control. VOT was first launched by Partners in Health in urban settings in Astana and Almaty. Healthcare professionals of the TB control services responsible for providing DOT received training in VOT methodology and Partners in Health identified components of VOT required at TB services, including an office equipped with a computer linked to the internet, a web camera, Skype installed on the computer or WhatsApp/Viber installed on smartphones of HCWs, together with containers to store the weekly supply of medication. The project has already shown positive results for 64 patients on therapy with new anti-TB drugs taken seven days/week and 98% regimen adherence.

Source: Compendium of good practices in the implementation of the Tuberculosis Action Plan for the WHO European Region 2016–2020. World Health Organisation Regional Office for Europe. Copenhagen 2020.

Treatment administration options should be tailored to the patient's needs and preferences. For example, a patient might not be able to reach a health facility on a daily basis to receive medication, or might prefer not going so frequently (if they face a discriminatory attitude from HCWs, fear other community members would notice, or simply because it would interfere with their personal and professional life). Self-administered treatment (SAT) can be one option in certain cases. Among pastoralists in the Somali region of Ethiopia, a study has shown that a modified SAT resulted in good treatment outcomes.[67]

Tuberculosis preventive treatment for people with latent TB infection

TB infection with mycobacterium tuberculosis can happen with no evidence of active tuberculosis (namely, no symptoms of TB and no signs of TB). The diagnosis of such TB infection is imperfect and relies on measuring the immunological response to mycobacterium tuberculosis antigens through tuberculin skin testing or an interferon-gamma release assay (IGRA) blood test.

There are certain groups of people who are at greater risk of TB infection or of developing active TB when they are infected, namely people living with HIV and children under 5 years of age and other household contacts of patients who have bacteriologically confirmed pulmonary TB. Among these high-risk groups, it is recommended that provided active TB is excluded, they should automatically receive preventive treatment for tuberculosis without the need to diagnose TB infection because the benefits of such treatment outweigh the risks: there is one caveat in that household contacts 5 years or older of HIV-negative index patients who live in a low TB incidence country should be tested for TB infection before TB preventive therapy is considered. There are other at-risk groups such as patients receiving dialysis, patients preparing for an organ or haematological transplant and patients with silicosis, but it is recommended that they should be systematically tested for TB infection and if found to be positive then they should receive preventive therapy. Ensuring adherence to TB preventive therapy for all these groups is important. Isoniazid on its own for 6-9 months is the standard of treatment here, although there are shorter alternative regimens now available which may make adherence much easier. More details can be found in the 'WHO consolidated guidelines on tuberculosis: Module 1: prevention – tuberculosis preventive treatment'.[68]

Box 15: TPT options

Tuberculosis preventive therapy options recommended by the World Health Organization for the treatment of TB infection regardless of HIV status:

- 6 or 9 months of daily isoniazid (IPT)
- 3-month regimen of weekly rifapentine plus isoniazid (3HP)
- 3-month regimen of daily isoniazid plus rifampicin (3HR)
- 1-month regimen of daily rifapentine plus isoniazid (1 HP) or 4 months of daily rifampicin alone (4R) may also be offered as alternatives.

Adapted from: WHO operational handbook on tuberculosis. Module 1: prevention - tuberculosis preventive treatment. Geneva: World Health Organization; 2020. Licence: CC BY-NC-SA 3.0 IGO.

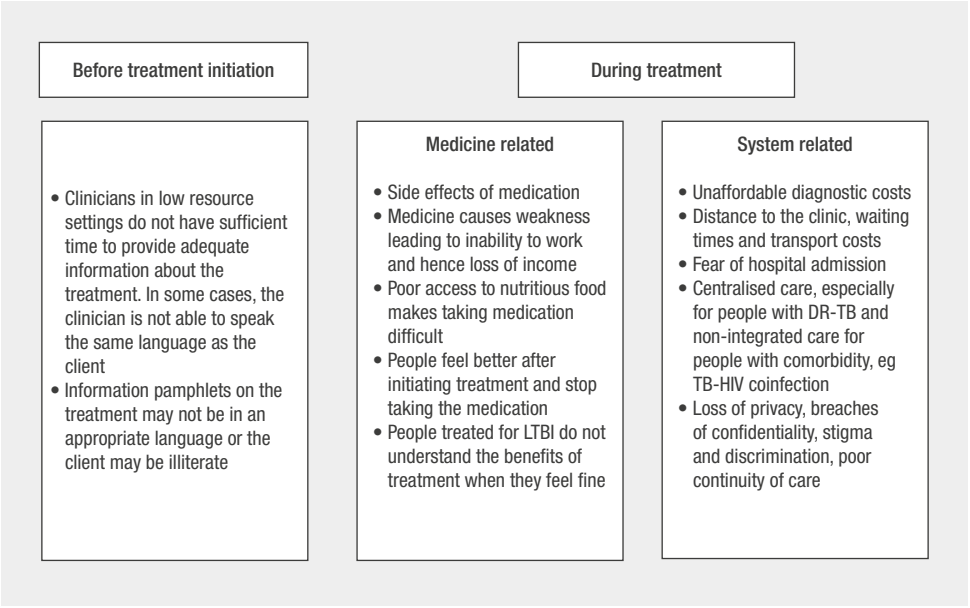
Barriers to treatment adherence

A substantial proportion of people with a formal TB diagnosis never start treatment, due to many of the same barriers they may face when trying to get diagnosed. A person who is diagnosed with TB but who fails to start treatment is described as being "pre-treatment lost to follow-up". Even after starting treatment, many people with TB will face one or more of the barriers described in the previous chapter (barriers to diagnosis) that may also prevent them from completing their treatment. For example, a person on TB treatment may still have associated transport costs, or fear stigma and discrimination as a direct consequence of TB treatment. This chapter will not repeat some of the barriers already mentioned but will try to point out specific instances that are unique to people on TB treatment.

Once a person with tuberculosis disease is identified using WHO recommended diagnostics, barriers in treatment can be classified as those experienced before treatment initiation and those faced during treatment.

Barriers during treatment initiation can be described as those that are a direct result of the medication provided and those that are related to the health system. These barriers occur alone or in combination to prevent patients from accessing TB treatment services, (see figure 6).

Figure 6: Barriers to treatment post detection



1. Barriers that may prevent a person starting treatment

TB treatment involves taking a combination of antibiotics over a long period. Adherence is essential to achieve a successful outcome. However, the antibiotics each have side effects that can prevent or discourage people from taking their medication. Therefore, information about the treatment is an essential part of the treatment itself. In resource poor settings and in remote rural areas, this may pose a challenge. The clinician responsible for starting a person with TB on treatment may not have enough time to devote to each patient or may lack the motivation (see chapter 5), knowledge or communication skills to provide quality consultations. In areas with indigenous populations especially, language is a barrier to effective communication between the clinician and the patient. Even where information leaflets are available, they may not be in the language the patient requires or accessible to patients with low literacy levels.

2. Barriers during treatment – medicine related

Side effects of medication are a key barrier to effective treatment. The side effects depend on the treatment regimen prescribed and can range from mild but annoying to severe and dangerous, sometimes warranting a change of medication. Dealing with side effects during the six months or more of treatment can prove very challenging for people, and adds to the burden of the illness itself.[69] Medication for drug-resistant tuberculosis can have more severe side effects, including partial or total loss of vision or hearing, changes in behaviour or personality, jaundice and peripheral neuropathy.[70] WHO has revised its guidelines on treatment of drug-resistant tuberculosis and WHO advice is to move away from all injectable drugs as soon as possible.

It is important to note that:

- first line drugs used to treat drug-sensitive TB are better tolerated than the second line medications for drug-resistant TB
- medication can also cause weakness, especially among patients with limited access to nutritious food, which may leave them unable to work and lead to a loss in income
- people with insufficient information about their treatment may stop or interrupt their treatment if they start to feel better
- people eligible for and requiring tuberculosis preventive therapy may find it difficult to understand why they require treatment in the absence of any illness, particularly if they experience side effects
- dosages for infants and young children may change as they gain in weight, and many will struggle to swallow the large and bitter tablets where child-friendly doses are not available.

Management of common side effects of the four first line antibiotics for drug-susceptible TB:

Healthcare workers can monitor for side effects by teaching patients how to recognise potential side effects, urging them to report any signs of side effects, and by asking them about side effects when they collect their medication.

Drug	*Adverse effects*	*Management*
Isoniazid	Peripheral neuropathy (pain in the feet) Hepatitis (e.g. jaundice)	Give pyridoxine (vitamin B6) Stop all medication if jaundice
Rifampicin	Gastrointestinal (pain and diarrhoea) Hepatitis (e.g. jaundice) Red urine	Symptomatic treatment Stop all medication if jaundice Reassure
Pyrazinamide	Arthralgia (pain in the joints) Hepatitis (e.g. jaundice)	Aspirin or NSAID Stop all medication if jaundice

Common side effects of second line antibiotics for drug-resistant TB:

Second line drugs have many more side effects than first line anti-tuberculosis drugs, but management is possible even in resource poor settings. The table shows the most common side effects, which require management by specialist centres.

Drug	*Adverse effects*	*Management*
Bedaquiline	Nausea Hepatitis (e.g. jaundice) Rarely heart toxicity	Give pyridoxine (vitamin B6) Stop all medication if jaundice
Linezolid	Gastrointestinal (pain and diarrhoea) Blood abnormalities (e.g. anaemia); peripheral neuropathy (burning sensation in hands or feet); optic neuritis (blindness)	Symptomatic treatment Dose reduction or stop medication – expert advice is needed
Ofloxacin, levofloxacin Moxifloxacin	Gastrointestinal (pain and diarrhoea) Arthralgia (pain in the joints) Rarely heart toxicity	Symptomatic treatment Aspirin or NSAID Stop medication
Ethionamide Prothionamide	Gastrointestinal (pain and diarrhoea) Hepatitis (e.g. jaundice)	Symptomatic treatment Stop all medication if jaundice
P-aminosalicylic acid	Gastrointestinal (pain and diarrhoea) Hepatitis (e.g. jaundice)	Symptomatic treatment Stop all medication if jaundice
Cycloserine, terizidone	Neurological and psychiatric disturbance	Stop medication if severe

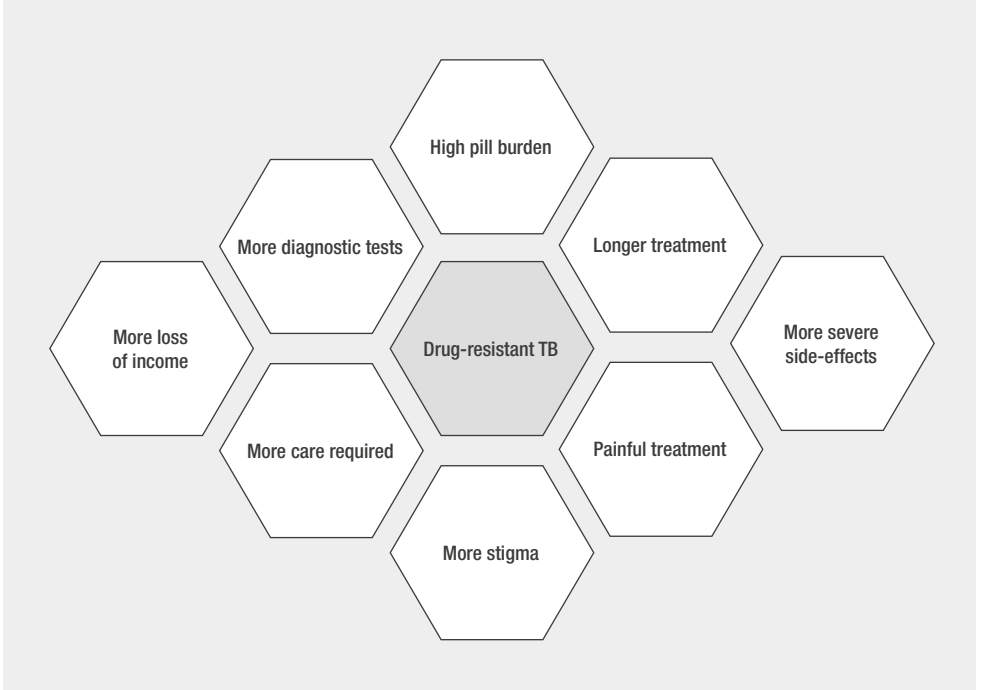
3. Barriers during treatment – system related

While TB treatment and diagnosis is free in most countries, any associated diagnostic costs can be prohibitive for poor patients. The long treatment may require regular trips to the clinic to collect medication or undergo testing, which may be unaffordable and take people away from work.

Other barriers to treatment adherence include potential loss of privacy and breaches in confidentiality by HCWs, lack of continuity among health personnel, and fear of admission to hospital (which, for example, may be costly or present drug users with a risk of withdrawal).[71] Migrant workers with TB, especially those crossing international borders, may travel back home without a proper transfer referral and medicine supply, which can lead to treatment interruption.

These barriers are often much bigger for people on treatment for drug-resistant tuberculosis, including MDR-TB and extensively drug-resistant TB (XDR-TB), (see figure 7).

Figure 7*:* Additional challenges for people on treatment for drug-resistant TB



Box 16: What can we do about system related barriers to TB treatment?
A few examples:

- utilise treatment adherence and treatment administration interventions recommended by the WHO (refer to 'TB treatment and treatment adherence for people diagnosed with TB' above)
- follow up actively on people who stop their treatment, to address their concerns and work together with them to bring them back into care
- provide medication refills for longer periods of time for people on TB treatment who face challenges in collecting medication from the clinic
- train and orient community groups on TB signs, stigma, diagnosis and treatment, e.g. women's groups or groups of PLWHA, to enable them to support people on TB treatment
- provide treatment information in locally appropriate formats, including audio-visual, pictorial and translated forms
- provide people on TB treatment with contact information for the outreach health worker or nurse so that they have free and regular access to treatment related information.

Starting treatment

People on TB treatment are more likely to cope with their illness and remain motivated to complete their treatment if the understand it. People beginning their treatment should receive certain key messages, which should be repeated throughout their treatment, including:

- TB is curable and TB treatment is completely free (regardless of immigration status in most countries).
- TB medication should be taken uninterrupted unless advised otherwise by the doctor.
- Side effects are possible with any medication. Most are nothing to worry about and should go away, though you should seek medical help for specific symptoms.
- TB treatment can make people feel better within a short period of time. However, it is important to continue taking treatment as the TB bacteria is still in the body. Interrupting treatment can make people seriously ill, and risks drug-resistance and onward transmission.
- Starting treatment quickly after diagnosis reduces the risk of transmission to others.

- The risk of passing TB on to family and friends can also be reduced through proper infection control measures such as proper cough etiquette, maintaining social distance, ensuring that the home is well ventilated and encouraging close contacts to be screened for TB.
- Additional tests will be advised by the clinician during treatment. These are required to ensure that the medication is working.
- If the person on TB treatment finds it difficult to take their treatment, she or he should ask for support from the clinic and their family.

Completion of treatment

Tests may be offered to people at the end of their treatment to make sure that they are clear of TB. More treatment will be required if tests show there is still TB bacteria in the body. Drug susceptibility tests may also be carried out if necessary, to exclude drug resistance. Most people however will be clear of TB after completing their prescribed course of treatment. Treatment is not stopped until a person with TB is cured[72] or unless the person with TB decides to stop his/her or treatment which is strongly discouraged.

People who have completed their treatment should be counselled and provided with the following information:

- life can return to normal once TB is cured
- many people who have beaten TB choose to tell others about their experiences - through community groups, social media or simply by sharing their story among family and friends – which is a good way to help others through treatment or to raise awareness about the illness and its effects
- it is possible to catch TB more than once, if you are unlucky enough to breathe in TB bacteria at another time, however this does not mean that TB is not curable or that you will always have TB
- it is important to take any new TB symptoms seriously, including new symptoms among friends or family, and get them checked out by a doctor.

Some people, although cured of TB, may be left with residual lung damage – particularly people who experienced long diagnostic pathways/delayed diagnosis and those with DR-TB. We should look to provide the appropriate care for their lung health after TB treatment is completed.

Sample questions for a guided conversation

During treatment

- What advice have you received about your treatment? Do you need further information on your treatment?
- What challenges do you expect may prevent you from completing your treatment?
- How will you get your medication from the clinic after the doses you have been provided are finished?
- How will you know that you have been cured or have become free of TB?
- Who will be supporting you during your treatment? Do you feel that they will be able to support you for the length of the treatment?
- Are you aware of any side effects of the medication you will be taking?
- Do you know what you should do if you experience side effects during your treatment?
- What will you do if your treatment supporter is not available?
- Will you have sufficient food available during your treatment? What will be your diet while you go through treatment?

After completing treatment

- How do you feel now that you have completed treatment?
- Do you have any other continuing symptoms linked to your lungs – breathlessness etc.?
- What will you do if your symptoms return?
- Do you think the attitude of your family and friends towards you will change now that you are cured?
- Now that you know more about TB, will you be able to look out for TB signs among your family and friends?
- If anyone you know or meet has TB symptoms, what will you do?
- Do you think that you can play an active role in your community in preventing TB?

Consolidating learning

- The case study described the role of a health outreach worker in supporting people to adhere to their TB treatment. Discuss with a colleague the benefits of having an outreach worker attached to your service.
- Discuss with your colleagues the common challenges that may prevent people on TB treatment from adhering to TB treatment. What can your service do to support people to overcome these challenges? What can you learn from the strategies that people affected by TB have adopted in order to complete their treatment?
- Protecting anonymity and maintaining confidentiality; discuss with your colleagues a recent success story where a patient completed TB treatment. What factors contributed to the patient successfully completing treatment? Ask your colleague to share a success story with you. This exercise works well if you invite a patient who has completed TB treatment to share her success story at a team meeting.
- Identify support services provided in the area by different actors such as government, NGOs or faith organisations. Identify the roles they play or could play in supporting people to complete their treatment.

Further reading

WHO. Consolidated Guidelines on Tuberculosis. Available at: *www.who.int/publications*

Module 1: Prevention – tuberculosis preventive treatment.

Module 2: Screening – systematic screening for active tuberculosis.

Module 3: Diagnosis – rapid diagnostics for tuberculosis detection.

Module 4: Treatment – drug-resistant tuberculosis treatment.

Guidelines for Treatment of Drug-susceptible Tuberculosis and Patient Care, 2017 update. Geneva: WHO; 2017. Available at: *www.who.int/tb/publications/2017/dstb_guidance_2017/en/*

Systematic Screening for Active Tuberculosis: principles and recommendations, 2013. Geneva: WHO; 2013. Available at: *www.who.int/tb/tbscreening/en/*

Consolidated Guidelines on Drug-resistant Tuberculosis Treatment, 2019. Geneva: WHO; 2019. Available at: *www.who.int/tb/publications/2019/consolidated-guidelines-drug-resistant-TB-treatment/en/*

An Activist's Guide to Rifapentine for the Treatment of TB Infection, 2020. New York: Treatment Action Group; Johannesburg: IMPAACT4TB; 2020. Available at: *www.treatmentactiongroup.org/wp-content/uploads/2020/04/rifapentine_guide_2020.pdf*

Quick Guide to Video-supported Treatment of Tuberculosis (VST), 2020. Geneva: WHO; 2020. Available at: *www.euro.who.int/en/health-topics/communicable-diseases/tuberculosis/publications/2020/quick-guide-to-video-supported-treatment-of-tuberculosis-2020*

7 Complications of TB, comorbidities and palliative care

Learning objectives

- to demonstrate an awareness of the importance of supporting the mental, emotional and spiritual health of people living with TB and complex comorbidities to alleviate suffering
- to understand the impact of caring for people with TB and complex comorbidities on family members, how to assess carers' need for PSS and offer appropriate support
- to appreciate the similarities and differences between religion and spirituality and how to assess and meet these needs in people from socially diverse backgrounds
- to understand the principles of palliative and end of life care, how they relate to treatment for TB and when to provide such care to people with TB.

Box 17: Case study: Drug-resistant TB and suffering, lessons from research in India

A research study carried out in India highlighted how the alleviation of suffering of people with MDR-TB was poorly addressed by professional services. The study identified three points of individual suffering: prognostic uncertainty; a sense of vulnerability in disclosing a diagnosis of MDR-TB to others for fear of stigma and discrimination; and, the trauma of drug treatment (including side effects such as visual disturbances, lethargy, nausea and vomiting). The study highlighted how patients were able to develop and access support from social networks and community structures, involving family, friends and members of the community, which provided highly personalised and holistic care and allowed people to overcome the physical and psychological barriers to treatment. The authors of the study concluded that there was an important role for palliative care services in the alleviation of suffering. [73]

Introduction

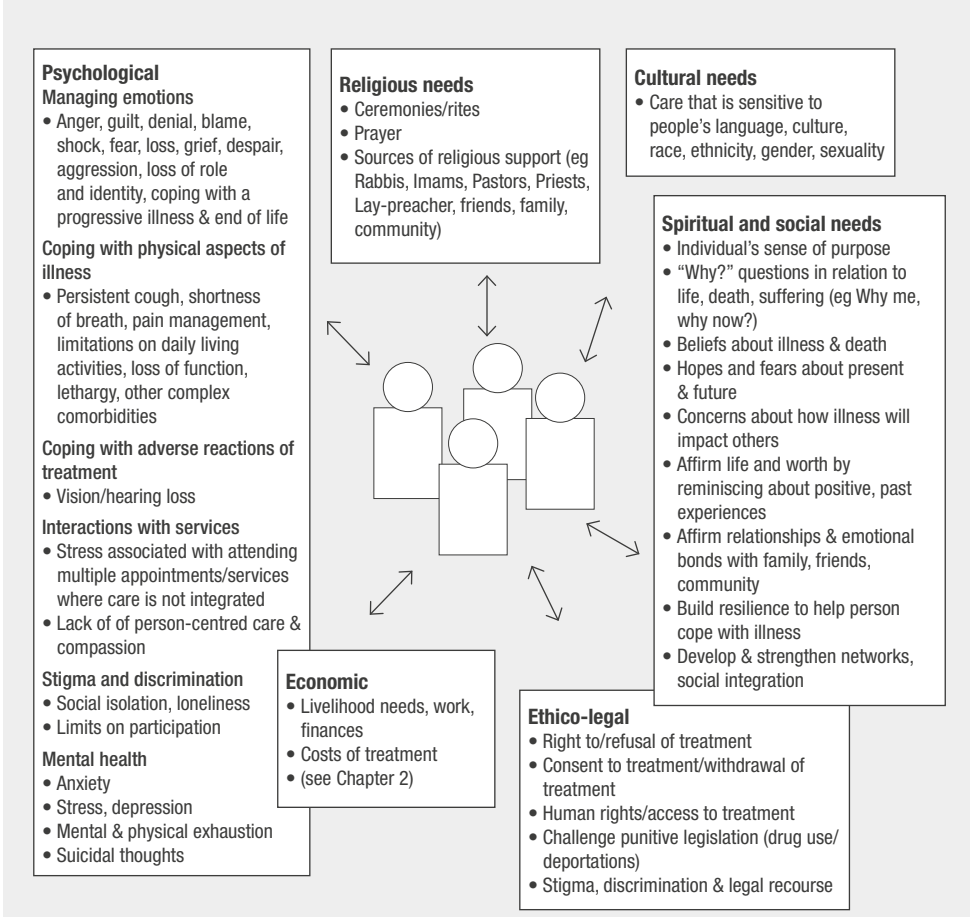
In this chapter, we focus on the PSS needs of people with TB and other comorbidities or long-term conditions. This chapter builds on the information provided in chapters 2 and 3. Most people with TB will require low level support as identified in the support pyramid in chapter 2 (i.e. levels 1 and 2). However, for those with more complex healthcare needs, including some forms of drug-resistant TB, higher intensity support will be needed requiring collaborative working with other specialist services and community organisations (see chapter 4). We provide examples of different comorbidities often associated with TB and highlight a range of resources that can be used to support people and their families. We acknowledge the impact caring for others has on unpaid carers' emotional and mental wellbeing. We discuss the importance of supporting and enabling families in their role as carers by assessing their support needs. We also acknowledge the role of families and communities in providing palliative and end of life care. We conclude with some guidance on how to ensure a safe discharge from the TB services and end the chapter with exercises to consolidate the learning gained in this chapter.

The psychological health of people with TB and complex comorbidities

The WHO End TB strategy aims to achieve zero deaths, disease and suffering for people affected by TB.[49] One of the components of the strategy is the provision of integrated, person-centred care which includes caring for people with long-term conditions, or comorbidities, including diabetes, HIV and substance misuse (alcohol and drugs), in addition to TB. People with long-term conditions are more likely to experience mental health issues, such as depression (see chapter 2). Poor emotional and psychological wellbeing are also associated with poorer quality of life and difficulties coping with illness. The End TB strategy recognises different components of the suffering experienced by people with TB and other long-term conditions, including: emotional, psychological, physical and economic 'pain'. Supporting the mental, emotional and spiritual health of those affected by TB, including caregivers, is particularly important where positive health outcomes are deemed unlikely, as in some forms of drug-resistant TB.

Collaborative approaches are therefore needed to caring for people with long-term conditions, and interventions that address mental health, enhance social interaction, prevent isolation, tackle stigma and discrimination and mitigate the catastrophic costs associated with TB and associated comorbidities (see the pyramid support model in chapter 2 and examples of collaborative working in chapter 4). People with multiple comorbidities may also have additional needs (e.g. religious and spiritual). These are highlighted in figure 8 and discussed throughout this chapter.

Figure 8: Psychosocial support for people with complex health needs and life-limiting illness



People living with diabetes mellitus (DM)

People with diabetes are at greater risk of developing TB, so it is important for diabetes services to screen for TB in areas with a medium to high TB burden and for TB services to consider screening for diabetes in those at risk. Approximately a quarter of people with diabetes also experience depression (see chapter 2 for a discussion of mental health and screening tools for depression).[74] Moreover people with TB and diabetes are more likely to experience frequent adverse treatment outcomes and will therefore require additional PSS.

Some adjunctive TB therapies involving steroids are associated with an increase in appetite and weight gain, which may result in stigmatisation of individuals as 'greedy' if they are seen to make additional demands on households' food resources, particularly where these are scarce. Food support packages may be necessary. Steroids can also cause challenges for people with diabetes that may require them to change their diabetic treatment regimen.

Supporting the psychological health of people with diabetes

Diabetes UK (an NGO) has developed resources for professionals to have conversations about emotional health and diabetes. They recommend starting the conversation with open questions (see chapter 3). They also suggest using a form for people to complete while waiting for their appointment, which allows them to identify the issues they are worried about or that they would like to discuss. A communication tool such as this would allow appointments to be more person-led and could easily be developed with the involvement of people affected by diabetes and TB, for use in services. For example, they could develop and comment on the content of the form (that is, what topics should be included).

TB and the Hepatitis C Virus (HCV)

There is a high incidence of TB amongst key populations living with Hepatitis C infection. However, many people do not know they have HCV, which does not have symptoms in its early stages, and may experience particular difficulties accessing HCV screening. HCV complicates TB treatment. It increases hepatotoxicity of the antibiotics used to treat TB and therefore exacerbates any liver disease. People with TB-HCV therefore may require longer periods of treatment for TB – so reduced dosages of TB antibiotics can be employed – and additional monitoring and support.

People with TB-HCV may also have greater psychosocial support needs because of the length of TB treatment, the toxicity of the TB drugs and particular barriers associated with accessing diagnostic services and adherence to treatment, including stigma.[75] A systematic review of the literature reported that people living with the Hepatitis C infection were more likely to experience poor physical and mental health, in part due to substance misuse, mental health issues and lack of social support, impacting people's ability to adhere to treatment.[76] A review of PSS practices for people living with TB-HIV and viral hepatitis in the European region reported on a novel project in the Ukraine by the Alliance for Public Health, which aimed to scale up accessible, community-based treatment for Hepatitis C in key populations. Participants in the study were offered psychological, advisory and practical assistance during the course of treatment by a social worker.[77]

People living with HIV

Documentation of people's HIV status is one of the ten priority indicators for monitoring the End TB Strategy.[52] Although preventable and curable, TB is the leading cause of death of PLWHA and accounts for 40% of AIDS-related deaths (based on figures in facilities where a post-mortem was conducted). However, in 50% of PLWHA TB was never diagnosed, so potentially life-saving TB treatment was not provided. High quality psychosocial care is an essential component of the prevention, early detection and effective treatment of communities at risk of TB-HIV.

Given the diverse spectrum of people at heightened risk of TB-HIV, including people who inject drugs, sex workers, and prisoners, different approaches will be required. The effects of stigma and discrimination are often intensified in these populations, who may be blamed for having contracted HIV and hence experience a double form of TB-HIV stigma through dual illness.[78] In some contexts TB associated with HIV is referred to as 'new' TB which serves to mark a difference from the 'old TB' and further stigmatises the individual and their families.[79]

Psychological health and HIV

The Medical Foundation for AIDS and Sexual Health (MEDFASH) has produced standards of psychological support for adults living with HIV (see section on further reading to access these). The standards describe the support that should be provided to enhance mental health and peoples' emotional, cognitive and behavioural wellbeing. The standards focus on:

- the promotion of mental health and wellbeing
- the early detection of psychological problems
- the provision of appropriate interventions for those who require them.[80]

The guidance also makes recommendations for the type of support that should be offered and the professional best placed to provide this care using a stepped care model.

People living with TB who misuse substances

People who use or inject drugs (PWUID) are at greater risk of contracting TB and hepatitis B and C. They are also more likely to experience poor treatment outcomes. The care needs of these groups are complex as MDR-TB, HIV and alcohol use are common in PWUID. PWUID are more likely to experience mental health issues such as depression (see chapter 2). Depression and alcohol/drug use are associated with poor access to HIV care and adherence to treatment and increased mortality from HIV and related co-morbidities.[81]

Provision of care is rendered more complex because of the criminalisation of drug use in many contexts and the fear of imprisonment, as well as stigma and discrimination towards substance misuse. Because of these complexities, WHO recommends integrated tuberculosis, HIV, hepatitis and harm-reduction services that respect people's human rights.[82] WHO recommends the need for open dialogue on the impact of punitive laws affecting people who use drugs and efforts to combat the TB pandemic with civil society organisations playing a key role.[82]

Psychological health and drug use

It is likely that specialist mental health services will need to be involved in the care of PWUID (see the support pyramid in chapter 2). Care at this level needs to be integrated or care coordinators appointed to coordinate care. The sharing of information is also key[81, 83] (see the case study about Michelle in chapter 4 for an example of the care coordinator role).

Palliative and end of life care

WHO (2020)[84] defines palliative care as "...an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." Given the levels of mortality among people being treated for MDR-TB and XDR-TB, especially in LMICs and among PLWHA, palliative care can be seen as a necessary part of the continuum of care for some TB patients.[85] The components of palliative care are detailed in Box 17.

The provision of psychological and socioeconomic support are crucial to enable adherence to treatment, and both people with TB and their families need support to come to terms with a life-limiting and, often, progressive illness. People with MDR-TB and XDR-TB not only tend to experience less favourable outcomes compared to those with drug-sensitive TB, but the long courses of treatment which involves potentially toxic therapies can cause more severe adverse reactions. People therefore have to cope with the double burden of the adverse effects of treatment in addition to their illness. People can face catastrophic costs associated with treatment and loss of work due to illness, stigma and discrimination which can also extend to their families – adding to the economic burden of disease.

Box 17: Components of palliative care when used at the end of life

- aims to alleviate suffering and provide relief from pain
- affirms life and regards dying as part of a normal process
- does not aim to hasten or postpone death
- integrates the psychological, social and spiritual aspects of person-centred care
- provides a support system to improve quality of life and positively influence the course of illness to assist people to live as actively as possible until death
- provides a support system to assist the family cope during their loved one's illness and deal with bereavement
- uses a multidisciplinary approach to address the needs of people and their families, including bereavement counselling where required
- is proactive and integrated into treatment in conjunction with other therapies.

(Adapted from Guidelines for TB and DR-TB palliative care and support[85])

Generalist versus specialist palliative care

All professionals should be trained in the basic principles of palliative care and how to provide emotional and psychological support and symptom management. However, where symptoms are more severe or complex, people may transition from generalist to specialist services which may be hospital or community-based, depending on context. Care in specialist services is more likely to be provided by multidisciplinary teams and some hospitals are set up to replicate a hospice environment with a less institutional feel. Home-based care may be provided by mobile teams.

Formal palliative care is recommended where TB treatment has failed or where it has been withdrawn. However, the availability of palliative care may vary according to the context. The case study at the beginning of this chapter introduced the idea of compassionate community palliative care developed through the informal networks of people with TB. A compassionate community is an international public health approach, developed to provide care outside of formal health service contact. There was a spontaneous development of compassionate neighbourhoods during the COVID-19 pandemic. See the section on further reading at the end of this chapter to find out about the development of one initiative in Colombia and other resources on how to help develop a compassionate community.

Grief, loss and compassionate care

Models of grief and loss, most notably the Kubler-Ross model,[76] depict people's experiences of grief as following a series of emotional stages involving denial, anger, bargaining, depression and acceptance. These models suggest grief is experienced in similar ways by the dying person and their loved ones. However criticisms of stage models of grief argue that the stages are neither distinct nor linear and that people express different emotions at different times rather than in stages.[86] The models have received further criticism because people who do not experience their grief in accordance with the stages of the models are often viewed as not coping. Rights-based, people-centred care, however, focuses on, and affirms, the experiences of individuals and their families. It recognises that people differ in their reactions to loss and adapt to loss in their own way over time. Grief may be expressed, or not, in very different ways and is influenced by factors such as gender and cultural customs. People with TB and their families can be supported by asking them what they are feeling and what kind of support they would find helpful and by adopting the principles of compassionate care (see chapter 3).

Meeting the emotional, spiritual and religious needs of people experiencing a progressive and life-limiting illness

Figure 8 illustrates the psychosocial support needs of those coping with a progressive, life-limiting illness, such as severe cases of TB which do not respond to treatment. Exploring the emotions which people living with a life-limiting illness are experiencing can provide insight into their state of mind. It is important to explore people's spiritual and religious beliefs which can indicate how they cope with serious illness, death, dying and, in the case of families, bereavement. Meeting the religious and spiritual needs of patients and their families is an important aspect of compassionate care. Religious leaders also have a role to play in caring for patients and their families during illness including, palliative and end of life care. They can offer religious instruction, perform rites and ceremonies in accordance with the wishes and beliefs of patients, and offer spiritual care and cultural understanding about illness and death. (see the further reading section at the end of this chapter for information about approaches to assessing the religious and spiritual needs of patients and their families). Box 18 outlines the different domains that should form part of an assessment for PSS.

Box 18: Psychosocial assessment of people requiring palliative care[85]

- demographic information
- social support system
- impacts of illness on daily living and relationships
- work/education history, skills and interests
- strengths and coping strategies
- self-care activities
- understanding of diagnosis and prognosis
- experience and comfort level with healthcare system
- goals/hopes/expectations
- fears/concerns
- previous and/or anticipated losses
- communication and information needs
- psychological issues and support needs.

Breaking significant news and conveying uncertainty: having difficult conversations with patients and their families about death and dying

The case study at the beginning of this chapter described how the "prognostic uncertainty" of patients' illness was a cause of their suffering. However, it is important that people, and their families, are given honest and truthful information about their illness and the limitations of any treatments provided.

NHS Education for Scotland has developed a range of video resources using animation (transcripts are also included) for professionals breaking the news to families about bereavement, and talking about death and dying openly and honestly to patients and families (see section on further reading).

Supporting carers to care for a family member

Families can play an important role in providing care (e.g. symptom and pain management, administration of medication, emotional support) to people with TB and particularly palliative and end of life care where this is provided at home or in a community setting. However, carers also have support needs and can suffer poor physical and mental health and financial pressures (through loss of work) as a result of their caregiving role. The aim of any intervention is to support carers to continue in their role to provide care and at the same time to protect themselves from getting infected while looking after family relatives with drug-resistant TB that may take longer to become non-infectious. Appropriate support can help ameliorate the impact of stress and the demands of care for caregivers and promote positive psychological and physical health outcomes as well as improved bereavement outcomes.[87] Initial support for carers aims to tackle the causes of stress (financial and other worries, exhaustion due to the demands of caring) and deal with the symptoms of stress. (See the stress cycle chapter 2 on the effects of stress on physical health and behaviour). Respite care or breaks for carers can help as can support with caring, household chores and other responsibilities. Support groups involving other carers can be set-up or carers can be signposted to these groups where they already exist.

There are tools to assess the need for support for carers. One tool specifically developed for use in palliative and end of life care is the Carer Support Needs Assessment Tool (CSNAT) which is intended for use in everyday practice.[88] The tool allows carers to identify areas where they need more support in 14 areas or domains with either their caring role, or for themselves, and could be used by a HCW as a basis for a guided conversation to identify jointly agreed actions (see Box 19). Alternatively, the Carers Alert Thermometer, developed by Edge Hill University, is a tool containing 10 questions which identify the support carers need to be able to provide care and the support they need for their own health and wellbeing. Each question has a traffic light system to score the level of need from low (green), medium (amber) to high (red) need. For more information about how to access this tool see the section on further reading at the end of the chapter. Generally, carers prefer to talk about their needs with someone with whom they have developed a trusting relationship.

Don't promise what you can't deliver

Remember that by conducting an assessment you may raise expectations about what your service can offer. It is important to identify resources or solutions where a need or gap has been identified. You may also need to manage people's expectations about what your service can and cannot provide, for example, equipment. It is unethical to conduct an assessment where you do not act on the outcomes or findings of the assessment.

Box 19: Guided conversation to support carers (adapted from Aoun et al 2015[86])

Support domains to enable the carer to care
Do you need more support with

- Understanding [name of person]'s illness
- Managing [name]'s symptoms including giving medication
- Providing personal care for [name] e.g. dressing, washing, toileting
- Knowing who to contact if you have a concern about [name]
- Equipment to help care for [name]
- Talking with [name] about his/her illness
- Knowing what to expect in the future when caring for [name]

Support domains for carers themselves

- Do you need more support with
- Having time for yourself in the day
- Your financial, legal or work issues
- Dealing with your feelings and worries
- Looking after your own health and ensuring you don't get infected with TB
- Your beliefs or spiritual concerns
- Practical help in the home
- Getting a break from caring

Discharge or transfer from tuberculosis services

Discharge planning for TB patients, or transfer to another service, should have regard to local or national guidance for discharge planning and bear in mind any risks associated with the environment where a person will be cared for and any individuals in that environment who may also be placed at risk. High risk settings include prisons, healthcare settings, residential facilities, homeless shelters and any congregate setting where other individuals may be vulnerable and at risk. Individuals at high risk include children under five, pregnant women, people taking antiretrovirals and other immunosuppressive therapies (e.g. chemotherapy for cancer).

Where people with TB are discharged to a home environment, this should be risk assessed to ensure a safe discharge for the patient, including the need for any aids or adaptations to the home environment to enable activities of daily living, and the prevention of falls. The home environment should be assessed, and information provided on how to minimise the risk of infection to others (e.g. the use of face masks, well ventilated rooms, physical distancing). The PSS needs of patients, their carers and families should also be assessed. Family members should be provided with information about who to contact, and what to do if any household member develops TB symptoms.

Where treatment has been successful, people should be advised that they could become re-infected with TB and given information about what to do, and who to contact, should they experience symptoms.

Breaking significant news about a diagnosis

Box 20: SPIKES Protocol (adapted from Baile et al 2000[89])

Step 1: Setting up the interview

- prepare what to say prior to the conversation and how much information to provide
- ensure an optimal environment, choose a quiet space free from distractions, put mobile phone on silent
- check whether an interpreter is needed
- identify appropriate information to share with patients
- allow adequate time so the appointment is not rushed.

Step 2: Assessing perceptions of illness and TB (see chapter 3 for information on asking culturally sensitive questions)

- use open-ended questions to assess how the patient perceives the medical situation
- use open-ended questions to find out patients' perceptions about TB, what do they know already, is the information accurate or based on myths
- explore patients' expectations and hopes.

Step 3: Inviting the need for information about the diagnosis

- patients have different preferences for how much they want to know about their diagnosis, illness and future outcomes
- invite patients to say how much information they would like at this stage
- inform patients how they can receive additional information and who they can talk to about any concerns that may arise once they have left the appointment.

Step 4: Providing knowledge and information

- assess level of comprehension and understanding to tailor the information provided
- use simple non-technical language without being patronising.

Step 5: Respond with empathy to the patient's emotions

- attend to how the patient is receiving the diagnosis of TB, both verbal and non-verbal cues, and their reactions such as denial, confusion, silence, shock, fear, anger, tears
- use open questions to ask what the patient is thinking or feeling
- check that the emotion is TB related or if it is a concern about something else
- use non-verbal communication to show empathy (e.g. nodding of the head)
- allow time and space for the patient to recover.

Step 6: Strategy and summary

- present patients with a clear care and treatment plan for the future to alleviate anxiety
- ask what can be done to ensure the care plan is followed and make it happen working collaboratively with the patient.

Consolidating learning

- Identify the different services that you work with/need to work with to provide collaborative care for people with multiple and complex health needs including those who require palliative and end of life care.
- Think about the different groups in the community that you care for (e.g. older/younger generation; people of different faiths; people from rural/urban areas) and consider the differences in their religious and spiritual needs with reference to the SOCIAL GRACES framework in chapter 3.
- Using role play where you take on the role of the doctor/nurse or other professional and your colleague adopts the role of person with TB, inform the individual that palliative and end of life care will be necessary. Notice how the person with TB reacts. How did it make you feel? How did you feel about breaking the significant news? Now reverse the roles and compare notes with your colleague. (This training exercise works well with actors playing the role of patients. Actors are asked to react to the significant news in different and, sometimes, unpredictable ways to see how professionals manage the situation).
- Using the guided conversation assessment for carers in box 19, role play an assessment with a colleague, taking it in turns to be the carer and the HCW. For carers you should identify the particular illness of the family member/relative you care for (e.g. MDR-TB, TB-HIV). After each role play note your feelings and reactions to asking the questions (in the role of HCW) and being asked the questions (in the role of carer). Compare your notes. Now discuss with your colleague how your service could meet the needs of those carers who respond 'Yes' to the different domains of need described in box 18.

Further reading

Assessing carers' needs

Edge Hill University. Carers' Alert Thermometer (CAT). *www.edgehill.ac.uk/carers/cat-information/*
More information on the Edge Hill University Carers' Assessment Thermometer (CAT) and how to register to use it.

Compassionate communities

Compassionate Communities UK. Creating a Compassionate Neighbourhood in light of COVID-19. *www.compassionate-communitiesuk.co.uk/videospodcasts*
A video podcast providing information about setting up a compassionate neighbourhood network based on experiences in Columbia.

The Public Health Palliative Care Initiative. Overview of tools and resources for building compassionate communities. *http://phpci.info/tools*
A range of resources, toolkits and charters to help set up a compassionate community.

Diabetes

Management of Diabetes Mellitus-Tuberculosis: A guide to essential practice, 2019. Geneva: International Union Against Tuberculosis and Lung Disease, 2020. Available at: *www.theunion.org/technical-publications/management-of-diabetes-mellitus-tuberculosis-a-guide-to-the-essential-practice*

Collaborative Framework for Care and Control of Tuberculosis and Diabetes, 2011. Geneva: WHO; 2011. Available at: *www.who.int/tb/publications/tb-diabetes-framework/en/*

Diabetes UK. Diabetes and Psychological Care. *www.diabetes.org.uk/professionals/resources/shared-practice/psychological-care*
A range of resources that can be used for other long term conditions including a resource

HIV

Standards for Psychological Support for Adults Living with HIV, 2011. Leicester: British Psychological Society; Letchworth, UK: British HIV Association; 2011. Available at: *www.bhiva.org/file/BbShtfyMFNKCz/Standards_for_psychological_support_for_adults_living_with_HIV.pdf*

Support Around Death. NHS Education for Scotland Bereavement Films for Professionals. *www.sad.scot.nhs.uk/video-wall/*
Breaking the news about bereavement and having difficult conversations.

GW Institute for Spirituality & Health. FICA Spiritual History Tool. *https://smhs.gwu.edu/gwish/clinical/fica/spiritual-history-tool*
Assessing spirituality using the F-I-C-A framework to provide support with a person's spiritual needs

Palliative care

The Worldwide Hospice Palliative Care Alliance (WHPCA). Global Atlas of Palliative Care at the End of Life. *www.thewhpca.org/resources/global-atlas-on-end-of-life-care*

Comprehensive Guidelines for TB and DR-TB Palliative Care and Support, 2015. USAID/TB CARE II Project. Available at: *www.urc-chs.com/sites/default/files/Related%20URC%20publication_Palliative%20Care%20and%20TB.pdf*
Includes guidance on breaking significant news and managing depression.

Appendix 1: TB facts

What is tuberculosis?

Tuberculosis (TB) is an infectious illness caused by the airborne bacteria Mycobacterium Tuberculosis. TB can cause serious health problems – particularly if it is not caught early. But the illness is curable and testing and treatment is free in the public sector. A person's TB diagnosis should be confidential and a person should be provided with TB services in any country regardless of immigration status.

TB is the leading cause of death from a single infectious agent,[2] the leading cause of death of people with HIV and a major contributor to antimicrobial resistance.

Most of the people who fall ill with TB live in low- and middle-income countries, but TB is present all over the world. About half of all people with TB can be found in eight countries: Bangladesh, China, India, Indonesia, Nigeria, Pakistan, Philippines and South Africa.[90]

How is tuberculosis transmitted?

TB is spread through the air when people with smear-positive pulmonary TB cough, sneeze or sing. People with TB in their lungs or throat send droplets into the air that contain the TB bacteria. People can become infected with TB if they breathe in these bacteria over a long period of time. The intensity, frequency and duration of exposure to an infectious person are factors that can determine if a person will get TB or not. But most people won't get ill because:

- prolonged, close contact is usually required with someone with infectious TB for a person to breathe in enough bacteria to be at risk
- most people's immune systems are strong enough to kill off TB bacteria.

Only patients with infected sputum (bacteriologically confirmed TB) pose a risk of transmission and once effective treatment starts, infectiousness drops rapidly, usually within a few days.

There are some factors that make a person more vulnerable to TB. These include a compromised immune system (people living with HIV, persons on immune-suppressant drugs, people with diabetes etc.), contacts of people with pulmonary TB, and people living in conditions where TB transmission is more likely due to crowding, lack of ventilation or poor access to health services, such as miners, prisoners and slum dwellers. Tobacco use (smoking) is also a risk factor.

TB cannot be spread through touch, sharing cutlery, bedding or clothes.

Where in the body can you get tuberculosis?

Tuberculosis mainly affects the lungs, but it can affect any part of the body, including the lymphatic glands, bones, abdomen and the nervous system. The second most common site of TB infection is in the lymph glands, often those in the neck. Lymph glands are small areas in the body that contain white blood cells that can swell up if they're infected.

TB that affects the lungs is called pulmonary tuberculosis (PTB) and TB in any other part of the body except the lungs is called extra-pulmonary TB (EPTB). EPTB can develop at any age and occurs more commonly in immunosuppressed persons, particularly people living with HIV and young children.

What are the symptoms of tuberculosis?

Common symptoms of TB disease include:

- prolonged cough
- blood with cough (haemoptysis)
- chest pain
- weakness or fatigue
- unexplained weight loss
- fever
- night sweats.

Often, these symptoms will be mild for many months, thus leading to delays in people seeking care and increasing the risk of them passing the infection to others. Each country has its own guidance regarding the symptoms that are identified in people during the TB screening process. These could be all of the above or a combination of the above symptoms and can vary by population type in some countries (see table 8).

Table 8: Chart for systematic screening of different population groups in Malawi

OPD/MNCH/Other adult	*Miners*	*HIV clinic/PLHIVs/ Prisoners*
1 Cough (2 weeks or more)	1 Cough (1 week or more)	1 Cough (any duration)
2 Fever (2 weeks or more)	2 Fever (1 week or more)	2 Fever (any duration)
3 Weight loss?	3 Weight loss?	3 Weight loss
4 Profuse night sweats? (2 weeks or more)	4 Profuse night sweats? (1 week or more)	4 Profuse night sweats? (any duration)
Anyone fulfilling any of the above criteria will be labelled a presumptive TB case	Anyone fulfilling any of the above criteria will be labelled a presumptive TB case	Anyone fulfilling any of the above criteria will be labelled a presumptive TB case

TB infection (latent TB) and TB disease

Someone has TB infection (also known as latent TB) if they are infected with the TB bacteria but do not have signs of active TB disease and do not feel ill. In simple terms, when a person has TB infection, it means that the TB bacteria are 'asleep' in the body. A person is not ill at that moment, but the TB bacteria can 'wake up' and make the person ill with TB in the future. A person with TB infection is well, has no symptoms and cannot pass on the disease, but there is a risk that they may develop active TB disease at some point in the future.

The WHO defines latent tuberculosis infection (LTBI) as 'a state of persistent immune response to stimulation by MTB antigens without evidence of clinically manifested active TB'.

About a quarter of the world's population is infected with MTB and thus at risk of developing active TB disease.[91]

The immune system can prevent TB infection from getting established in the body or, in the case of LTBI, from spreading. If the immune system fails to kill or contain the infection, it can spread within the lungs or to other parts of the body and symptoms will develop within a few weeks or months. This is known as active TB.

How is TB diagnosed?

TB bacteria in the body can be detected through a skin test (tuberculin skin test) or an IGRA blood test. However, a positive skin test or blood test cannot determine whether a person has TB infection or TB disease. There are a range of tests to show that you have TB disease. These include sputum test, x-ray, biopsy and a culture test – as well as the presence of symptoms.

Chest x-ray

An x-ray by itself cannot diagnose primary MTB infection but it can provide some clues to the diagnosis. A chest x-ray can show damage in the lungs, but further tests are required to prove the damage relates to TB – such as sputum and culture tests or scans. It can also support a clinical diagnosis of tuberculosis. However, many patients are never unwell enough to require a chest x-ray, while in some people with TB the x-ray may appear normal.

Testing sputum

Ideally, finding the TB bacteria is the best form of diagnosis. A laboratory will use a microscope or newer molecular tests to look at a sputum sample for TB bacteria. If there are TB bacteria in the sputum sample, it indicates tuberculosis of the lungs or throat (pulmonary TB). This test also helps doctors to understand how infectious the individual may be. Testing using a microscope may not be sensitive enough to diagnose TB where only a few bacteria are present in the sample provided. Another shortcoming of smear microscopy is its non-specificity, where there is a high level of false positives because the test mistakes non-tuberculous mycobacteria (NTM) as being TB. Nonetheless, in areas of high TB prevalence, positive smears have a very high probability of being MTB but WHO recommends that they should be followed up by newer tests.[92]

The WHO now recommends rapid molecular tests such as GeneXpert (called CBNAAT or cartridge based nucleic acid amplification test in India) as the initial diagnostic test for detecting MTB in adults and children. The test simultaneously detects the presence of MTB complex MTBC and resistance to rifampicin (RIF) within two hours. In comparison, standard cultures can take up to six weeks for MTBC to grow.

Biopsy

If it is thought that a person has TB, but not in the lungs or throat, the doctor may take a biopsy to test for TB. This is a small sample of tissue or fluid taken from the area where the TB is thought to be.

Culture test

This test uses sputum or tissue samples to grow any TB bacteria that may be there. If MTB grows in a culture medium, specific tests can be carried out to determine if the bacteria are sensitive or resistant to anti-tuberculosis drugs. This helps ensure that the person with TB is put on a combination of drugs that will best cure them. As TB culture grows slowly, it may take up to eight weeks to get some of the results.

Bacteriologically versus clinically diagnosed TB

A bacteriologically confirmed TB case is where a biological specimen from a person with TB is shown as positive by smear microscopy, culture or any other WHO recommended diagnostics (WRD) such as Xpert MTB/RIF, lateral flow urine lipoarabinomannan assay (LF-LAM) or TrueNAT. All such cases should be recorded and/or notified to health authorities, regardless of whether TB treatment has started.

In some cases, a biological specimen tested from a person with TB does not detect the presence of MTB. However, a clinician can start TB treatment based on a combination of a person's medical history, clinical examination and radiological examination. A clinically-diagnosed TB case is one that does not fulfil the criteria for bacteriological confirmation but has been diagnosed by a clinician or other medical practitioner who has decided to give the patient a full course of TB treatment.

Classification of bacteriologically diagnosed TB

Bacteriologically diagnosed TB cases are classified according to the anatomical site of disease (PTB and EPTB as discussed earlier), the history of previous treatment, the HIV status of the person with TB and drug resistance.

History of previous treatment

A person on TB treatment can be one who is a new TB patient (has never been treated for tuberculosis before or has taken anti TB drugs for less than one month) or a person who has previously been treated for TB. Tuberculosis in a person previously treated for TB is further classified by the outcome of the previous treatment (see Box 21).

Box 21: Classification based on history of previous treatment[93]

'Relapse' patients have previously been treated for TB, were declared cured or treatment completed at the end of their most recent course of treatment and are now diagnosed with a recurrent episode of TB (either a true relapse or a new episode of TB caused by reinfection).

'Treatment after failure' patients are those who have previously been treated for TB and whose treatment failed at the end of their most recent course of treatment. 'Treatment after loss to follow-up' patients have previously been treated for TB and were declared lost to follow-up at the end of their most recent course of treatment. Other previously treated patients are those who have previously been treated for TB but whose outcome after their most recent course of treatment is unknown or undocumented. Patients with unknown previous TB treatment history do not fit into any of the categories listed above.

HIV status of a person with tuberculosis

A person with TB can either be classified HIV positive, HIV negative or as HIV status unknown. HIV status unknown refers to any individual with bacteriologically confirmed or clinically diagnosed TB who has no HIV testing result and/or no other documented evidence of enrolment in HIV care.

Drug-sensitive and drug-resistant tuberculosis

Drug-sensitive TB responds to the standard, first-line TB drugs – isoniazid (H), rifampicin (R), pyrazinamide (Z) and ethambutol (E) – and is treated using a six-month rifampicin-based regimen (2HRZE/4HR).

Tuberculosis cases are classified in categories based on drug susceptibility testing (DST) of clinical isolates confirmed to be MTB, as follows:

Monoresistance

Resistance to one first-line anti-TB drug only.

Rifampicin resistance

The TB bacteria are resistant to rifampicin with or without resistance to other anti-TB drugs. This type of drug resistance is diagnosed using GeneXpert instruments and it is then called "Rifampicin-resistant TB (RR-TB)". RR-TB is regarded as similar to MDR-TB and treated with an MDR-TB treatment regimen.

Polydrug resistance

Resistance to more than one first-line anti-TB drug (other than both isoniazid and rifampicin)

Multi-drug resistance

Resistance to at least both isoniazid and rifampicin is called MDR-TB. Treatment of MDR-TB is complicated and involves using drugs from three groups: Group A – levofloxacin or moxifloxacin, bedaquiline, linezolid; Group B – clofazimine, cycloserine or terizidone; Group C – ethambutol, delaminid, pyrazinamide, imipenem-cilastatin or meropenem, amikacin, ethionamide or prothionamide, para-aminosalicylic acid. Short regimens of 9-12 months can be used or longer regimens of 18-24 months, depending on the drug susceptibility status of the TB bacteria. Interested readers are referred to the most recent WHO Guidelines for more detailed information.

Pre-extensively drug-resistant TB (pre-XDR-TB)

TB caused by Mycobacterium tuberculosis (M. tuberculosis) strains that fulfil the definition of multidrug resistant and rifampicin-resistant TB (MDR/RR-TB) and which are also resistant to any fluoroquinolone.

Extensively drug-resistant TB (XDR-TB)

TB caused by Mycobacterium tuberculosis (M. tuberculosis) strains that fulfil the definition of MDR/RR-TB and which are also resistant to any fluoroquinolone and at least one additional Group A drug (Group A drugs are the most potent group of drugs in the ranking of second-line medicines for the treatment of drug-resistant forms of TB using longer treatment regimens and comprise levofloxacin, moxifloxacin, bedaquiline and linezolid).

Further reading

Consolidated Guidelines on Drug-resistant Tuberculosis Treatment, 2019. Geneva: WHO; 2019. Available at: *www.who.int/tb/publications/2019/consolidated-guidelines-drug-resistant-TB-treatment/en/*

Xpert MTB/RIF Assay for the Diagnosis of Pulmonary and Extrapulmonary TB in Adults and Children, 2013. Geneva: WHO; 2013. Available at: *https://apps.who.int/iris/bitstream/handle/10665/112472/9789241506335_eng.pdf*

Implementing Tuberculosis Diagnostics: policy framework, 2015. Geneva: WHO; 2015. Available at: *https://apps.who.int/iris/bitstream/handle/10665/162712/9789241508612_eng.pdf?sequence=1*

Tuberculosis: Practical guide for clinicians, nurses, laboratory technicians and medical auxiliaries, 2017. Geneva: Médecins Sans Frontières; Boston: Partners in Health; 2017. Available at: *https://medicalguidelines.msf.org/viewport/TUB/latest/tuberculosis-20321086.html*

Rapid Communication: Key changes to the treatment of drug-resistant tuberculosis, 2019. Geneva: WHO; 2019. Available at: *www.who.int/tb/publications/2019/WHO_RapidCommunicationMDR_TB2019.pdf?ua=1*

Definitions and Reporting Framework for Tuberculosis, 2013, updated 2020. Geneva: WHO; 2013. Available at: *https://apps.who.int/iris/bitstream/handle/10665/79199/9789241505345_eng.pdf?sequence=1*

References

1 Framework on Integrated, People-Centred Health Services, 69th World Health Assembly, April 2016. Geneva: WHO; 2016.
Available at: *https://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_39-en.pdf?ua=1*

2 Global Tuberculosis Report 2020. Geneva: World Health Organisation; 2020.
Available at: *www.who.int/tb/publications/global_report/en/*

3 General comment no. 14, The right to the highest attainable standard of health (article 12 of the International Covenant on Economic, Social and Cultural Rights), 2000. Geneva: UN Committee on Economic, Social and Cultural Rights; 22nd session, 2000).
Available at: *https://digitallibrary.un.org/record/425041?ln=en*

4 Declaration of the Rights of People Affected by Tuberculosis 2018. : TBpeople; Stop TB Partnership; Available at: *www.stoptb.org/assets/documents/communities/Declaration%20of%20the%20rights%20of%20people%20affected%20by%20TB%20-%20A5%20english%20version.pdf*

5 UN High-Level Meeting on TB Key Targets and Commitments, 2018. Geneva: Stop TB Partnership; 2018. Available at:
www.stoptb.org/assets/documents/global/advocacy/unhlm/UNHLM_Targets&Commitments.pdf

6 WHO Guidelines on Hand Hygiene in Health Care: First Global Patient Safety Challenge Clean Care Is Safer Care, 2009. Geneva: WHO; 2009.
Available at: *www.ncbi.nlm.nih.gov/books/n/whohand/partv_ch2/*

7 Psychosocial Support to People with TB, HIV and Viral Hepatitis in the Continuum of Care in the WHO European Region, 2020. Copenhagen: WHO Regional Office for Europe; 2020.
Available at: *www.euro.who.int/en/health-topics/communicable-diseases/hivaids/publications/2020/psychosocial-support-for-people-with-tb,-hiv-and-viral-hepatitis-in-the-continuum-of-care-in-the-who-european-region.-report-july-2020*

8 Adapted from the IASC Psychosocial Support Pyramid Model. Save the Children's Resource Centre. Foundation Model 7, Psychosocial Support, 2009.
Available at: *https://resourcecentre.savethechildren.net/node/8605/pdf/arc-modf7-3-h4-2009_0.pdf*

9 Sah, S., Guerrero, O., (June 2016). A Programme Evaluation of DAPP Malawi's TB Activities in Mulanje and Thyolo Districts.

10 Chikovore, J., Pai, M., Horton, K.C., et al, (2020). Missing Men with Tuberculosis: the need to address structural influences and implement targeted and multidimensional interventions. BMJ Global Health 2020;5:e002255. Available at: *https://gh.bmj.com/content/5/5/e002255.full*

11 KNCV Tuberculosis Foundation. Tuberculosis Stigma Reduction for Healthcare Institutions: the KNCV Stigma Reduction Toolbox 2018. Available at: *www.kncvtbc.org/en/kb/tb-stigma/*

12 Jaramillo, E., Sahu, S., Van Weezenbeek, C., (2017). Ending TB-Related Stigma and Discrimination. The International Journal of Tuberculosis and Lung Disease, 2017;21(11), S2-S3.

13 Macintyre, K., Mitchell, E.M.H., Daftary, A., Craig, G. (2018). TB Stigma Theory and Measurement in KNCV TB Stigma Measurement Guidance eds pp11-23. Available at *https://www.paitbgroup.org/wp-content/uploads/Resources/TB_Stigma_Measurement_Guidance.pdf*

14 KNCV Tuberculosis Foundation. From the inside out: dealing with self stigma and shame: A pilot toolkit for people with TB dealing with stigma and shame. 2018.

15 Craig, G., Daftary, A., Engel, N., O'driscoll, S., Ioannaki, A., (2017). Tuberculosis Stigma as a Social Determinant of Health: a systematic mapping review of research in low incidence countries. International Journal of Infectious Diseases, 2017;56, 90-100.

16 van der Land, L., Mitchell, E.M.H., van de Berg, S., Leimane, L., (2018). Measuring Secondary Stigmas Among TB-affected Workers and Families in KNCV TB Stigma Measurement Guidance eds pp163-183. Available at: *www.paitbgroup.org/wp-content/uploads/Resources/TB_Stigma_Measurement_Guidance.pdf*

17 Ambaw, F., Mayston, R., Hanlon, C., Medhin, G., Alem, A., (2018). Untreated Depression and Tuberculosis Treatment Outcomes, Quality of Life and Disability, Ethiopia. Bulletin of the World Health Organization, 2018;96(4), 243.

18 Rehm, J., Samokhvalov, A.V., Neuman, M.G. et al, (2009). The Association Between Alcohol Use, Alcohol Use Disorders and Tuberculosis (TB). A systematic review. BMC Public Health 9, 450; 2009. Available at: *https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-9-450*

19 Story, A., Murad, S., Roberts, W., Verheyen, M., Hayward, AC., (2007). Tuberculosis in London: the importance of homelessness, problem drug use and prison. Thorax, 2007;62(8), 667-71. Available at: *https://thorax.bmj.com/content/62/8/667*

20 Van Rensburg, A.J., Dube, A., Curran, R., Ambaw, F., Murdoch, J., Bachmann, M., et al, (2020). 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. Infectious Diseases of Poverty, 2020;9(1), 4.

21 Sweetland, A.C. et al, (2018) Tuberculosis: an opportunity to integrate mental health services in primary care in low-resource settings. The Lancet Psychiatry, 5, 12 pp 952-954. Available at: *https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(18)30347-X/fulltext*

22 Hwang, T., Wares, D., Jafarov, A., Jakubowiak, W., Nunn, P., Keshavjee, S., (2013). Safety of Cycloserine and Terizidone for the Treatment of Drug-resistant Tuberculosis: a meta-analysis. The International Journal of Tuberculosis and Lung Disease, 2013;17(10), 1257-66.

23 Under digital technologies Adepoju, P., (2020). Africa Turns to Telemedicine to Close Mental Health Gap. The Lancet Digital Health, 2020. Available at: *www.thelancet.com/journals/landig/article/PIIS2589-7500(20)30252-1/fulltext*

24 Fairburn, C.G., Patel, V. (2017). The Impact of Digital Technology on Psychological Treatments and Their Dissemination. Behaviour Research and Therapy, 88, 19–25; 2017. Available at *https://www.sciencedirect.com/science/article/pii/S0005796716301371?via%3Dihub*

25 Perez-Bret E, Altisent R, Rocafort J. Definition of compassion in healthcare: a systematic literature review. International journal of palliative nursing. 2016;22(12):599-606.

26 Steyn, M., Van Der Merwe, N., Dick, J., Borcherds, R., Wilding, R., (1997). Communication with TB Patients; a neglected dimension of effective treatment. Curationis, 1997;20(1), 53-6.

27 Compassion in practice: Nursing, midwifery and care staff: Our vision and strategy. London: Department of Health; 2018. Available at: *www.england.nhs.uk/wp-content/uploads/2012/12/compassion-in-practice.pdf*

28 Essence of Care 2010: Benchmarks for Communication. London: Department of Health; 2011. Available at: *www.gov.uk/government/publications/essence-of-care-2010*

29 Norouzinia, R., Aghabarari, M., Shiri, M., Karimi, M., Samami, E., (2016). Communication Barriers Perceived by Nurses and Patients. Global Journal of Health Science, 2016;8(6), 65.

30 Brathwaite, B., (2020). Diversity, Health Inequality and Nursing. Diversity and Cultural Awareness in Nursing Practice, 2020:6.

31 Smedley, B.D., Stith A.Y., Nelson, A.R., editors, (2003). Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare, 2003. Washington (DC): National Academies Press (US); 2003. PMID: 25032386. Available at: *https://pubmed.ncbi.nlm.nih.gov/25032386/*

32 Burnham, J., (2018). Developments in Social GRRRAAACCEEESSS: visible–invisible and voiced–unvoiced 1. Culture and Reflexivity in Systemic Psychotherapy: Routledge; 2018, 139-60.

33 Nolte, L., (2017). (Dis)gracefully Navigating the Challenges of Diversity Learning and Teaching: reflections on the Social Graces as a diversity training tool. Context, 2017.

34 Adapted from: Using Conversations to Assess and Plan People's Care and Support, 2018. Leeds: Skills for Care; 2018. Available at: *www.skillsforcare.org.uk/Documents/Leadership-and-management/Workforce-commissioning/Conversational-assessment/Using-conversations-to-assess-and-plan-peoples-care-and-support.pdf*

35 Kleinman, A., Benson, P., (2006). Anthropology in the Clinic: the problem of cultural competency and how to fix it. PLoS Med, 2006;3(10), e294.

36 Ali, M., (2018). Communication 5: Effective listening and observation skills. Nursing Times, 2018, 114(4).

37 Lukersmith, M.S., Millington, M., Salvador-Carulla, L., (2016). What is case management? A scoping and mapping review. International journal of integrated care, 2016;16(4).

38 A Case Management Tool for TB Prevention, Care and Control in the UK, 2019. London: Royal College of Nursing (RCN); 2019.
Available at: *www.rcn.org.uk/professional-development/publications/pub-006194*

39 WHO. Health systems strengthening glossary. *www.who.int/healthsystems/hss_glossary/en/*

40 Picker. Principles of Person Centred Care. *www.picker.org/about-us/picker-principles-of-person-centred-care*

41 The Impact of COVID-19 on the TB Response: A Community Perspective, 2020. Washington DC: ACTION; Amsterdam: GCTA; London: Global TB Caucus; Nairobi: KANCO; Montreal: McGill International TB Center; London: RESULTS; Geneva: Stop TB Partnership; Community and NGO Delegations; Kyviv: TBpeople; Montreal: TB PPM; Smyrna, GA: We Are TB; 2020. Available at: *www.stoptb.org/assets/documents/resources/publications/acsm/Civil%20Society%20Report%20on%20TB%20and%20COVID.pdf*

42 Healthworkers, 2006. Geneva@WHO; 2006.
Available at *https://www.who.int/whr/2006/06_chap1_en.pdf*

43 Miler, J.A., Carver, H., Foster, R. et al, (2020). Provision of Peer Support at the Intersection of Homelessness and Problem Substance Use Services: a systematic 'state of the art' review. BMC Public Health 20, 641 (2020). Available at: *https://doi.org/10.1186/s12889-020-8407-4*

44 Croft, L.A., Hayward, A., and Story, A., (2013). Tuberculosis Peer Educators: personal experiences of working with socially excluded communities in London. The International Journal of Tuberculosis and Lung Disease, vol 17 10 (Suppl 1), 36-40

45 What Religious Leaders Can Do About HIV, 2003. New York: UNICEF; New York: World Conference of Religions for Peace, Geneva: UNAIDS; B14 Available at:
www.unicef.org/publications/index_19024.html

46 Médecins Sans Frontières. Five Deadly Barriers in Effective TB Care.
www.msf.org.za/stories-news/news-our-projects/five-deadly-barriers-effective-tb-care

47 Tackling Tuberculosis in Under-Served Populations: A Resource for TB Control Boards and their partners, January 2019. London: Public Health England. Available at:
www.gov.uk/government/publications/tackling-tuberculosis-in-under-served-populations

48 WHO Western Pacific. Tuberculosis in the Western Pacific.
www.who.int/westernpacific/health-topics/tuberculosis

49 Framework for Conducting Reviews of Tuberculosis Programmes. Geneva: WHO. Available at:
www.who.int/tb/publications/tb_framework_checklist3.pdf

50 Vlassoff, C., Bonilla, E., (1994). Gender-Related Differences in the Impact of Tropical Diseases on Women: what do we know? Journal of Biosocial Science, 1994;26, 37–53.

51 Vlassoff, C. (2007). Gender Differences in Determinants and Consequences of Health and Illness. Journal of Health, Population and Nutrition, 2007;25(1), 47-61.

52 The End TB Strategy, 2014. Geneva: WHO; 2014. Available at: *www.who.int/tb/strategy/en/*

53 Protocol for Survey to Determine Direct and Indirect Costs Due to TB and to Estimate Proportion of TB-Affected Households Experiencing Catastrophic Total Costs Due to TB, 2015. Geneva: WHO; 2015. Available at: *www.who.int/tb/advisory_bodies/impact_measurement_taskforce/meetings/tf6_background_5a_patient_cost_surveys_protocol.pdf?ua=1*

54 Craig, G.M., Zumla, A., (2015). The Social Context of Tuberculosis Treatment in Urban Risk Groups in the United Kingdom: a qualitative interview study. International Journal of Infectious Diseases, 2015;32, 105-10.

55 Rhodes, T., Simic, M., (2005). Transition and the HIV Risk Environment. BMJ, 2005, 331(7510), 220-3.

56 WHO. TB and HIV, and other comorbidities. *www.who.int/tb/areas-of-work/tb-hiv/en*

57 Adams, L.V., Basu, D., Grande, S.W., Craig, S.R., Patridge, M.T., Panth, N., Trump Redd, V., Phalaste, M., Singo, A., Osewe, P., Mulley, A. G., (2017). Barriers to Tuberculosis Care Delivery Among Miners and their Families in South Africa: an ethnographic study. International Journal of Tuberculosis and Lung Disease, 21(5), 571–578. The Union 2017.

58 WHO. TB in Prisons. *www.who.int/tb/areas-of-work/population-groups/prisons-facts/en*

59 Kalonji, G.M.P. et al, (2019). Factors Associated with Prison Survival: Study in the Democratic Republic of Congo. Santé Publique, vol. 31, no. 5, 2019,715-722.

60 Mental Health Foundation. Mental Health Statistics: Homelessness. *www.mentalhealth.org.uk/statistics/mental-health-statistics-homelessness*

61 Chandrakumar, D., Padmapriyadarsini, C., Menon, A.P., Muniyandi, M., Adinarayanan, S., Sekar, G., Kavitha, D., Tripathy, S.P., Swaminathan, S. Tuberculosis Among the Homeless in Chennai City, South India. Transactions of The Royal Society of Tropical Medicine and Hygiene, Volume 111, Issue 10, October 2017, 479–481.
Available at: *https://academic.oup.com/trstmh/article/111/10/479/4811852*

62 Getahun, H., Gunneberg, C., Sculier, D., Verster, A., Raviglione, M., (2012). Tuberculosis and HIV in People Who Inject Drugs: evidence for action for tuberculosis, HIV, prison and harm reduction services. Current Opinion in HIV and AIDS, 2012;7(4), 345-353. DOI:10.1097/COH.0b013e328354bd44.
Available at: *https://europepmc.org/article/med/22678489*

63 Tollefson, D., Bloss, E., Fanning, A., Redd, J.T., Barker, K., McCray, E., (2013). Burden of Tuberculosis in Indigenous Peoples Globally: a systematic review. International Journal of Tuberculosis and Lung Disease, 2013, 17(9), 1139–50.

64 Key Population Brief: Indigenous Peoples, 2018. Geneva: Stop TB Partnership; 2018.
Available at: *http://www.stoptb.org/assets/documents/resources/publications/acsm/6_27-UNOPS-KPB-Indigenous-Print.pdf*

65 Mendes, A.M., Leite, M.S., Langdon, E.J., Grisotti, M.O., (2018). Desafio da atenção primária na saúde indígena no Brasil. Rev Panam Salud Publica, 2018;42:e184.
Available at: *https://doi.org/10.26633/RPSP.2018.184*

66 Guidelines for Treatment of Drug-susceptible Tuberculosis and Patient Care, 2017 update. Geneva: WHO; 2017. Licence: CC BY-NC-SA 3.0 IGO.
Available at: *www.who.int/tb/publications/2017/dstb_guidance_2017/en/*

67 Khogali, M., Zachariah, R., Reid, T., Alipon, S.C., Zimble, S., Mahama, G., Etienne, W., Veerman, R., Dahmane, A., Weyeyso, T., Hassan, A., Harries, A., (2014). Self-Administered Treatment for Tuberculosis Among Pastoralists in Rural Ethiopia: how well does it work? International Health, 2014 Jun;6(2), 112-7. DOI: 10.1093/inthealth/ihu008. Epub 2014 Mar 16. PMID: 24639343.

68 Consolidated Guidelines on Tuberculosis: Module 1: Prevention. Geneva, WHO; 2020. Available at: *www.who.int/publications/i/item/who-consolidated-guidelines-on-tuberculosis-module-1-prevention-tuberculosis-preventive-treatment*

69 TB Alert. Side effects. *www.tbalert.org/about-tb/global-tb-challenges/side-effects*

70 TB Alert - The Truth About TB. Multi-drug Resistant TB. *www.thetruthabouttb.org/wp-content/uploads/2016/08/MDR_leaflet_2015.pdf*

71 de Vries, S.G., Cremers A.L., Heuvelings, C.C., et al, (2017). Barriers and Facilitators to the Uptake of Tuberculosis Diagnostic and Treatment Services by Hard-to-Reach Populations in Countries of Low and Medium Tuberculosis Incidence: a systematic review of qualitative literature. The Lancet Infectious Diseases, 2017;17(5), e128-e143. DOI:10.1016/S1473-3099(16)30531-X.

72 TB Alert - The Truth About TB. Treatment. *www.thetruthabouttb.org/treatment/after-treatment*

73 Sawyer, J.M., Asgr, R., Fordham, F.N.T., Porter, J.D., (2018). A Public Health Approach to Palliative Care in the Response to Drug-resistant TB: an ethnographic study in Bengaluru, India. BMC Palliative Care, 2018;17(1), 120.

74 Collaborative Framework for Care and Control of Tuberculosis and Diabetes, 2011. Geneva: WHO; 2011. Available at: *www.who.int/tb/publications/tb-diabetes-framework/en*

75 Tuberculosis and Hepatitis C, 2015. London: The Hepatitis C Coalition; 2015. Available at: *www.hcvaction.org.uk/sites/default/files/resources/Hep%20C%20coalition%20-%20TB%20and%20hep%20c.pdf*

76 Kübler-Ross, E., (2005). On Grief and Grieving: Finding the Meaning of Grief Through the Five Stages of Loss. Simon & Schuster.

77 The Alliance for Public Health. Scaling Up Accessible and Effective Hepatitis C Virus Treatment through Community-Based Treatment Model for Most Vulnerable Populations in the Resource-Constrained Ukraine. *http://aph.org.ua/en/our-works/ukraine/scaling-up-accessible-and-effective-hcv-treatment-through-community-based-treatment-model-for-most-vulnerable-populations-in-the-resource-constrained-ukraine*

78 Daftary, A., (2012). HIV and Tuberculosis: the construction and management of double stigma. Social Science and Medicine, 2012;74(10), 1512-9.

79 Chileshe, M., Bond, V.A., (2010). Barriers and outcomes: TB patients coinfected with HIV accessing antiretroviral therapy in rural Zambia. Aids Care, 2010;22(sup1), 51-9.

80 Standards for Psychological Support for Adults Living with HIV, 2011. Leicester: British Psychological Society; Letchworth, UK: British HIV Association; 2011. Available at: *www.bhiva.org/file/BbShtfyMFNKCz/Standards_for_psychological_support_for_adults_living_with_HIV.pdf*

81 Buckingham, E., Schrage, E., Cournos, F., (2013). Why the Treatment of Mental Disorders is an Important Component of HIV Prevention Among People who Inject Drugs. Advances in Preventive Medicine, 2013;2013.

82 Getahun, H., Baddeley, A., Raviglione, M., (2013). Managing Tuberculosis in People Who Use and Inject Illicit Drugs. Bulletin of the World Health Organization, 2013;91, 154-6.

83 Accessibility and Integration of HIV, TB and Harm Reduction Services for People Who Inject Drugs in Portugal: a rapid assessment, 2012. Copenhagen: WHO Regional Office for Europe; 2020. Available at: *www.euro.who.int/__data/assets/pdf_file/0005/165119/E96531-v6-Eng.pdf*

84 WHO. WHO Definition of Palliative Care. *www.who.int/cancer/palliative/definition/en*

85 Comprehensive Guidelines for TB and DR-TB Palliative Care and Support, 2015. USAID/TB CARE II Project. Available at: *www.urc-chs.com/sites/default/files/Related%20URC%20publication_Palliative%20Care%20and%20TB.pdf*

86 Aoun, S.M., Grande, G., Howting, D., Deas, K., Toye, C., Troeung, L., et al, (2015). The Impact of the Carer Support Needs Assessment Tool (CSNAT) in Community Palliative Care Using a Stepped Wedge Cluster Trial. PloS one, 2015;10(4):e0123012.

87 Ewing, G., Brundle, C., Payne, S., Grande, G., National Association for Hospice at Home, (2013). The Carer Support Needs Assessment Tool (CSNAT) for Use in Palliative and End-of-Life Care at Home: a validation study. Journal of Pain and Symptom Management, 2013;46(3), 395-405.

88 Access to Innovative HCV Treatment for Key Populations, 2018. Kyiv: Alliance for Public Health; 2018. Available at: *http://aph.org.ua/wp-content/uploads/2019/01/Zvit-VGS__EN.pdf*

89 Baile, W.F., Buckman, R., Lenzi, R., Glober, G., Beale, E.A., Kudelka, A.P., (2000). SPIKES—a six-step protocol for delivering bad news: application to the patient with cancer. The Oncologist. 2000;5(4):302-11.

90 WHO. Tuberculosis. *www.who.int/health-topics/tuberculosis#tab=tab_1*

91 NHS. Tuberculosis (TB). *www.nhs.uk/conditions/tuberculosis-tb*

92 Tuberculosis: Practical guide for clinicians, nurses, laboratory technicians and medical auxiliaries, 2017. Geneva: Médecins Sans Frontières; Boston: Partners in Health; 2017. Available at: *https://medicalguidelines.msf.org/viewport/TUB/latest/tuberculosis-20321086.html*

93 Definitions and reporting framework for tuberculosis – 2013 (updated December 2014 and January 2020). Geneva: WHO; 2020. Available at: *https://apps.who.int/iris/bitstream/handle/10665/79199/9789241505345_eng.pdf?sequence=1*

ABOUT THE INTERNATIONAL UNION AGAINST TUBERCULOSIS AND LUNG DISEASE (THE UNION)

The Union is a global scientific organisation with the mission to improve health among people living in poverty. We do that by conducting scientific research, working with governments and other agencies to translate research into better health for people around the world, and delivering projects directly in the field. The Union is made up of a global membership body of people who help to advance our mission, and a scientific institute that implements public health projects within countries. For more than 100 years, we have been leaders in the fight against some of the world's biggest killers, including tuberculosis, lung diseases and tobacco use.

ABOUT TB ALERT

TB Alert is the UK's national tuberculosis charity with a mission to increase access to effective treatment for all. For over 20 years TB Alert has worked both in the UK and internationally on:

- raising public and professional awareness about TB, addressing barriers to treatment, and providing support to people during their treatment
- bringing together statutory health services, NGOs, community-based organisations and people affected by TB to plan and deliver better TB services
- advocating for the policies and resources to improve prevention, care and control for people and communities affected by TB.

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