



Guidelines for Providing Palliative Care to Patients with Tuberculosis

**Hospice
Palliative
Care
Association**
of South Africa



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I am very pleased to be able to introduce the HPCA Guidelines for Providing Palliative Care to Patients with Tuberculosis and thank the contributors:

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And other members of the HPCA TB task team.

The authors have drawn on the WHO STOP TB Initiative and on the South African Department of Health TB control guidelines as well as training material from the Centre for Disease Control (CDC) in developing this tool.

TB is considered to be a curable infection and these guidelines promote early identification of people infected with TB through active case finding, effective treatment of the infection and empathetic support to promote successful completion of treatment. Unfortunately TB is a leading cause of death in patients co-infected with HIV. This makes infection control, intensified case finding, INH preventative therapy and treatment support important in controlling TB in our communities. It is also of the utmost importance that people with advanced TB who are dying from the co-infection, are cared for respectfully with the attention to detail in control of distressing symptoms and provision of emotional and spiritual support. Family support and support of health care workers, including infection control and screening for TB, is also addressed in these guidelines.

The practical advice will be of value for staff and volunteers in hospices and in other health facilities and we hope will provide useful guidance for the compassionate care of people infected with TB – those who will recover as well as those for whom the TB infection proves incurable.

DR LIZ GWYTHYER
CEO of HPCA



no end to caring

Palliative Care is an approach that improves the quality of life of patients and their families facing life-threatening illnesses, 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.

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INTRODUCTION – TB AND PALLIATIVE CARE

Although tuberculosis (TB) is curable, according to the World Health Organisation (WHO) it is the major cause of death in people infected with HIV, many of whom live in the developing world and are poor and malnourished. According to the USAID Report on Infectious Diseases, South Africa has the second highest incidence of TB worldwide with an incidence of 948/100 000¹. In the United States the incidence is 5/100 000. WHO classifies an epidemic as 130/100 000 so the epidemic of TB in South Africa has reached critical proportions. The problem is being exacerbated by an increasing burden of drug resistant TB.

In terms of its definition, the goal of palliative care is to improve the quality of life for people with a life-threatening illness and their family members. HIV infected people with TB, particularly drug resistant TB, clearly fall into this category. Palliative care services contribute to the improvement of the quality of life of people with TB infection, both individually and collectively, through the following activities:

- Making the person feel valued and reducing the stigma associated with TB by providing and modelling respectful, holistic care to the patient and family.
- Limiting the spread of TB by implementing effective infection control in both the home care and in-patient settings.
- Intensifying case finding by identifying people with potential TB infection through regular screening in line with government health policies and then referring them for further investigations, diagnosis and treatment. This applies to all new patients, as well as any patients on the programme and their family members or friends who have symptoms associated with the disease, such as cough, night sweats, fever and weight loss. Workplace policies need to reflect TB screening for staff and volunteers because health care workers are at increased risk.
- Providing effective treatment support by empowering patients and their families with knowledge about the illness. This should cover the spread of TB, infection control, including cough hygiene, the safe collection and disposal of sputum, TB treatment and the management of side effects. In the in-patient setting, staff members provide DOT (Directly Observed Treatment). With home based care, staff members are not usually able to visit all patients on a daily basis. Here it is their responsibility to encourage the patient to identify a family member or neighbour as a treatment supporter.
- Integrating HIV and TB care by advocating for, or prescribing, anti-retroviral treatment (ART) for HIV+ patients in whom

TB is diagnosed and then providing them and their families with the necessary information and support to promote treatment adherence.

- Actively promoting Isoniazid preventive therapy (IPT) in HIV infected people (patients and staff) in whom active TB has been excluded.
- Collaborating with partners in the formal and informal health care sector to provide an optimal continuum of care for patients with multi-drug resistant TB (MDR) and extensive drug resistant TB (XDR). For example, in some parts of South Africa, palliative care clinicians have been invited to serve on the provincial bodies responsible for decision making regarding patients with drug resistant TB. These decisions include the discharge of patients into the community and the discontinuation of futile treatment.
- Assessing the risk to household members, especially children, and the capacity to provide effective infection control in the home, prior to the discharge of patients with drug resistant TB.
- Providing compassionate end of life care to TB patients and bereavement follow up to families.
- Providing palliative care training to health care workers in TB hospitals so that those patients with drug resistant TB who cannot be cared for at home, because it is not possible to ensure separate sleeping arrangements and adequate infection control, receive holistic and respectful care.
- Palliative care organisations should take every opportunity to assist the health care services to improve TB management. This could include treatment adherence support, infection control, health education, contact tracing and screening, delivery of medication, serving on the provincial M/XDR-TB review committee to assist in decision making regarding appropriate medication for terminally ill patients.

Palliative Care services can promote the optimal health and professional and personal development in staff and volunteers by:

- Having a good work place policy in place and creating a nurturing environment that encourages staff to know and disclose their own HIV and TB status.
- Incorporating TB aspects into hospice risk management and "Care for the Caregiver" programmes.
- Ensuring that all staff and volunteers have been given appropriate TB training, followed by regular in-service training.
- Encouraging staff to deliver presentations at conferences and participate in TB-related research.

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CHALLENGES ASSOCIATED WITH TB IN THE PALLIATIVE CARE CONTEXT

THESE INCLUDE:

- Fear of infection. Resistance to wearing an N95 respirator when having close contact with TB patients, for fear of causing the patient to feel stigmatized.
- Combining the goals of TB cure with TB care and focusing on care during the terminal phase of the illness. The balancing of the rights and responsibilities of patients. This may result in uncertainty about allowing contact between patients with advanced drug resistant TB towards the end of their lives and their families.
- Minimising the risk of complicated grief when there has to be forced separation within families because of the risk of contracting drug resistant TB.

THERE ARE NO EASY ANSWERS TO ANY OF THESE CHALLENGES

This document outlines a framework for treating and managing TB patients with palliative care needs. It should be read in conjunction with the latest Department of Health National Tuberculosis Management Guidelines² (doh.gov.za) and the HPCA Clinical Guidelines³ (www.hospicepalliativecares.co.za). It aims to provide guidance on:

- Liaising with relevant partners, particularly in the formal health care sector, to promote infection control and the successful management of a TB patient in the community.
- Promoting the integration of TB and HIV management in the hospice programme.
- Patient and family education.
- Treatment support.
- Providing holistic care including optimal pain and symptom control.
- Promoting dignified end of life care and family support.
- Facilitating coping with loss and grief as well as bereavement follow up.

IMPLEMENTING TB CARE IN PALLIATIVE CARE PROGRAMMES

Each HPCA member organisation needs to carefully consider how best to address the four I's recommended by the South African National Department of Health⁴.

Intensified case finding
Infection control
INH preventive therapy (IPT)
Integration of HIV and TB

3.1 INTENSIFIED CASE FINDING

All palliative care programmes need to ensure that screening for TB is a priority. This needs to be done using the attached screening tool (Appendix 1). TB screening needs to be part of the initial assessment of all new patients admitted to the programme. Patients and household members already on the palliative care programme, as well as staff and volunteers who are coughing, complain of tiredness, have night sweats or have significant weight loss within a short period of time should also be screened. Staff members and volunteers should be screened at the time of employment and thereafter at least annually.

If one or more of the questions on the TB screening tool, are answered with a Yes, the person needs to be referred to the nearest Primary Health Care clinic for further investigations, diagnosis and treatment. Continued liaison between the hospice and the clinic is vital to ensure that there is collaboration with regard to diagnosis, treatment and support. Policies and procedures for screening, referral and follow up need to be documented and implemented.

Children under 5 years are a particularly vulnerable group. If an adult in the household is diagnosed with TB, all children under 5 years and all children who are HIV+ need to be referred to the clinic for TB testing, and a decision about either full TB treatment or INH preventative therapy (IPT).

3.2 INFECTION CONTROL

Persons with undiagnosed, untreated and potentially contagious TB are often seen in both In Patient Units and Home Based Care settings. TB is the most common opportunistic infection and the leading cause of death in persons living with HIV and AIDS (PLWHA).

Health care workers and other staff are also at particularly high risk of infection with TB because of frequent exposure to patients with infectious TB disease. Health care workers

who are HIV+ are at greater risk of developing TB disease. An important indicator of an effective infection control plan is the annual rate of new TB infections in the staff working in a particular facility⁵.

TB is caused by the germ, *Mycobacterium tuberculosis*. People who have TB disease in their lungs can release tiny particles containing *M. tuberculosis* into the air by coughing or sneezing. These infectious particles are invisible to the naked eye and can remain suspended in the air for many hours, unless removed by natural or mechanical ventilation. A person who inhales one or more of these particles can become infected with *M. tuberculosis*.

The Difference between TB Infection and TB Disease (Tuberculosis)

TB Infection

- TB infection occurs when TB germs invade the body. If the body's immune system is healthy, it is able to contain this invasion. The bacteria remain inactive or dormant. They are still alive and can become active later. This condition is referred to as latent TB infection (LTBI). Because of the high incidence of TB in South Africa, the majority of the population has latent TB infection.
- A healthy person with a strong immune system has a 10% chance of developing TB during his/her lifetime while an HIV+ person has a 10% chance per year of developing TB.

TB Disease

- This occurs when the invasion is not contained or when latent TB progresses and the infection begins to spread.

Such a person will develop the signs and symptoms of tuberculosis.

- Most TB disease occurs in the lungs (pulmonary TB). In persons with HIV infection, however, TB in other parts of the body (extra-pulmonary TB) is not uncommon.
- A person with pulmonary TB usually has a cough and with advanced disease may cough up blood (haemoptysis).
- General symptoms of TB include fever, sweating at night, loss of appetite, weight loss, and fatigue.
- With appropriate treatment, TB disease can be cured, even in persons with HIV infection. However, without treatment TB can be fatal.

TB can be infectious when it occurs in the lungs or larynx. In general, someone with TB disease of the lungs or larynx should

IMPLEMENTING TB CARE IN PALLIATIVE CARE PROGRAMMES

be considered infectious until the person has:

- completed at least two weeks of TB treatment and shows an improvement in clinical symptoms.

In the case of drug resistant TB, the person has:

- had two consecutive negative sputum smears on two different days. At least one sputum should be an early morning specimen.

Reducing the Risk of Spreading TB in the In Patient Unit and in the Home

Proper infection control measures have the greatest impact on preventing TB transmission. If the production of droplet nuclei containing *M. tuberculosis* can be eliminated in the hospice, the risk of exposure of patients and staff to TB is also eliminated, and no further controls are needed. However, since it is not possible to eliminate all exposure, additional environmental control measures must be added to reduce the concentration of potentially infected droplet nuclei in the air. Patients, family members and staff need to be trained to maintain simple but effective environmental control measures at all times. Everyone needs to understand the principals of infection and environmental control measures. These should become part of routine everyday practice.

Work Practice and Administrative Controls

There are five components to good work practice and administrative controls:

1. Written infection control plan.
2. On going training of all staff.
3. Regular inspections to assess the risk of infection and the quality of control measures.
4. Education of patients and increasing community awareness.
5. Liaison with TB control programmes in the formal health care sector.

Infection Control Plan

TB needs to be included in the organisation's infection control plan, in line with the HPCA Standards⁶. It should include the following:

1. As part of the first assessment, all patients should be screened for symptoms of TB, previous TB treatment or contact with TB. Where appropriate family and friends should be screened as well.
2. Anyone who is coughing must be given advice on respiratory hygiene/cough etiquette and provided with a surgical mask or tissues to cover the mouth and nose. Tissues and masks should be disposed of in the appropriate waste containers.

3. Optimal ventilation is provided.

4. Fans and air conditioners need to be correctly positioned and maintained.

5. Safe sputum collection forms part of infection control. (See Appendix 2).

6. Hand washing is particularly important after contact with respiratory secretions.

7. All staff and volunteers should be trained on TB infection control.

8. TB should be included in the organisation's risk management and quality improvement programmes.

Training of Staff

Infection prevention and control are effective only if all staff working in the organisation understand the importance of the infection prevention and control policies and their role in implementing them. As part of training, each staff member and volunteer should receive job-specific instruction. Training on TB infection control should be included in the orientation programme and continuing education should be provided to all employees and volunteers at least annually. Training should include the following:

- Basic concepts of *M. tuberculosis* transmission and pathogenesis, i.e. the difference between infection and disease.
- Risk of TB transmission to health care workers and staff.
- Signs and symptoms of TB.
- HIV and TB co-infection and how TB presents in immune-compromised patients.
- Importance of the infection control plan and the responsibility that each staff member has to implement and maintain infection prevention and control practices.
- Specific infection prevention and control measures and work practices that reduce the likelihood of transmitting TB.
- Measures staff can take to protect themselves from TB.

Staff members should be encouraged and supported to know their HIV and TB status. When management is aware of a staff member's HIV status, where possible, the staff member should be reallocated to a work area where the risk of contracting TB is lower⁷.

Education of Patients and Family and Community Awareness

Educating patients, families and communities to recognise symptoms of TB and to seek health care and further investigations should be routine. In addition, patients should

IMPLEMENTING TB CARE IN PALLIATIVE CARE PROGRAMMES

understand how to protect themselves, and others, from exposure to TB by simple cough hygiene measures.

Environmental Control Measures

Environmental controls are the second line of defence for preventing the spread of TB in health care settings. Controlled natural ventilation can reduce the risk of spreading *M. tuberculosis*.

Natural ventilation relies on open doors and windows to bring in air from the outside. "Controlled" implies that checks are in place to make sure that doors and windows are maintained in an open position that enhances ventilation. Fans may also assist to distribute the air. Fans should be directed to blow air towards an open window or door leading to the outside of the building. Designing waiting areas and rooms so that they maximise natural ventilation can help reduce the spread of TB.

If patients are asked to provide sputum specimens for TB diagnosis onsite, they should do so in an adequately ventilated area or outside in the open air and away from other people, not in small rooms such as toilets or other enclosed areas.

3.3 INH PREVENTIVE THERAPY (IPT)

IPT consists of giving a prophylactic course of INH for a six-month period to adults and children who are at risk of contracting TB. INH preventive therapy is recommended for HIV infected adults in whom tuberculosis (active disease) has been excluded. A history of TB in the past is not a contra-indication for IPT. The only contra-indications besides active TB are liver disease and alcohol abuse. Liver toxicity is an uncommon but serious side effect. Severe liver damage may occur in about 1% of adults on INH. Hepato-toxicity tends to occur in patients with chronic hepatitis or severe alcohol abuse. IPT should be stopped if jaundice occurs.

Vitamin B6 (pyridoxine) 25 mg per day should be given concomitantly with INH to prevent the occurrence of peripheral neuropathy⁸.

In children, INH prophylaxis is given to well children under five years of age, and HIV infected children of any age, who have been exposed to someone with untreated tuberculosis. Various studies have shown that IPT is safe and effective for people on ART and for pregnant mothers without symptoms of TB. Because health care workers are at increased risk of contracting TB it is important that they know their HIV status. All HIV+ health care workers without TB symptoms should be given IPT.

The recommended dose for adults = INH 5 mg/Kg/day (Maximum 300 mg)

The paediatric dose = INH 10mg/Kg/day

People on IPT need to be given initial adherence counselling and ongoing treatment support.

3.4 INTEGRATION OF HIV AND TB

Although TB is a curable illness, it is the leading cause of death in HIV infected people. HIV increases the risk of contracting tuberculosis from 10% over a lifetime to 10% per year. It is therefore imperative that all HIV+ patients are screened for TB and are then either started on treatment for TB or are put onto INH preventive therapy (IPT). Whenever an HIV+ patient is diagnosed with tuberculosis, all their household members and contacts should be screened and referred for counselling and testing for both TB and HIV. The same applies to HIV infected staff and volunteers.

It is important for TB patients with HIV infection to be started on ART as soon as possible, ideally within 2-8 weeks of starting their TB treatment. Patients with a low CD4 count can present with a sudden and severe deterioration in their general condition a few weeks after commencing treatment for either or both HIV and TB. This is known as IRIS (Immune Reconstitution Inflammatory Syndrome) as it occurs when the previously suppressed immune system starts working again. These patients require intensive nursing care and are often admitted to In Patient facilities.

There are numerous myths, misconceptions and fears surrounding both HIV and TB. By modelling respectful holistic care, providing up to date accurate information and using the influence they have with other community role players, hospice teams can make a real contribution towards decreasing the stigma associated with both these illnesses.

DRUG RESISTANT TB

Currently less than 10% of the estimated number of patients with drug resistant TB are being diagnosed and adequately treated. About 50% of patients found to have drug resistant TB have never been treated for TB previously. This alarming finding indicates that the main cause of the problem is transmission from persons with undiagnosed or inadequately treated drug resistant TB⁹. It has also been shown that hospitalisation during the initiation of TB treatment for drug susceptible TB is a major risk factor in developing MDR-TB. This re-emphasises the danger of exposure to drug resistant TB in hospitals with multi-bed wards. Isolation, prompt diagnosis and effective treatment are vital to stop the further spread of drug resistant TB⁵.

Prevention is very important as treatment for drug resistant TB is prolonged and costly. Even with the best treatment available, only 60% of patients with MDR-TB are eventually cured. In XDR-TB the cure rates are much less. Re-infection rates are also high, especially in HIV+ persons.

The current reality is that most patients with extensive drug resistant TB will die from their disease. Their proper management thus must include adequate attention to symptom control, end of life care and family support.

Currently there are insufficient beds available in TB hospitals in South Africa for all the known drug resistant TB patients. However, not all these patients need to be treated in special wards. With careful planning and selection, many patients can be treated at home.

4.1 CRITERIA FOR ADMISSION OF PATIENTS WITH A CONFIRMED DIAGNOSIS OF MDR/TB TO A PALLIATIVE CARE PROGRAMME

All patients with a confirmed diagnosis of XDR-TB should be admitted to specialised state facilities for drug resistant TB. Palliative care organisations can assist by providing palliative care training to staff working in these state facilities.

4.1.1 In patient unit

Patient related criteria

- Selected patients with MDR-TB may be considered for admission to In Patient facilities where there is a specific need for specialised palliative care.
- Such patients should be on effective 2nd line TB treatment

and should be sputum negative.

- Patients should understand their diagnosis, the purpose of the admission to the IPU as well as the proposed length of stay.
- The referring institution should give at least 24 hours notice prior to admission, so that adequate preparations can be made.
- Patients should come with their TB treatment cards, at least a two week supply of all their medication and an adequate supply of Ng5 respirators for the nursing staff.
- Arrangements must be in place for an ongoing and uninterrupted supply of medication.

Facility-related criteria

- In Patient facilities admitting such patients should have an isolation room with windows that open to the exterior of the building.
- Where possible natural ventilation with open windows and assisted by suitably positioned fans, should be encouraged.
- Patients should restrict their movements to designated isolation areas.
- All treatment should be directly observed and recorded in the patient's green card.
- Drug related side effects should be carefully monitored and managed in consultation with referral institutions and local clinics.
- Infection control measures should be implemented.
 - Protective clothing – apron, gloves
 - Dedicated handwashing facility
 - Staff and visitors to wear Ng5 respirators
- There should be open communication about all aspects of appropriate infection control. Every effort should be made to assist patients and their families to cope with the added burden of isolation.

Staff-related criteria

- There is bound to be a great deal of fear about caring for patients with MDR-TB. Open communication is vital to ensure that all staff understand the principles of appropriate infection control and, at the same time, the need to provide compassionate care.
- Proper infection control should become part of normal daily routine.
- Everyone should be encouraged to know their HIV status.
- Immune compromised staff members should be discouraged from being directly involved in care of these patients.

4.1.2 Palliative home-based care programmes

Patient related criteria

- Prior to the admission of a person with drug resistant TB to the home based care programme, a home visit should be done. Families need to be helped to assess the feasibility of home based care.

This includes checking:

- the availability of separate sleeping arrangements
- the identification of a suitable carer
- the knowledge and skill needed for appropriate infection control. (See 7.3)
- that all contacts have been screened
- that all children under the age of 5 years are on MDR/XDR-TB treatment or prophylaxis (IPT)
- Patients admitted to the home care programme should have their TB treatment cards and at least a two week supply of all their medication.
- Good communication with the referring hospital needs to be maintained for obtaining advice and, where necessary, arranging re-admission.
- The nearest regional pharmacist needs to be informed so that arrangements are put in place so that an uninterrupted supply of effective 2nd line TB drugs can be obtained.
- Roles and responsibilities need to be discussed and clarified.

5

MANAGING TB IN CHILDREN (INCLUDING DRUG RESISTANT TB)

The diagnosis of TB in children relies on a thorough assessment of all evidence derived from a comprehensive history, clinical examination and relevant investigations. Children with TB are usually not a risk to other children or adults. However, some children, mainly school-aged children and adolescents, have smear-positive TB with cavities on chest x-ray. These children are as infectious as smear-positive adults and other children in contact with them must be investigated as if they were in contact with an adult with infectious TB.

Children are treated using the same principles as adults. Parents and caregivers should be counselled about TB and the importance of adherence to the treatment regime. Improvement of symptoms and weight gain indicate that children are responding to treatment.

This chapter should be read in conjunction with Childhood TB. A learning programme for professionals. Desmond Tutu Tuberculosis Centre. 2010. A free on-line edition is available at www.electricbookworks.com.

ETHICAL CONSIDERATIONS

Multi-drug resistant TB raises the challenge of balancing the human rights of an infected individual with the general good of society at large. It also raises the obligations and responsibilities of the authorities to provide effective treatment and care in a humane and dignified way. The co-operation of all parties is necessary to achieve a balance of these rights and responsibilities. In the interest of the good of society it may be necessary to suspend or curtail some of the rights of an individual patient for a specific period of time. Such action should only be taken when all other efforts to achieve voluntary co-operation have been exhausted.

The Patient's Charter for Tuberculosis Care¹⁰ sets out a number of rights and responsibilities. The first two rights are:

Care

- The right to free and equitable access to tuberculosis care, from diagnosis through treatment completion, regardless of resources, race, gender, age, language, legal status, religious beliefs, sexual orientation, culture, or having another illness.
- The right to receive medical advice and treatment which fully meets the new International Standards for Tuberculosis Care, centering on patient needs, including those with multidrug-resistant tuberculosis (MDR-TB) or tuberculosis-human immunodeficiency virus (HIV) co-infections and preventative treatment for young children and others considered to be at high risk.
- The right to benefit from proactive health sector community outreach, education, and prevention campaigns as part of comprehensive care programs.

Dignity

- The right to be treated with respect and dignity, including the delivery of services without stigma, prejudice, or discrimination by health providers and authorities.
- The right to quality healthcare in a dignified environment, with moral support from family, friends, and the community¹¹.

The Charter also sets out a number of responsibilities that each patient has. These include:

Follow Treatment

- The responsibility to follow the prescribed and agreed treatment plan and to conscientiously comply with the instructions given to protect the patient's health, and that of others.

- The responsibility to inform the health provider of any difficulties or problems with following treatment or if any part of the treatment is not clearly understood.

Contribute to Community Health

- The responsibility to contribute to community well-being by encouraging others to seek medical advice if they exhibit the symptoms of tuberculosis.
- The responsibility to show consideration for the rights of other patients and healthcare providers, understanding that this is the dignified basis and respectful foundation of the tuberculosis community.

The best way to manage drug resistant TB is to prevent it before it happens. Every health care worker needs to be up to date in their knowledge of TB and its management. All organisations need to promote effective infection control.

PALLIATIVE CARE FOR PATIENTS WITH TB (INCLUDING DRUG RESISTANT TB)

7.1 CLINICAL GUIDELINE TO CARE FOR THE PALLIATIVE CARE TB PATIENT

In patients with drug resistant TB who are not benefitting from TB treatment, there may come a point when such treatment is stopped. There is however, much that can be done to provide good palliation of troublesome symptoms.

7.1.1 Pain control:

Try to identify the cause:

- Inflammation due to TB infiltration of the lung, pleura or other internal organs.
- Muscle strain due to excessive coughing.
- Bone pain from TB infiltration into the spine or bone.
- Joint pain from gout (precipitated by PZA) or septic arthritis.
- Painful feet: Drug induced peripheral neuropathy – INH or ARVs.

Treatment:

Follow the guidelines for pain control in the HPCA Clinical Guidelines

Mild pain: Paracetamol 2x 500 mg tabs 4-6 hourly

Moderate pain: Codeine phosphate 30-60 mg 4 hourly

Severe pain: Morphine sulphate 5-10 mg 4 hourly

Bone pain: Ibuprofen 200-400 mg 8 hourly

Neuropathic pain: Vit B6(pyridoxine)100mg (except in pregnancy) and Amitryptiline 25 mg nocte

7.1.2 Nausea and Vomiting

Nausea and vomiting in TB patients can have a wide variety of causes and it is important to try to identify the specific cause.

Side effect of TB drugs

- Some drugs such as INH, Rifampicin or PZA may cause hepato-toxicity.
- Check for signs of jaundice and if possible measure the patient's liver enzymes (an ALT is adequate).

a. Side effect of ARVs

Consider lactic acidosis.

Refer such patients to hospital for investigations and management.

b. Opportunistic Infections or other complications such as IRIS.

If the patient also complains of severe persisting headache, consider raised intracranial pressure or meningitis.

Such patients should also be referred for investigation.

Management of mild nausea and vomiting after the above conditions have been excluded:

- Give metoclopramide 10mg 8 hourly for a day or two and then review.
- TB drugs should ideally be taken on an empty stomach but in some cases of troublesome nausea and vomiting a light meal may be given beforehand for a day or two to see if the drugs are better tolerated.

7.1.3 Breathlessness and coughing

Troublesome breathlessness and excessive coughing may be relieved by low dose oral morphine. Start with 5 mg 4 hourly and increase the dosage gradually if required.

7.1.4 Drugs and side effects

Pain: See 7.1.1

Nausea: See 7.1.2

Rash: Urticaria: Chlortrimeton 2-4 mg nocte for 2 days then review.

Generalised non-itchy rash associated with ulceration of mouth and inflamed conjunctiva (Steven-Johnson Syndrome): Refer to local hospital.

7.1.5 Night Sweats

This may require frequent changes of sheets and pyjamas. It resolves as the patient starts responding to TB treatment.

7.2 NUTRITIONAL SUPPORT

- Encourage small frequent meals until the patient's appetite returns.
- Add Vit B Co 1 daily.
- Impoverished patients: Arrange for nutritional supplements and food parcels.

7.3 FAMILY'S/CARER'S HEALTH

The home based care team can assist greatly by ensuring that all family members are screened for TB using the 4 questions. (See Screening tool – Appendix 1) Any person suspected of having TB should be referred to the nearest primary health clinic for further assessment. The family should be assisted to maximise infection control in the home. (See 7.3)

END OF LIFE CARE

Although TB is curable, it is the leading cause of death in HIV+ patients. As with end of life care for all patients, the aim is to promote physical and emotional comfort and open, honest communication.

- **Pain control:** Paracetamol, or Codeine with Paracetamol, relieves moderate pain. Codeine also helps control coughing and other cough suppressants can be added. Stronger analgesics, including morphine, should be used when indicated.
- **Relief of respiratory insufficiency:** Morphine provides significant relief from respiratory insufficiency and should be prescribed when indicated.
- **Nutritional support:** Often small and frequent meals are best for a terminally ill person. Intake will decrease as the patient's condition deteriorates. Treat nausea and vomiting or any other conditions that interfere with nutritional support.
- **Ongoing psychosocial support:** Ongoing support must be rendered to patient and the family. Depression and anxiety, if present, should be addressed.

According to patient and family needs, informing them about the likely disease process and preparing them for potential end of life traumatic events.

- **Ancillary medicines.** These medicines should be reviewed and continued only if they add to the patient's comfort.
- **Nursing care.** Mouth care, prevention of bedsores, bathing and prevention of muscle contractures should form part of routine care.
- **Infection control measures.** The patient who is taken off TB treatment because of failure remains infectious. Infection control measures should be continued.

BEREAVEMENT CARE

When a person is given a potentially life-threatening diagnosis, such as cancer, HIV or XDR-TB, shock, fear and anxiety about the future may be experienced. Taking into account all the potential losses that people may experience throughout the illness process, bereavement begins at the onset of diagnosis and continues after death¹². The early identification of people at risk of complicated grief and bereavement is an important aspect of holistic care.

BEREAVEMENT ASSESSMENT:

When doing a bereavement assessment with the family after death due to TB, and within the context of limited resources, all psychosocial factors are considered. The following specific factors may be linked to XDR-TB.

Factors linked to XDR-TB

- The stigma around death related to XDR TB. This may prevent the bereaved sharing their grief, or talking to others about what has happened.
- Feelings of family shame after a death could occur if the patient was non-compliant or manifested irresponsible behaviour that resulted in death.
- Prolonged hospitalisation and isolation of the patient from the family could impact on the grieving process.
- The absence of a social support network.
- Fear of TB infection and of own death.
- The length of the illness.
- Hidden losses that cannot be openly mourned.

The following factors may also influence the grief process:¹³

- Culture and belief systems within the community.
- The type of relationship, the closeness or alienation experienced.
- Age of the bereaved, personality and past experiences of handling crises.
- Gender, changes in roles and responsibilities.
- Habitual use of alcohol or drugs in order to cope in times of personal difficulty.
- Previous psychiatric illness.
- Support systems (family, friends, church).
- Financial problems.
- Concurrent stresses, other family members that may be ill.

Support to bereaved families includes:

Practical issues

Assist the family to find practical solutions for specific problems. These might be gender related and can include:

- No provision for funeral arrangements or funeral policy.
- No income if deceased was the breadwinner.
- Facilitating the application for child support or care dependency grants where applicable.
- Support and future care of vulnerable children.
- If the deceased had life insurance; helping the survivors with the necessary steps for this to be paid out.
- Liaising with the child and family organisations in the community as appropriate.

Social and Emotional support includes

- Non-judgemental and compassionate listening.
- Allowing the opportunity for the expression of feelings, thoughts and experiences.
- Counsel, or refer appropriately on issues such as depression, anxiety, fear, stigma, superstitions, isolation, loneliness and rejection.

CONCLUSION

It is clear that TB patients, particularly if they are HIV+ or have drug resistant TB, benefit from the range of services that palliative care programmes can provide. In addition, HPCA member organisations are uniquely placed to make a significant contribution towards reducing the impact of the TB epidemic by addressing the 4 I's – increased case finding, infection control, IPT and the integration of HIV and TB. Collaboration with the formal health sector regarding the management of TB patients provides an opportunity to expand the reach of palliative care in line with HPCA's vision of Quality Palliative Care for all.

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APPENDIX 1

TB SCREENING TOOL

Organisation:	
Date:	
Name:	
Indicate whether the person being screened for TB is a:	
<input type="checkbox"/> Patient:	
<input type="checkbox"/> Family/Household member:	
<input type="checkbox"/> Staff Member :	
<input type="checkbox"/> Volunteer:	

	YES	NO
1. Coughing for 2 weeks		
2. Losing weight in the past four weeks		
3. Sweating a lot at night		
4. Fever		

If “yes” to one or more of the questions, suspect TB

Clinically evaluate the patient using national guidelines for diagnosing TB. If required refer for further investigations including a sputum for microscopy and culture

Complementary Questions:	YES	NO
5. Have you been treated for Tuberculosis?		
6. Did you complete your TB treatment?		
7. Have you been in contact with someone diagnosed with Tuberculosis in the past year, e.g. same household or at work?		

REFERRAL	
Name of health care facility:	
Contact person:	
Contact number:	
Date of referral:	

Acknowledgements to NDOH for source document

APPENDIX 2

Hospice in Patient Unit and Home Based Care Tuberculosis Infection Control Audit Tool



Hospice:				IPU Scoring		HBC Scoring		Comments
Date:								
Criteria			Rating	Score	Rating	Score		
Managerial	1	Written Infection Control plan	Complaint	2	Complaint	2		
	2	Designated infection Control Person or Committee						
	3	TB Infection Control training done for all staff						
	4	Natural ventilation check (evidence of an open window policy)						
	5	Quarterly Risk Management assessments conducted						
	6	Follow up system in place within palliative care programme: TB patients, contacts and suspects						
	7	Liaison between the hospice and DOH referral facility regarding sputum results						
	8	Checking that TB patients green cards are updated						
	9	Evidence of TB Treatment provided						
	10	Information of TB Control is provided to patient, family and visitors						
	11	TB Screening done on all new patients admitted to IPU and HBC						
	12	TB Screening done on all new staff and annually on staff						
	13	Policies and procedures are in place for safe collection of sputum						
	14	Training or poster evidence of promoting open windows, cough and sneeze etiquette						
Administrative	15	HIV/AIDS/TB workplace policy in place and implemented						
	16	Regular maintenance of directional fans						
	17	Regular maintenance of extractor fans						
	18	Regular maintenance of air conditioners						
	19	If UV lighting is used, routine maintenance is scheduled by trained personnel						
	20	Patients with a productive cough are educated and supplied with suitable containers for the disposal of sputum						
	21	Infection Control Guidelines are implemented including the disposal of infected waste in all settings						
Personal Protective Equipment	22	N-95 or FFP2 respirators are readily available for staff and IPU MDR-TB patients						
	23	Masks are readily available for patients and visitors						
	24	N95 Respirators are correctly used and stored						
Total Score:				2		2		
Number of criteria not applicable:				0		0		
Number of criteria assessed on:				1		1		
Hospice % score				100%		100%		
Conducted by:								

APPENDIX 3 – SAFE SPUTUM COLLECTION

1. Label the sputum bottle first with all the patient's information.
2. The sputum should be collected in a well ventilated, dedicated area that is only used for sputum collection. An outside area can also be used as long as it has privacy and does not allow other to watch. Do not use toilets for sputum collection.
3. Explain the steps slowly and in brief points.
4. The person should first rinse out their mouth with water to remove any pieces of food.
5. Demonstrate how to give a deep cough from the bottom of the chest:
 - Beginning with deep breathing.
 - Cough forcefully.
 - Repeat this three times before spitting into the bottle.
6. Give the patient the sputum bottle, without the lid to spit it into the bottle.
7. The patient must fit the sputum bottle underneath the lower lip and spit into the sputum bottle.
8. Ask the patient to take care not to spill sputum on the outside of the sputum bottle.
9. Don't stand in front of a patient while s/he coughs.
10. If the patient is in bed at home:
 - a. Move the bed until the patient is in front of an open window or door.
 - b. The patient must turn their head towards the open window or door when coughing and spitting into the sputum bottle.
11. Supervise the collection, but do not stand in front of the patient.
12. Be ready to replace the lid on the sputum bottle immediately after the patient coughed up sputum.
13. Make sure the patient coughed enough sputum into the sputum bottle (about a teaspoon full).
14. Close the sputum bottle by turning the lid three times to ensure that it is completely closed.
15. . Wash your hands after closing the sputum bottle.
16. Take the sputum bottles as soon as possible to the health facility in a cooler bag or box. Don't expose the sputum bottles to direct sunlight.



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