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**REVIEW ON PALLIATIVE CARE
WITH FOCUS ON 18 HIGH
TUBERCULOSIS PRIORITY
COUNTRIES, 2020**

Abstract

Tuberculosis (TB) is, and should be, a curable disease; however, each year significant numbers of patients acquire or develop drug-resistant TB, which has a much lower cure rate. Patients with drug-resistant TB have a high prevalence of symptoms; hence, staff caring for these patients should have some familiarity with palliative care, so that general palliative care principles are available to all patients. The timely identification, and addressing, of adverse events occurring during the treatment course is considered as general palliative care for those receiving curative treatment. This publication summarizes the general palliative care approach, which is recommended for use in settings and services that occasionally treat palliative care patients, but do not provide palliative care as the main focus of their work. The review focuses on 18 high TB priority countries of the WHO European Region.

Keywords

TUBERCULOSIS – prevention and control

PALLIATIVE CARE

TUBERCULOSIS, MULTIDRUG-RESISTANT – prevention and control

EXTENSIVELY DRUG-RESISTANT TUBERCULOSIS – prevention and control

COMMUNICABLE DISEASE CONTROL

DELIVERY OF HEALTH CARE

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Contents

Acknowledgements	iv
Abbreviations.....	iv
Background.....	1
Palliative care for TB.....	2
Overview	2
Palliative care provision models	4
How to ensure best practice in integrated palliative care.....	7
Professional education	9
Patient assessment in palliative care	11
Symptoms and conditions	12
Pain.....	12
Cough.....	15
Haemoptysis.....	16
Shortness of breath.....	17
Anorexia and fatigue	17
Nausea.....	18
Psychological and psychiatric care.....	18
Delirium.....	18
Anxiety.....	19
Depression.....	20
Palliative sedation	21
Ethical issues	22
Minimal set of standards on palliative care in drug-resistant TB care for discussion and development.....	22
Conclusion	23
Useful free-access resources	25
References.....	26

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Abbreviations

EAPC	European Association for Palliative Care
IV	intravenous
M/XDR-TB	multidrug and extensively drug-resistant tuberculosis
PHQ	Patient Health Questionnaire
SC	subcutaneous
SSRI	selective serotonin reuptake inhibitor
TB	tuberculosis
XDR-TB	extensively drug-resistant tuberculosis

Background

WHO Regional Committee for Europe resolution EUR/RC65/17 Rev. 1 on a tuberculosis action plan for the WHO European Region 2016–2020 was endorsed in 2015 to strengthen and intensify efforts to address the alarming problem of tuberculosis (TB) in the Region. Since then, the Region has made noticeable progress and achievements including having the fastest decline in TB incidence in the world compared to other WHO regions and a TB burden among the lowest in the world. Yet, TB still poses a public health threat in most countries of the WHO European Region, particularly high-priority countries,¹ and the Region has the highest rates of drug-resistant TB.

The *Tuberculosis surveillance and monitoring in Europe 2020* report shows an increasing trend in extensively-drug-resistant TB (XDR-TB) and that the treatment success rate of new and relapse TB cases, as well as some multidrug-resistant TB cases, are still below global and regional targets.

In order to provide equitable access to quality treatment and continuum of care for all people with TB, the Tuberculosis Action Plan for the WHO European Region specifically addresses the use of palliative care services for TB patients.

The traditional understanding of palliative care is that it is only instituted in the terminal phase of an illness, once life-prolonging or curative treatment has ended (1). However, the current meaning of palliative care is care that aims to relieve suffering in all stages of disease and does not have to be limited to end-of-life care. Palliative care may be provided along with curative or life-prolonging treatments. WHO defines palliative care as services that are designed to prevent and relieve suffering for patients and families facing life-threatening illness, through early management of pain and other physical, psychosocial and spiritual problems (2).

According to estimates, over 4.4 million people who died in Europe in 2014 experienced serious health-related suffering and needed palliative care, while only 14% of these people had access to palliative care (3,4).

In 2000, palliative care was included in the United Nations International Covenant on Economic, Social and Cultural Rights, which states: “States are under the obligation to *respect* the right to health by, *inter alia*, refraining from denying or limiting equal access for all persons ... to preventive, curative and palliative health services” (5). Later, in 2012, a declaration on palliative care and multidrug and extensively drug-resistant TB (M/XDR-TB) was developed with the involvement of leading experts in the field (6,7). The sixty-seventh World Health Assembly passed a resolution appealing to Member States to incorporate palliative care services into the mainstream health care system (8). WHO identified drug-resistant TB as one of the most common conditions in adults requiring palliative care (9). Breathlessness, pain and worry, as well as the need for psychological

¹ The 18 high-priority countries in the WHO European Region are: Armenia, Azerbaijan, Belarus, Bulgaria, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, the Republic of Moldova, Romania, the Russian Federation, Tajikistan, Turkey, Turkmenistan, Ukraine and Uzbekistan.

advice and social support, are some of the most burdensome palliative care problems experienced by patients with drug-resistant TB (10,11).

In 2016, WHO released its first guide on palliative care: Planning and implementing palliative care services: a guide for programme managers (12); followed in 2018 by guidelines outlining how to integrate palliative care into primary health care. These guidelines provide the Essential Package of Palliative Care for Primary Health Care and describe how to implement palliative care within primary care in a way that strengthens health care systems (13). Following implementation of the Tuberculosis Action Plan for the WHO European Region 2016–2020, available published sources of information from the Region were reviewed with the results reflected in this publication. This report also includes information shared by national TB programmes and reports on other TB projects in the Region.

Palliative care for TB

Overview

TB is, and should be, a curable disease; however, each year an increasing number of patients acquire or develop drug-resistant TB, which has a much lower cure rate (14,15). While the expectations are to have increasing numbers of treatment success rates, a proportion of patients will always require some form of palliative care. The availability of palliative care should not replace the intention to treat successfully all patients, which means that both palliative care and pathognomonic treatment should be presented and available for patients. Patients with drug-resistant TB have a high prevalence of symptoms; hence, staff caring for these patients should have some familiarity with palliative care, so that general palliative care principles are available to all patients (16,17). The timely identification, and addressing, of adverse events occurring during the treatment course is considered as general palliative care for those receiving curative treatment. Comprehensive guides on management of adverse events emerging throughout curative treatment of drug-resistant TB can be found elsewhere (18,19). A general palliative care approach is used in settings and services that occasionally treat palliative care patients, but do not provide palliative care as the main focus of their work (20). Specialist palliative care is provided by specialized palliative care professionals who treat patients with more complex problems.

The expansion of drug resistance to the drugs used to treat TB has ushered in an era of programmatically incurable TB in which insufficient effective drugs remain to construct a curative regimen (21). The availability of newer drugs, such as bedaquiline and delamanid, has not solved this problem and resistance to both medicines in the same patient has already been reported (22). The constant presence of HIV, which is permanently fuelling the TB epidemics, should always be considered, as TB/HIV coinfection and especially the combination of drug-resistant TB and HIV significantly deteriorates the treatment outcomes. All services mentioned in this publication should be equally applied to any category of TB patients, including children, patients with coinfections and comorbidities like TB/HIV coinfection, diabetes etc.

While there is no single indicator that determines whether treatment is failing, a point will be reached when it is clear that the patient is not going to improve. Signs that indicate treatment failure include (17):

- persistent positive smears or cultures after eight months of treatment;
- extensive and bilateral lung disease with no option for surgery;
- high-grade resistance with no option to use additional agents; and
- deteriorating clinical condition, usually including weight loss and respiratory insufficiency (17,23).

Termination of treatment should be considered in the following circumstances (17).

- The patient no longer consents to treatment.
- There is negligible chance of success, even when the patient wishes the treatment to continue. This would apply to those who are chronic defaulters, for whom the treatment may not be effective and may result in amplification of resistance or treatment failure, and in patients with advanced terminal disease.

Decisions on treatment discontinuation should always be made by a multidisciplinary team, which should include the individuals being treated and their support network (21). Any patient whose treatment is discontinued should be eligible to receive specialized palliative care services. At the time of initiation of palliative care services, a comprehensive assessment should be conducted to identify the patient's current problems and needs, and a care plan developed according to need. For patients with a high symptom burden and a deteriorating condition, the care plan and service delivery should begin immediately (17).

Some TB patients die within several weeks of withdrawal of active treatment; however, many survive for months or years (24). The five-year survival rate for XDR-TB is 23% (25). This survival rate aligns with the TB mortality rate from prechemotherapeutic times of approximately 50%, with about 25% of TB cases having chronic disease (24,26,27).

TB, and M/XDR-TB, is a contagious disease and, if not treated properly, threatens the people surrounding the infected person, including health care workers and patients' families (17). Due to the risk of infection, TB patients are often abandoned by their families and it is difficult to employ and retain staff for provision of palliative care.

The development of TB and M/XDR-TB, the progress of the disease and the major medical and nonmedical factors of unsuccessful treatment outcomes are closely connected to lifestyle, tobacco smoking, alcohol and drug addiction, malnutrition, lower levels of education, social marginalization and poverty (28,29). Therefore, antisocial behaviour is frequently seen in people whose TB and M/XDR-TB treatment has failed. Discharging patients whose treatment has failed into the community, along with the challenges in organization of medical care, can cause socioeconomic

problems for patients. These patients often do not have anywhere to live due to the lost links with family, and community residential facilities often decline access because of concerns about infection control. Patients may end up living in single rooms with many other family members (24). Patients with advanced illness, and their caregivers, frequently experience profound financial and social strain (30).

For untreatable or dying patients with drug-resistant TB, one immediate requirement is the provision of community residential and palliative treatment care facilities, by adapting existing structures if necessary, to prevent continuing transmission within hospitals and communities (24). Such facilities should be available not only for dying patients, ensuring that their end of life occurs in a safe and dignified setting, but also for people for whom treatment has failed to provide them somewhere that they could reside on a long-term voluntary basis. These facilities would provide social, educational and recreational opportunities and would also be places where patients would receive good nutrition and care from support groups and multidisciplinary teams in an infection-controlled setting. These facilities would reduce transmission within the community and to family members, including children (24).

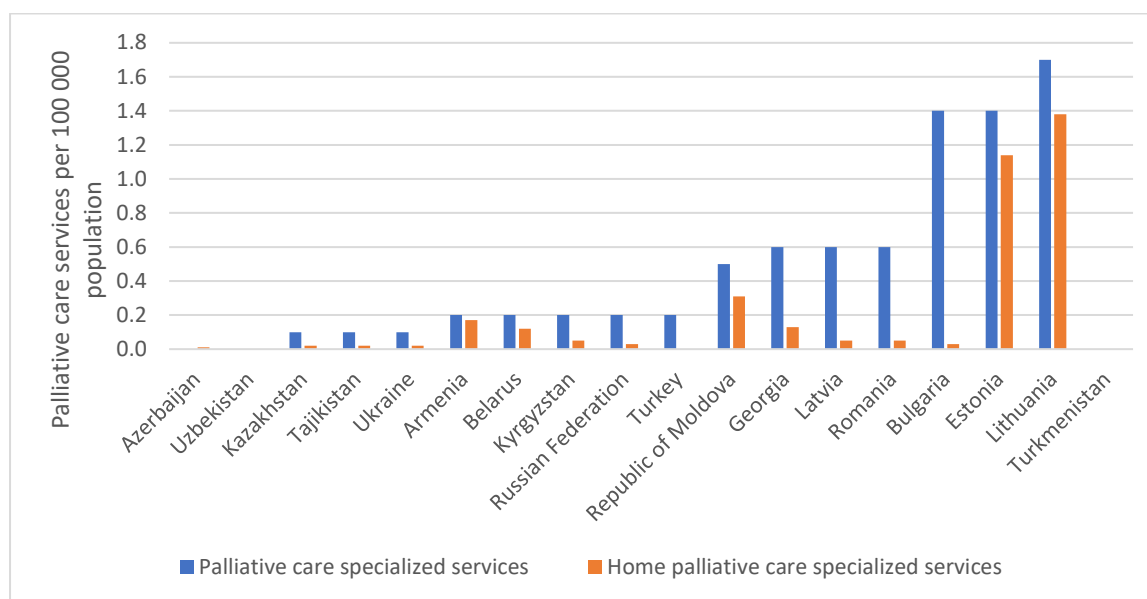
Palliative care provision models

It is helpful to distinguish between a generalized palliative care approach and the provision of specialized or formal palliative care services. All TB professionals should be familiar with basic palliative care principles and symptom management and should use these skills while caring for their patients (17). When a patient has difficulty managing symptoms, or reaches the point where TB treatment is ended, it may be best to offer a transition to specialized palliative care services.

Overall, palliative care provision models may differ between countries (31). Specialized palliative care services may be available in the community or may be provided within government-run TB facilities and programmes. A specialized service should have an interdisciplinary team and should meet the standards required of palliative care operations. Home care teams work in patients' homes or long-term care facilities, in collaboration with basic health teams or nursing home staff (4). Alternatively, care can be provided in hospitals in separate palliative care units, or through mobile teams or consultation services, often referred to as hospital support teams. There may be palliative care units in highly specialized hospitals (4). There are also mixed models in which resources are combined. Palliative care teams in the hospice and community must be prepared to implement infection control guidelines when needed (32).

It is generally recommended that two specialized palliative care services (one home care team and one hospital team) are available for every 100 000 inhabitants (4). However, the availability of palliative care services in the 18 high-priority countries for TB in the WHO European Region is much lower than that figure (33) (Fig. 1 and Table 1).

Fig. 1. Availability of palliative care services in the 18 high-priority countries for TB in the WHO European Region



Source: European Association for Palliative Care (EAPC) Atlas of Palliative Care in Europe 2019 (4).

Table 1. Selected data on adult palliative care services in the 18 high-priority countries for TB in the WHO European Region

Country	Inpatient hospices	Inpatient units in hospitals /hospital support teams	Home teams	Adult palliative care services per 100 000 inhabitants
Armenia	1	1	5	0.2
Azerbaijan	0	0	1	0.01
Belarus	9	0	11	0.2
Bulgaria	47	9	44	1.4
Estonia	0	3	15	1.4
Georgia	2	15	5	0.6
Kazakhstan	8	0	4	0.07
Kyrgyzstan	4	5	3	0.2
Latvia	0	11	1	0.6
Lithuania	1	9	39	1.7
Republic of Moldova	3	5	10	0.5
Romania	10	103	9	0.6
Russian Federation	63	0	258	0.2
Tajikistan	0	7	2	0.1
Turkey	10	153	1	0.2
Turkmenistan	–	–	–	–
Ukraine	7	53	6	0.1
Uzbekistan	–	–	–	–

Source: EAPC Atlas of Palliative Care in Europe 2019 (4).

Only some countries report that no national funding is available to support the provision of palliative care. Funding models vary from grants and loans to the receipt of annual national support via various methods: some countries have a contract with the national health fund and get donations for hospices; others report having regional economic rates from regional health and social care funds (4).

The availability of policy documents on palliative care for the 18 high-priority countries for TB in the WHO European Region varies significantly and requires further development (Table 2). Of these countries, only Armenia has a national law on palliative care (4). In Bulgaria, palliative care has been included in the basic health care package but only for patients with oncological diseases (4).

Table 2. Selected data on palliative care for the 18 high-priority countries for TB in the WHO European Region

Country	National laws specific to PC	National legislation or decrees relating to PC	National legislation on end-of-life care	National general law on health care with reference to PC	National PC plan or strategy	Allocated funds from national health budget for PC	Inclusion of PC in list of health services provided at primary care level	Inclusion of PC in basic package of health services
Armenia	Yes	Yes	No	Yes	Yes	Yes	No	Yes
Azerbaijan	No	No	No	Yes	No	Yes	Yes	Yes
Belarus	No	Yes	No	Yes	No	Yes	Yes	Yes
Bulgaria	No	No	No	Yes	No	Yes	Yes	Yes
Estonia	No	Yes	Yes	No	No	No	Yes	No
Georgia	No	Yes	Yes	Yes	No	Yes	Yes	Yes
Kazakhstan	No	Yes	No	Yes	No	Yes	Yes	Yes
Kyrgyzstan	No	No	No	Yes	Yes	Yes	Yes	Yes
Latvia	No	Yes	No	Yes	No	Yes	Yes	Yes
Lithuania	No	Yes	No	No	No	Yes	Yes	Yes
Republic of Moldova	No	Yes	No	Yes	No	Yes	Yes	No
Romania	No	Yes	No	Yes	Yes	Yes	Yes	Yes
Russian Federation	No	No	No	Yes	Yes	Yes	Yes	Yes
Tajikistan	No	No	No	Yes	Yes	Yes	–	No
Turkey	No	Yes	No	Yes	Yes	Yes	Yes	Yes
Turkmenistan	–	–	–	–	–	–	–	–
Ukraine	No	Yes	No	Yes	No	Yes	Yes	Yes
Uzbekistan	No	Yes	No	Yes	Yes	No	–	–

Note: PC – palliative care.

Source: EAPC Atlas of Palliative Care in Europe 2019 (4).

Information on successful models of integrating palliative care into TB treatment is very rare. There is some literature on the ongoing work towards improving the palliative care in high-burden TB countries (34,35). Ideally, palliative care for TB patients should be linked with local palliative care and

hospice teams (36). However, low access to and availability of palliative care overall in these 18 high-priority countries inevitably contribute to challenges in organization of palliative care for TB patients. Delivery of palliative care from within respiratory clinical services by existing staff with additional training, with clear referral criteria to palliative care specialists for complex cases, is established in a few countries worldwide (36,37). In South Africa, for example, patients with TB or M/XDR-TB can be provided with palliative care at home, in palliative TB care hospices, in palliative care facilities, in TB hospitals and/or general hospitals or in primary health care facilities (17).

The best ways to organize palliative care in general, and palliative care for TB patients in particular, is still under discussion (20). It is also understood that integrated palliative care needs should be addressed at a number of distinctive levels; for example, the integration of palliative care into treatment guidelines, interdisciplinary collaboration between professionals, the integration of the supportive role of informal caregivers, and the integration of community care and institutional care arrangements (20).

How to ensure best practice in integrated palliative care

A recently published study on integrated palliative care identified excellent examples of palliative care in Europe, and included recommendations on how to ensure best practice for the integration of palliative care (31). These recommendations may also be relevant for the establishment of best practices in palliative care for TB.

Best practices treat patients and their families as whole persons. Inability to work and associated financial constraints, challenges with maintaining valued roles within the family and the community, as well as exhaustion of family/caregivers, can all contribute to social suffering.

Best practices develop integrated care plans and pathways. Frequently, the integration of palliative care was achieved via multidisciplinary meetings or service collaborations. Pathways create the ability to structure the caregiving process and to allocate roles and responsibilities that may stimulate advance care planning.

Best practices integrate palliative care via informal relationships but subsequently provide more formal structures. Palliative care initiatives often started with a lot of volunteering and pioneering by professional caregivers. Palliative care needed to find its position in the medical domain, the nursing domain and the social care domain. To achieve this, informal relationship building is pivotal to integrate and connect palliative care to better established disciplines and services. For example, it is necessary to start up multidisciplinary patient meetings, to establish referral patterns and to connect hospice, home and hospital care for patients with advanced and progressive illnesses. This can be rewarding but also exhausting when the network grows, with a risk that these informal relationships are only accessible via the mobile phones of a few palliative care leaders. In addition, standardization of work processes may be lacking; for example, there may be too many informal streams of information between professional palliative caregivers and other health care professionals, and a lack of systematically organized shifts and on-duty calls for patients' visits. To become best practice, therefore, informal relationships need to be transformed into more formal patterns and structures,

which include agreed frameworks of care quality and mechanisms to transfer information and patient referrals.

Best practices have to develop an integrated workplan on human and financial resources. The work overload of palliative care professionals continues to be a cause for concern. Work overload may be the result of several factors, including inefficient work patterns, lack of educated professionals or lack of budget to attract sufficient numbers of employees. Unfortunately, all of these can limit the integration of palliative care. Funding is an essential resource for palliative care. Budget shortages can put pressure on employees, which can leave them exhausted. Most initiatives are confronted with health system limitations when they cross the borders between home care, hospice care and hospital care. Some initiatives overcome this by finding creative ways to integrate palliative care in the health system by combining several budget sources; some raise project funding and others find private donations.

Best practices integrate palliative care in society as a visible locus of action. Palliative care needs to be visible in the community. If a palliative care initiative is known in a region for having the expertise and knowledge on palliative care, it will become a natural focus for all palliative care activities in that region, and will become a central, visible hub in the regional care network. Europe has a specific need for exemplary models of palliative care for TB patients, especially in the 18 high-priority countries.

Best practices are open to future sustainability. In the short term, barriers to integrated care may be fixed. In the long term, however, many of these variables could change. A current lack of educated professional caregivers, for example, can be influenced in the longer term by the provision of more education activities. Ongoing pressure in the political field can help for countries in which a lack of regulations is a barrier. Best practices can often take a long time to achieve; they do not appear immediately but are gradually built upon previous experiences and results.

Best practices promote integrated access to palliative care facilities for all patients in need. Current regulations and funding for palliative care are often directed towards end-of-life care for cancer patients. Patients often require prognostication (e.g. life expectancy of less than six months) for access to palliative care facilities in many, but not all, European countries. Access to palliative care teams is severely limited by these restrictions. For patient groups whose prognostication is more difficult, including patients with TB, no promising practices have been identified in Europe.

Best practices act on different levels simultaneously. Professionals and policy-makers that want to foster palliative care integration have to take into account several dimensions: (i) the holistic approach to the needs of patients and their relatives; (ii) the professional and family caregiver network that supports the patient; (iii) the operational procedures that organize work structures, including shifts, out-of-hours arrangements, budgets and human resources; (iv) the organizational arrangements between social care, home care, hospice care and hospital care needed to create a visible space for a palliative care hub; and (v) the national or regional health system policy (regulations, health insurance, funding) that supports access to palliative care for all who need it.

Integrated palliative care requires leadership. Connecting caregivers from several disciplines may create an administrative and bureaucratic problem of its own. This is particularly the case when palliative care needs to be delivered across home care, hospice care and hospital care, where each sector has their own policies and regulations. Palliative caregivers should ensure that all professionals, settings and bureaucracies stay focused on the needs of the patients. A deep understanding of the palliative patient population and the local health care system is needed, together with the courage to develop new and sometimes unexpected care arrangements. The integration of palliative care is also, therefore, a matter of creative leadership. A strong motivation to develop palliative care is pivotal, as it requires endurance and patience. Best practices need the *best* leaders. But, rather than a strong hierarchical leadership, best practices in palliative care need creative and collaborative leadership that gets people together in a place where they can flourish, to build networks, to informally influence people and structures, and to keep the needs of patient and family at the forefront of care. These sorts of leadership skills can be found in several professions, including medicine, nursing and other allied health care professionals.

Professional education

The lack of proper palliative care education and training opportunities in the palliative medicine field has been repeatedly identified as a barrier to the development of the discipline. Across Europe, there is significant diversity in capacities to provide palliative care education to doctors and nurses (4) (Table 3). Of the 18 high-priority countries for TB in the WHO European Region, Azerbaijan, Belarus and Uzbekistan still do not have national palliative care organizations.

Table 3. Selected data on palliative care education for the 18 high-priority countries for TB in the WHO European Region

Country	Medical schools teaching PC	Nursing schools teaching PC	Specialization in palliative medicine	National PC association
Armenia	0/4	0/10	Yes	Armenian Pain Control and Palliative Care Association
Azerbaijan	2/2	7/7	Yes	No
Belarus	8/15	0/16	Yes	No
Bulgaria	6/6	9/10	No	Bulgarian Long-term and Palliative Care Society
Estonia	1/1	0/2	No	Pallium
Georgia	8/13	2/3	Yes	Georgian National Association for Palliative Care
Kazakhstan	5/11	0/63	No	Kazakhstan Association for Palliative Care
Kyrgyzstan	–	27/27	No	Association for Palliative and Hospice Care in Kyrgyzstan
Latvia	2/2	2/2	Yes	Children's Palliative Care Society
Lithuania	0/2	7/9	No	Lithuanian Association of Palliative Medicine
Republic of Moldova	1/1	5/5	No	National Association of Palliative Treatment
Romania	6/12	6/12	Yes	Romanian National Palliative Care Association
Russian	62/62	425/425	Yes	Russian Association of Palliative Care

Country	Medical schools teaching PC	Nursing schools teaching PC	Specialization in palliative medicine	National PC association
Federation				
Tajikistan	2/2	11/11	No	National Palliative Care Association of Republic of Tajikistan
Turkey	1/98	0/138	Yes	National Palliative Care Association of Turkey
Turkmenistan	–	–	–	–
Ukraine	1/17	6/108	Yes	All-Ukrainian Association of Palliative and Hospice Care
Uzbekistan	–	–	No	No

Note: PC – palliative care.

Source: EAPC Atlas of Palliative Care in Europe 2019 (4).

Given the marked shortage of trained palliative care professionals in proportion to the potential requirement for inpatient, outpatient and home palliative care services, there is a critical need to refine the utilization of subspecialty palliative care services (38).

Resource-limited settings may require different approaches.

- Primary palliative care curricula for non-palliative care specialists and primary care clinicians help to ensure that clinicians have the training needed to manage pain and symptoms and discuss care goals with patients and families (39).
- Palliative care telehealth consultation and education can help rural providers deliver care. The Project ECHO (Extension for Community Healthcare Outcomes) model has been successful in delivering geriatric care education and consultation to rural providers (40). This model is currently being adapted to provide palliative care education and indirect consultation, thus allowing basic palliative care services to be provided to populations that would otherwise have minimal access (41,42).
- Limited consultation visits (usually limited to one to two initial visits, with potentially more visits in the future depending on outcomes) might suffice if focus is needed on a specific issue. In this model, the consulting clinician would make specific recommendations that would then be implemented by the primary treating team (38).

All health workers should receive at least a basic training in palliative care to enable them to undertake routine assessment of patients with TB and to provide symptom control and support for their problems (36). In addition, TB programmes should take advantage of palliative care education providers and national palliative care associations already available in the country for establishment of relevant capacities in TB services.

The basic course on palliative care for professionals includes the following modules (17):

- introduction to palliative care and WHO policy on palliative care and TB
- human rights
- palliative care assessment
- drug-resistant TB treatment and palliative care

- breaking bad news
- ethics
- psychosocial and spiritual issues and effective communication
- pain assessment/management and treatment of adverse effects
- dyspnoea treatment
- nausea treatment
- dermatology
- constipation and gastrointestinal symptoms
- delirium management
- haemoptysis management
- anxiety and depression treatment
- infection control
- burnout prevention
- grief, loss and bereavement support
- community engagement.

Patient assessment in palliative care

This section provides a brief overview of palliative symptoms specific to pulmonary TB and describes approaches to the management of symptoms and conditions associated with patients in need of palliative care. It should not be considered as providing instructions for management. For clinical guidelines on palliative symptom assessment and management, health care professionals should refer to the palliative care association of the relevant country.

It is particularly important for families and carers that health care professionals take a holistic approach to care involving a wider assessment of the patient, including psychological, social and spiritual needs, as well as any physical symptoms that may be present (43).

Assessments should consider the specific symptoms of pulmonary TB, which are the most common symptoms among patients, including cough, haemoptysis and shortness of breath, as well as the nonspecific symptoms that are common for any site of TB, including fatigue and malnutrition, night sweats, and types and levels of pain. Moreover, assessments focused on palliative care should detect the main physical symptoms, and emotional, psychological and spiritual questions, as well as any family or social problems (44). Initial assessments allow comprehensive palliative care plans to be created for patients (17).

A number of validated multiple-symptom assessment tools are in wide usage in palliative and end-of-life care settings, including the Revised Edmonton Symptom Assessment Scale (45), the Memorial

Symptom Assessment Scale (46) and the Rotterdam Symptom Checklist (47). Each identified symptom should be further investigated and, potentially, addressed. Instruments are available that focus only on one symptom, such as dyspnoea or pain, such as the Brief Pain Inventory (48). However, detailed instruments such as these are not available for all symptoms, and patients may not be able to answer multiple questions from many instruments (49). To optimize time management, patient-completed pre-consultation assessment forms can be utilized. An example of such a form is the PEACE tool that assesses the Physical, Emotive, Autonomy, Communication, Economic and Transcendent domains (50).

The palliative care programme for TB patients in South Africa uses the Palliative Performance Scale version 2, which is intended for use by any health care professional to measure a patient's performance status (51).

Symptoms and conditions

Pain

Access to pain medication

Opioids are the most widely recommended pain and shortness of breath relief medicines in palliative care. Seven opioids are included in the WHO essential medicines list (codeine, oral morphine immediate release, oral morphine controlled release, injectable morphine, oxycodone immediate release, oral methadone and transdermal fentanyl) (52). However, fewer than three are routinely available in institutions and pharmacies (53). There are several barriers to access.

- **Outdated health care policies discouraging use and administration.** Globally, over 80% of countries have strict policies governing access to pain medications, which serve as substantial barriers to patients. These includes restrictions on types of hospitals, and even wards, where opioids can be administered, the dose and time interval allowable by a single prescription, and the type of health care provider that could prescribe these agents.
- **Administrative barriers.** Even where these agents are available, the process by which patients procure opioids can be a significant barrier, including the paperwork required to prescribe, the cost of agents (often not subsidized by the government) and the limits on the dose that can be prescribed.
- **Lack of provider education and empowerment.** There is a worldwide lack of education on safe prescription of pain medications, which may lead to discomfort among providers on how to safely prescribe these drugs.
- **Cost of medicines.** Findings of the Opioid Price Watch indicate that compared with the international reference price (US\$ 0.47 per dose), the median price of a morphine oral solid immediate-release tablet (10 mg) is 5.8 times higher in low- and middle-income countries than in high-income countries (54).

There is a wide difference in access to opioid medicines in the WHO European Region, with problems related to availability, affordability and prescription limitations (4). Table 4 has an overview of the availability of opioids in the 18 high-priority countries.

Table 4. Selected data on opioid availability in the 18 high-priority countries for TB in the WHO European Region

Country	General availability of oral morphine (immediate release)	Special prescription form for opioids	Prescription limits	Patient registration as an opioid user	Professionals allowed to prescribe
Armenia	No	Yes	Few days	Yes	All physicians
Azerbaijan	No	Yes	Few weeks	No	All physicians
Belarus	Yes	Yes	Few days	No	All physicians
Bulgaria	No	Yes	Few weeks	No	All physicians
Estonia	Yes	Yes	Few weeks	No	All physicians
Georgia	No	Yes	Few days	Yes	All physicians
Kazakhstan	Yes	Yes	Few weeks	No	All physicians
Kyrgyzstan	Yes	Yes	Few days	–	–
Latvia	Yes	Yes	Few weeks	No	All physicians
Lithuania	No	Yes	Few weeks	No	All physicians
Republic of Moldova	Yes	Yes	Few weeks	No	All physicians
Romania	Yes	Yes	No limit	No	All physicians
Russian Federation	No	Yes	Few weeks	No	All physicians
Tajikistan	–	Yes	Few days	No	–
Turkey	Yes	Yes	Few weeks	No	All physicians
Turkmenistan	–	–	–	–	–
Ukraine	Yes	Yes	Few weeks	No	All physicians
Uzbekistan	–	–	–	–	–

Source: EAPC Atlas of Palliative Care in Europe 2019 (4).

Assessment and management

Pain may have various origins in patients with TB and M/XDR-TB; that is, pain can be associated with the organ affected by TB and can occur for other reasons. The causes of pain in the event of TB or M/XDR-TB can be (17):

- pulmonary or pleural inflammatory infiltration, or infiltration of other internal organs
- muscle tension due to severe cough
- bone pain due to TB infiltration in the vertebral column or bones
- pain caused by arthralgia or septic arthritis.

As pain is subjective; self-report is considered to be the gold standard and the most accurate measure of pain. Assessment recommendations are as follows (55):

- all patients should be screened for pain at every contact; and
- pain intensity must be quantified, documented and the quality characterized by the patient, whenever possible.

The PQRST pain assessment method,² which includes the numeric Pain Rating Scale, helps to accurately assess, describe and document a patient's pain, which is important for determining the appropriate treatment options and for evaluating the response to treatment (19).

The recommendations of the European Society for Medical Oncology for analgesic choice according to pain severity are (56):

- **mild:** acetaminophen (paracetamol) and/or a nonsteroidal anti-inflammatory drug (NSAID) are agents that are also effective as adjuncts for treating more severe pain, at least in the short term and unless contraindicated;
- **mild to moderate:** weak opioids such as codeine, tramadol and dihydrocodeine, in combination with non-opioid analgesics;
- **moderate to severe:** oral morphine; and
- **neuropathic pain:** vitamin B6 (pyridoxine) 100 mg and tricyclic antidepressants (amitriptyline 25 mg before bed).

Although oral administration is advocated, patients presenting with severe pain that needs urgent relief should be treated and titrated with parenteral opioids, usually subcutaneous (SC) or intravenous (IV) (56).

Recommendations regarding alternative strong opioids include the following.

- Oral hydromorphone or oxycodone (immediate release and modified release) and oral methadone are effective alternatives to oral morphine; however, methadone should be initiated by physicians with experience and expertise in its use.
- Transdermal fentanyl and transdermal buprenorphine are best reserved for patients whose opioid requirements are stable, and are usually the treatment of choice for patients who are unable to swallow, have poor tolerance of morphine or poor compliance.
- Buprenorphine has a role in the analgesic therapy of patients with renal impairment and who are undergoing haemodialysis treatment.

For opioid-tolerant patients who have breakthrough pain of intensity ≥ 4 (on a scale of 0–10) or whose goals of pain control and function are not met, management is as follows (56).

- Administer a rescue dose of a short-acting opioid, equivalent to 10–20% of the total long-acting or regularly scheduled oral opioid dose taken in the previous 24 hours.
- Assess efficacy and adverse effects every 60 minutes for oral opioids and every 15 minutes for IV opioids.
- If pain assessment is unchanged or increased, increase the rescue dose by 50–100%.
- If the pain score decreases, repeat the opioid dose and reassess at 60 minutes for oral opioids and 15 minutes for IV opioids.

² The PQRST method is Provocation/Palliation, Quality/Quantity, Region/Radiation, Severity Scale and Timing.

- If the pain score remains unchanged after two to three cycles, consider changing the route of administration from oral to IV or explore alternative management strategies.
- If the pain score decreases to 0–3, give the current effective dose as needed over 24 hours before proceeding to subsequent management strategies.
- Ongoing need for repeated rescue doses may indicate a need for adjustment of the regularly scheduled opioid dose.
- Consider rapidly acting transmucosal fentanyl for brief episodes of incident pain not attributed to inadequate dosing of around-the-clock opioids.

Subsequent management is based on the continued pain rating score and includes the following:

- regular doses of opioids, with rescue doses as needed
- management of constipation
- social support and education for patients and families.

For ongoing care, if an acceptable level of comfort and function has been achieved and the patient's 24-hour opioid requirement is stable, convert to an extended-release oral medication (if feasible) or another extended-release formulation (e.g. transdermal fentanyl).

Cough

In the case of pulmonary TB, cough is persistent. During the course of the disease, bloody sputum or haemoptysis may occur. Nevertheless, cough may be caused by other reasons, including nonspecific pulmonary infections, influenza, chronic bronchitis and bronchiectasis, pulmonary tumours (Kaposi sarcoma, non-Hodgkin lymphoma in HIV-positive patients with TB), aspiration, sinusitis following treatment with nasal drops, reflux, spontaneous pneumothorax etc. (17). The cough reflex may reduce if treated with opioid antitussive drugs and opioid analgesics, such as morphine. A sodium cromoglicate inhaler may prevent cough in patients with TB (17).

For cough caused by mucus hyper-production, the following may be used (17):

- steam inhalations; and
- if the volume of sputum exceeds 30 ml per day, forced expiration techniques with postural drainage should be applied.

For watery mucus consider using:

- hyoscine 10 mg every eight hours; or hyoscine butylbromide 20–120 mg in oral doses taken at certain intervals, or via continuous SC infusion;
- a scopolamine transdermal patch 1.5 mg, 1–3 patches applied every 72 hours or glycopyrrolate (0.2 mg SC every 4–6 hours or 0.2–0.4 mg orally every eight hours); and
- antihistamines, for example diphenhydramine, 25–50 mg, every 4–6 hours.

For cough caused by bronchial spasm, bronchodilators (e.g. salbutamol inhaler), or inhaled or systemic corticosteroids may be used.

For cough caused by gastric reflux, proton-pump inhibitors (omeprazole) or H₂-receptor antagonists (ranitidine) should be used.

For dry, non-productive cough the following may be considered:

- a general cough mixture; and
- codeine 10–20 mg every four hours; dextromethorphan, 25 mg or more times a day, morphine, starting from 2.5 mg every four hours; and
- lidocaine inhalation 3–5 ml 2% solution (without epinephrine) 3–4 times a day or bupivacaine 0.25% (5 ml) 3–4 times a day; inhalations should not be made before or within one hour after eating or drinking.

For productive cough in patients who cannot cough effectively consider using:

- inhalations with 2.5% saline solution, 5 ml every 2–6 hours, or humidifying
- mucolytics: acetylcysteine, bromhexine.

For productive cough in weak patients:

- codeine 10–20 mg every four hours, not more than 60 mg a day
- morphine 2.5–5 mg every four hours.

Haemoptysis

Haemoptysis is a particularly alarming symptom for both patients and their relatives and usually requires immediate counselling by health care workers or referral to a specialized hospital. Haemoptysis is usually caused by TB; however, it can also be related to bronchitis, thromboembolism or tumours. Usually haemoptysis requires emergency care; however, in the case of palliative care, procedures such as intubation, bronchoscopy and bronchial artery embolization are not recommended. Instead, the use of strong opioids and midazolam or diazepam is recommended to reduce fear and anxiety (58).

The use of red towels and dark-coloured sheets and blood collection containers can calm patients with severe haemoptysis down (59). The dark colour makes blood less noticeable, which, in turn, makes the patient and family less stressed. If the patient has a high risk of bleeding, or a fear of secondary asphyxia due to haemoptysis, it is useful to have a syringe prefilled with short-acting benzodiazepines, such as midazolam or lorazepam. The families must be aware of a possibility of excessive bleeding and must be instructed on how to inject a tranquillizing agent, if there is a need to mitigate the patient's suffering.

Shortness of breath

Shortness of breath often causes anxiety in patients and people who take care of patients.

The most effective drugs for treatment of shortness of breath are opioid analgesics such as morphine (17). Respective doses of opioid analgesics can reduce the intensity of shortness of breath without reducing breathing rate. Patients taking opioids will have less shortness of breath, yet they may have rapid breathing. This information must be conveyed to the families since relatives may interpret tachypnoea as a sign of shortness of breath.

For symptomatic relief, the following interventions may be used, as appropriate (57,60):

- temporary ventilator support for severe, reversible conditions;
- oxygen therapy;
- benzodiazepines for anxiety;
- increasing ambient airflow directed at the face or nose;
- providing cooler temperatures;
- promoting relaxation and stress reduction; and
- providing educational, emotional and psychosocial support for patients and family caregivers, and referring to other disciplines as appropriate.

For patients with a life expectancy of weeks to days, the recommendations are as follows:

- reduce excessive secretions with scopolamine, hyoscyamine or atropine
- implement oxygen therapy, if the patient reports subjective relief with it
- institute sedation as needed
- discontinue fluid support
- consider low-dose diuretics if fluid overload may be a contributing factor.

Anorexia and fatigue

This is one of the most frequent problems in TB patients (17). Increased food intake cannot solve the problem of significant TB-related weight loss since cachexia (extreme emaciation) is a syndrome caused by metabolic disorders. TB-associated cachexia is not a result of ordinary calorie imbalance and rarely responds to aggressive parenteral or enteral nutrition. It is important to manage the symptoms of pain and depression in addition to fatigue and cachexia.

The social values of food must be maintained even if patients only consume very small amounts of food (57). Families should be provided with information that patients are not starving, but that they are suffering from the expected metabolic effects of TB.

- Psychostimulants and antidepressants may be useful in managing subjective symptoms of fatigue.

- Patients with anaemia may be helped with blood transfusions, if available.
- Prednisolone 5–15 mg a day, up to six weeks, can be useful in the event of severe anorexia and asthenia (61).
- Vitamin B1 should be administered daily since it plays a core role in production of energy from carbohydrates and is involved in production of RNA and DNA.
- In the event of nausea and vomiting, prescribe antiemetic agents.
- Offer small but frequent portions of the patient's favourite foods; do not force the patient to eat. Food should be taken in small portions until appetite revives.

Nausea

For patients with opioid-related nausea, opioid rotation is an appropriate choice. For patients with gastroparesis, metoclopramide is a reasonable first choice (62). For treatment of nonspecific nausea at the end of life, haloperidol 1 mg orally or 0.5 mg SC/IV every 6–8 hours as needed is recommended (62). The total dose in 24 hours should be limited to no more than 6 mg oral or 3 mg IV/SC. Nausea usually requires lower and less frequent dosing than does delirium (62). Higher doses are associated with more side-effects (62).

If anxiety is thought to an important component, a benzodiazepine may be helpful (62). A corticosteroid such as dexamethasone may be helpful because of its nonspecific effect on the chemoreceptor-trigger zone. Addition of a 5-HT₃ antagonist, such as ondansetron, or an anticholinergic agent, such as scopolamine, or an antihistamine, such as meclizine, could be considered in cases that are refractory to higher haloperidol doses (62).

Psychological and psychiatric care

The availability of qualified mental health professionals, including psychologists, psychiatrists, social workers and counsellors, is limited in the 18 high-priority countries for TB in the WHO European Region. Efforts to fund and recruit staff with these skills is an important part of the integration of palliative care into the TB treatment system (17). An interdisciplinary team is incomplete without the inclusion of mental health professionals.

Delirium

In advanced serious or life-threatening illness, delirium is common, but it is reversible in up to 50% of cases (63). The mnemonic FACT is useful to remember the diagnostic criteria of delirium:

- Fluctuating cognitive deficit(s) with acute onset
- Attention deficits, and either:
- Consciousness level disturbance or
- Thought disorganization.

Several tools are available to screen for delirium, including the Confusion Assessment Method, the Bedside Confusion Scale (ability to recite the months backwards and assessment of consciousness state (64)), use of serial-sevens, and spelling a word such as “farm” or “world” backwards.

Haloperidol is standard therapy for the symptomatic management of medically ill patients presenting with delirium, especially when there is evidence of psychomotor agitation, delusions, or hallucinations (65). Typical doses are 1–2 mg of oral haloperidol or 1 mg SC/IV with repeat doses every two hours until settled, then every 6–8 hours as needed, titrated against symptoms. A 50% dose reduction is appropriate for older adults and in patients with a history of extrapyramidal reactions to neuroleptics or antiemetics. A reasonable alternative to haloperidol for managing delirium is a second-generation antipsychotic, such as aripiprazole, quetiapine, olanzapine or risperidone (65).

For patients with persistent agitated delirium despite the use of haloperidol, a single dose of lorazepam in conjunction with haloperidol rather than haloperidol alone is recommended (65).

Anxiety

Anxiety is common in patients with an advanced serious or life-threatening illness. Anxiety may also be the result of a pre-existing anxiety disorder, substance abuse, delirium or undertreated symptoms, most commonly pain. Significant factors that may exacerbate anxiety include concerns about future symptom control, the course of the disease and progressive loss of autonomy leading to death. A screening item “Are you bothered by feeling nervous, anxious or unable to stop worrying?” can be used. The Hospital Anxiety and Depression Scale is a useful screening tool for anxiety and depression, and is widely used within the palliative care setting (66).

When anxiety symptoms do not interfere with treatment or are not intolerable to the patient, no specific interventions are required beyond the reassuring and empathic responses of staff members (17). Medication or a combination of behavioural and medication therapies should be considered in some cases. Most patients with anxiety or terminal agitation can be comfortably managed with lorazepam, with intermittent doses titrated up as needed (starting at 1 mg orally or SC/IV every six hours as needed) or even as a continuous infusion (62). Delirium can sometimes be mistaken for anxiety, but delirium is better managed with haloperidol (62). In patients with restlessness/agitation, this may be part of a terminal delirium or arise from other psychological or physical distress (62). For practical purposes, it may not be possible to determine the exact cause (62). However, if a patient has been treated for delirium and is still agitated and distressed, the addition of a benzodiazepine such as lorazepam may be helpful (62).

Selective serotonin reuptake inhibitor (SSRI) antidepressants, such as paroxetine, are recommended for the management of generalized anxiety disorder. Doses used are often lower than the doses for depression. The time for effect may be up to six weeks, which may limit their use among palliative care patients. It is also important to warn patients of the potential for an initial worsening of symptoms.

Depression

Mood disorders are frequent in patients with a serious and/or life-threatening illness. As an example, a meta-analysis showed a 25% combined prevalence of all types of depression and a 38% prevalence of mood disorders among palliative care patients (67). In general, abbreviated screening instruments, such as Patient Health Questionnaire-2 (PHQ-2) (68) or a single-item inquiry (“Have you been depressed most of the time for the past two weeks?”) appear to be as effective as longer instruments to screen for depression. Other simple screening strategies for mood disorder and psychosocial distress include PHQ-9 (69).

Psychological therapies can be effective but may need to be brief due to limited life expectancy. Cognitive behavioural therapy has been increasingly used and can improve some outcomes in palliative care (17). Evidence is limited concerning the effectiveness of antidepressant medication in terminally ill patients but they are recommended in moderate to severe depression (61,70). Psychostimulants are very rarely used despite some evidence of benefit (71).

SSRIs (17) that may be used are:

- sertraline 50 mg once daily
- citalopram 20 mg once daily
- paroxetine 20 mg once daily
- fluoxetine 20 mg once daily.

Recommendations are that sertraline and citalopram are well tolerated and should be considered for first-line treatment starting at a low dose and slowly titrating up. SSRIs are less sedative than tricyclic antidepressants and have few antimuscarinic effects, low cardiotoxicity and may have a faster onset of action than the tricyclics. Gastrointestinal side-effects such as nausea are dose-related.

- Fluoxetine in particular may cause restlessness and anxiety and should be used with caution. Consider using a benzodiazepine as a short-term adjunct on commencement.
- Mirtazapine, 15–45 mg oral dose., is an alpha adrenoceptor antagonist and increases central noradrenaline and serotonin transmission. It may increase appetite and cause sedation during initial treatment.

Tricyclic antidepressants that may be considered are:

- amitriptyline 10–150 mg per day
- dosulepin 25–150 mg per day
- imipramine 10–150 mg per day
- lofepramine 70–210 mg per day.

Tricyclic antidepressants may take several weeks to lift depression. Amitriptyline and dosulepin are relatively sedative in comparison with imipramine and lofepramine. They all have anti-muscarinic properties to greater or lesser degrees and therefore may be associated with symptoms such as

hypotension, dry mouth and difficulty in micturition. Doses should gradually be increased to avoid unnecessary side-effects.

Palliative sedation

Palliative sedation refers to use of non-opioid drugs, including benzodiazepines, barbiturates, and propofol, to control refractory symptoms (e.g. pain, dyspnoea, agitated delirium) that have been assessed and treated by an interdisciplinary team (palliative physician, pain expert, psychosocial counsellor and chaplain) and have not responded to conventional symptom management (62).

In 2009, EAPC published guidelines to address the key clinical issues surrounding palliative sedation. The recommendations in the guidelines are intended to be modified to reflect local culture, legal considerations and the specific needs of the home, hospital or hospice-based setting.

The recommendations include the following (72).

- Sedation can be considered for patients with intolerable distress due to physical symptoms and a lack of other methods of palliation.
- Continuous deep sedation should be considered only in the very terminal stages of illness with expected death within hours to days at most.
- Evaluation should be performed by a clinician with expertise in palliative care; whenever possible, evaluation should be multidisciplinary.
- Assessment should include estimates as to whether death is anticipated within minutes to hours, hours to days, days to weeks or longer, and the evaluation of the patient's capacity to make decisions about ongoing care; if decisional capacity is in doubt, evaluation by a psychiatrist may be required.
- For patients with decisional capacity, the aims, benefits and risks of the proposed sedation should be discussed with the patient and preferably with participation of family members.
- For patients lacking capacity to decide, and without advance directives, permission should be obtained from a legally recognized proxy.
- In actively dying patients who have no advanced directive or health care proxy and are in severe distress, comfort measures, including the use of sedation if necessary, is the standard of care.
- If the family members are not participants in the decision process, permission should be sought to inform them of the decision.
- The level of sedation should be the lowest level necessary to provide relief of suffering.
- Intermittent or mild sedation should be attempted first.

The presence of refractory psychological symptoms does not necessarily indicate a far advanced state of physiological deterioration; sedation should be reserved for patients in advanced stages of terminal disease under the following circumstances.

- Symptoms should be designated as refractory only after repeated assessment by clinicians with psychological treatment expertise who have established a relationship with the patient

and family and have attempted routine approaches for anxiety, depression and existential distress.

- Evaluation should be conducted by a multidisciplinary team that includes psychiatrists, chaplains, ethicists and persons providing direct care for the patient.
- In the rare cases in which sedation is appropriate, sedation should be delivered on a respite basis for 6–24 hours with planned downward titration.
- Continuous sedation should be considered only after repeated trials of respite sedation with intensive intermittent therapy.

Initial screening can utilize patient-completed pre-consultation responses, such as the PEACE tool, which specifically queries about these issues in one question (item 15) (50). Additional questions probing socioeconomic distress include the following.

- What kind of help do you need at home? Cooking and shopping? Help with your medications? Getting around the house? Transportation to appointments? Additional equipment or supplies?
- Has your illness created a financial strain on you and your family?
- Do you worry that you may become a burden to your family?

Ethical issues

Treatment discontinuation raises ethical questions about health risks posed by infectious patients to household contacts, close family and to the community (21). Should such patients be confined involuntarily to a health facility to protect third parties from infection (24)? This is the classic trade-off between the rights of the individual (to autonomy, freedom of movement and respect) and that of the community (to an environment that is not harmful to health) (73). Although forced isolation might be a consideration in some settings, this should only be done as a last resort if there is demonstrable evidence of the risk of infection to vulnerable contacts (e.g. children or HIV-positive people) and after all other treatment and infection control options have been exhausted (74).

Minimal set of standards on palliative care in drug-resistant TB care for discussion and development

A minimal set of standards should consider the following:

1. establishment of an interdisciplinary working group on palliative care for TB, which, among other responsibilities, will explore linking and aligning with the local palliative care community;
2. establishment of TB palliative care models acceptable for the country's settings: palliative care in home settings, at a hospice for palliative TB care, in palliative care facilities, in TB hospitals and/or general hospitals, in primary health care facilities with relevant support teams: hospital support teams or home care or long-term care facilities teams; development of standards for

communication and operation within the palliative care network and between various levels of palliative care provision;

3. integration of the supportive role of informal caregivers and integration of community care and institutional care arrangements;
4. identification, advocacy and facilitation of policy updates including preparation/translation/dissemination of clinical guidelines etc.; integration of palliative care into treatment guidelines and interdisciplinary collaboration between professionals;
5. set criteria for referral to palliative care specialists for complex cases and development of a manual on comprehensive needs assessment and individual palliative care plans.
6. establishment of community stay and palliative treatment care facilities with proper infection control measures by adapting existing structures for:
 - (a) dying patients to ensure safe and dignified settings for end of life; and
 - (b) people for whom treatment has failed, where they could voluntarily reside on a long-term basis with social, educational and recreational facilities and would receive good nutrition and care from support groups and a multidisciplinary team;
7. performance of palliative care for drug-resistant TB needs assessment and development of a timed/budgeted national plan for addressing of identified gaps; and
8. establishment of exemplary models of palliative care for drug-resistant TB patients in Europe, specifically in the 18 high-priority countries for TB in the WHO European Region.

Conclusion

Palliative care aims to relieve suffering in all stages of disease. WHO has identified drug-resistant TB as one of the most common conditions requiring palliative care for adults. Breathlessness, pain and worry, as well as the need for psychological advice and social support, are some of the most burdensome palliative care problems experienced by patients with drug-resistant TB. The timely identification, and addressing, of adverse events occurring during the treatment course, is considered as general palliative care for those receiving curative treatment. All TB professionals should be familiar with basic palliative care principles and symptom management and should use these skills while caring for their patients.

Any patient for whom the decision is taken to discontinue treatment should be eligible to receive specialized palliative care services. Whereas some TB patients die within several weeks of withdrawal of active treatment, many survive for months or years. For untreatable or dying patients with drug-resistant TB, one immediate requirement is the provision of community residential and palliative treatment care facilities, by adapting existing structures if necessary, to prevent continuing transmission within hospitals and communities. Such facilities should be available not only for dying patients, ensuring that their end of life occurs in a safe and dignified setting, but also for people for whom treatment has failed to provide them somewhere that they could reside on a long-term voluntary basis. These facilities would provide social, educational and recreational opportunities and

would also be places where patients would receive good nutrition and care from support groups and multidisciplinary teams in an infection-controlled setting. These facilities would reduce transmission within the community and to family members, including children.

General palliative care provision models may differ between the countries. All health workers should receive at least a basic training in palliative care to enable them to undertake routine assessments of patients with TB and to provide symptom control and support for their problems. In addition, TB programmes should take advantage of palliative care education providers and the national palliative care associations already available in their country for establishment of the relevant capacities in TB services. For clinical guidelines on palliative symptom assessment and management, health care professionals should refer to the palliative care association of the relevant country. Attempts should be made to ensure at least the minimal set of standards for palliative care in drug-resistant TB.

Useful free-access resources³

World Hospice Palliative Care Alliance

Country reports and needs assessments. In: Worldwide Hospice Palliative Care Alliance [website]; 2015 (<http://www.thewhpc.org/resources/category/country-reports-and-needs-assessments>).

Laws, regulations and national strategies on palliative care. In: Worldwide Hospice Palliative Care Alliance [website]; 2015 (<http://www.thewhpc.org/resources/category/laws-regulations-and-national-strategies>).

Palliative care toolkits and training manual. In: Worldwide Hospice Palliative Care Alliance [website]; 2015 (<http://www.thewhpc.org/resources/category/palliative-care-toolkits-and-training-manual>).

Standards, clinical guidelines and protocols. In: Worldwide Hospice Palliative Care Alliance [website]; 2015 (<http://www.thewhpc.org/resources/category/standards-clinical-guidelines-and-protocols>).

Clinical guidelines and handbooks on palliative care

Clinical practice guidelines for quality palliative care, fourth edition. Richmond: National Coalition for Hospice and Palliative Care; 2018 (https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf).

Guidance for the management of symptoms in adults in the last days of life. Regional Palliative Medicine Group (RPMG); updated January 2018 (http://www.professionalpalliativehub.com/sites/default/files/RPMG%20End%20of%20Life%20Guidance%202018_0.pdf).

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Palliative Care in partnership. Management of symptoms in palliative care: the role of specialist palliative care allied health professionals. Belfast: Public Health Agency; March 2018 (<http://www.professionalpalliativehub.com/sites/default/files/Management%20of%20Symptoms%20in%20Palliative%20Care%20-%20The%20Role%20of%20Specialist%20Care%20Allied%20Health%20Professionals.pdf>).

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