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Holistic care of complicated tuberculosis in healthcare settings with limited resources

Trevor Duke,^{1,2,3} Sharon Kasa Tom,⁴ Harry Poka,⁵ Henry Welch^{3,6}

¹Centre for International Child Health, University of Melbourne, Parkville, Victoria, Australia

²Intensive Care Unit, Royal Children's Hospital, Parkville, Victoria, Australia

³Discipline of Child Health, School of Medicine and Health Sciences, University of Papua New Guinea, Moresby, Papua New Guinea

⁴Department of Paediatrics, Wabag General Hospital, Wabag, Papua New Guinea

⁵Department of Paediatrics, Sir Joseph Nombri Memorial Kundiawa General Hospital, Kundiawa, Simbu, Papua New Guinea

⁶Department of Pediatrics, Baylor College of Medicine, Baylor International Pediatric AIDS Initiative, Houston, Texas, USA

Correspondence to

professor Trevor Duke, University Department of Paediatrics, Royal Children's Hospital, Parkville, Victoria 3052, Australia; trevor.duke@rch.org.au

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ABSTRACT

In recent years, most of the focus on improving the quality of paediatric care in low-income countries has been on improving primary care using the Integrated Management of Childhood Illness, and improving triage and emergency treatment in hospitals aimed at reducing deaths in the first 24 hours. There has been little attention paid to improving the quality of care for children with chronic or complex diseases. Children with complicated forms of tuberculosis (TB), including central nervous system and chronic pulmonary TB, provide examples of acute and chronic multisystem paediatric illnesses that commonly present to district-level and second-level referral hospitals in low-income countries. The care of these children requires a holistic clinical and continuous quality improvement approach. This includes timely decisions on the commencement of treatment often when diagnoses are not certain, identification and management of acute respiratory, neurological and nutritional complications, identification and treatment of comorbidities, supportive care, systematic monitoring of treatment and progress, rehabilitation, psychological support, ensuring adherence, and safe transition to community care. New diagnostics and imaging can assist this, but meticulous attention to clinical detail at the bedside and having a clear plan for all aspects of care that is communicated well to staff and families are essential for good outcomes. The care is multidimensional: biomedical, rehabilitative, social and economic, and multidisciplinary: medical, nursing and allied health. In the era of the Sustainable Development Goals, approaches to these dimensions of healthcare are needed within the reach of the poorest people who access district hospitals in low-income countries.

INTRODUCTION

In low-income countries central nervous system (CNS) manifestations of tuberculosis (TB) are common, and many children with pulmonary TB present with, or develop, complicated forms of chronic lung disease. These conditions present challenges for paediatric doctors, nurses and allied healthcare workers. A variation of the 'inverse care law'¹ is that the most complex patients present in hospital settings which have the least resources to manage them, including in district and provincial hospitals. In the last two decades the major focus of improving quality of paediatric care in these settings has been around triage and emergency care, and reducing deaths in the first 24 hours of hospitalisation.² Children with complicated forms of TB are often both acutely and chronically ill, and there has been minimal focus on approaches to

such disease processes in resource-limited settings. This includes effective models for ensuring ongoing community care.

This paper outlines some of the practical challenges of these illnesses in the acute and chronic phases, beyond those of antimicrobial chemotherapy, especially where resources are limited. These settings are typically small hospitals, often in rural or remote regions, with basic laboratory facilities and essential medicines.³ In such settings, a meticulous approach to the diagnosis, supportive care and monitoring of children with complex TB-related disease can achieve good outcomes. It is the attention to the most accurate diagnosis possible given the resources available, identification and avoidance of complications, supportive care, a focus on nutrition and physiotherapy, together with care provided by parents or caregivers that results in improved quality of life for many such children.

Articles have been published in the last few years on the epidemiology of childhood TB, multidrug resistance and advances in chemotherapy.⁴⁻⁷ Here, we focus on the clinical aspects of management, not to understate the challenges of antimicrobial therapy in an era of increasing drug resistance, but to convey that comprehensive approaches to improving the quality of clinical care are needed, and are accessible to district-level and provincial-level hospitals.

CONSIDERATIONS OF COMPLEX CARE IN DISTRICT-LEVEL HOSPITALS

WHO promotes an overall approach to all seriously ill children which includes triage, emergency treatment, history, examination, laboratory tests, diagnosis and differential diagnoses, treatment, supportive care, monitoring, discharge planning and follow-up.³ These stages of management are relevant to complicated TB infection, and represent a standard of care that is possible in a first-referral-level hospital. Care of chronically ill children, which is described in this paper, does not need to be high technology care or expensive care, and is not beyond the capacity of many district and provincial hospitals. Some technologies which are mentioned in this paper, such as CT scans and GeneXpert PCR testing, are unavailable in most district hospitals in rural settings. However, these are merely adjuncts to diagnosis in selected cases, and there is limited evidence that use of such technology in children with suspected TB improves outcomes. The majority of treatment decisions in most patients can be made effectively on clinical grounds. This is not substandard care, or unethical care, it represents optimal clinical care in a realistic environment. For



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referral beyond the district or provincial hospital clinical care to a tertiary level of care, the specific benefit to the child of such referral should be identified. Sometimes, the benefit of tertiary referral is less than what we as healthcare professionals or the family might imagine, if good medical, nursing and rehabilitative care is in place at a first-referral-level hospital.

CNS TUBERCULOSIS

Clinical presentation, history, examination and investigations

The clinical presentation of CNS TB varies, including meningitis, seizures and acute encephalopathy, raised intracranial pressure which may manifest as chronic headaches, visual disturbances, cranial nerve palsies, focal motor deficits such as hemiplegia or hemiparesis, hydrocephalus, movement disorders including dystonia, coma and progressive loss of developmental milestones. Raised intracranial pressure in TB may result from the space-occupying nature of a tubercular granuloma, brain oedema, cerebral infarction, venous thrombosis or hydrocephalus. The manifestations of CNS TB overlap with other diagnoses, including CNS tumours, stroke, viral encephalitis, HIV encephalopathy, cryptococcal meningitis and postinfectious inflammatory encephalopathies such as acute disseminated encephalomyelitis. In settings with limited diagnostic capacity, many children with acute or subacute febrile encephalopathy or elevated intracranial pressure are empirically treated as tuberculous meningitis (TBM) because of failure to improve after antibiotic treatment for bacterial meningitis, or because their history suggests exposure to infectious TB. This is a practical approach and sometimes the only safe course of action.

Diagnostic specificity is enhanced by good history taking, including being very clear about the onset of illness and what the child was like developmentally before becoming unwell. Sometimes the onset is obvious and the demarcation between the child's normal state and sickness is clear, but often it is necessary to ask probing questions about the attaining of normal developmental milestones in the months preceding the onset of illness. For example, an infant who at 6 months was able to sit unaided and smile and laugh, but now at 8 months has decreased conscious state, wasting and spasticity indicates a recent deterioration in neurological state, which favours a subacute encephalopathy such as CNS TB as a diagnosis over cerebral palsy of perinatal origin.

Diagnostic specificity is also enhanced by cerebrospinal fluid (CSF) examination, with moderate-to-high lymphocyte count (100–1000 cells/microlitre) and protein (100–500 mg/dL). If available, acid-fast bacilli staining, culture and GeneXpert MTB/Rif testing of CSF can increase specificity.^{8,9} However, the ideal volume of CSF needed to do these tests is 6–8 mL, and the CSF should be centrifuged to test the supernatant. Sensitivity is low so no laboratory test on CSF can exclude TBM.¹⁰

CT scanning, if available, can be useful in specific circumstances, including where the clinical diagnosis is in doubt, or there is a suspicion of developing hydrocephalus. The typical findings of CNS TB include diffuse basal leptomeningeal enhancement on contrast-enhanced CT, hydrocephalus, supratentorial and brainstem infarction, and tubercular granulomas.^{11–13} Precontrast hyperdensity of the basal cisterns has been reported to also be a specific feature of TBM in children.¹⁴ Large ventricles, from hydrocephalus and/or cerebral atrophy occur in up to 70% of children with TBM who have CT scans.¹² Tubercular granulomas with caseation have central heterogeneous enhancement and a ring-enhancing capsule (figure 1); once a tubercular granuloma proceeds to liquefaction, the CT appearance is that of



Figure 1 CT scan showing cerebellar ring-enhancing lesion in a child with tuberculosis.

a hypodense central component with peripheral ring enhancement. Tubercular granulomas occur in up to 70% of children with TBM at presentation or some stage during treatment.¹²

Supportive care and monitoring

Children with CNS TB have many supportive clinical needs, outlined in table 1. Medical and nursing staff are responsible for coordinating these aspects of care and ensuring that the child receives holistic care. Many people are involved, especially physiotherapists, nutrition nurses and the parents or other family caregivers.

Adjunctive treatments and complications

Adjunctive treatment with dexamethasone has some benefit in CNS TB, more so for tubercular granulomas, especially if there is surrounding oedema. Various regimens are used.¹⁵ If using dexamethasone: give 4 weeks of 0.4 mg/kg once a day x 1 week, 0.3 mg/kg once a day x 1 week, 0.2 mg/kg once a day x 1 week, 0.1 mg/kg once a day x 1 week, followed by 2–4 weeks of further tapering. If using prednisolone: 1 mg/kg two times a day for 2 weeks, then 1 mg/kg once a day for 2 weeks, then 0.5 mg/kg/day for 2 weeks then cease.

Children with TBM may develop hydrocephalus, prevalence rates are estimated as high as 70% in children having neuroimaging.¹⁵ Hydrocephalus can develop while a child is undergoing treatment, so this can be a reason for deterioration after commencing treatment. It is often difficult to identify the cause of deterioration while on treatment; which can include non-adherence with medications, multidrug-resistant TB (MDR TB) or development of hydrocephalus, stroke or epilepsy. A child with TBM who deteriorates on treatment or does not seem to be improving should be considered for cerebral imaging where possible. On CT scan, sometimes it can be challenging to distinguish between ventriculomegaly because of cerebral atrophy (not under pressure) and hydrocephalus; both are often present in chronic CNS TB. In true hydrocephalus, the ventricles are large

Table 1 Supportive care needs for children with central nervous system TB

System	Supportive care requirements
Airway and lung protection	Positioning—15–30° head up Oral suctioning Nasogastric feeding Chest physiotherapy Glycopyrrolate if excessive watery secretions requiring frequent suctioning
Nutrition	Regular nutritious feeding using standard formula or F75/F100 if malnourished Calculate and review daily caloric requirement Micronutrients Iron supplementation if likely iron deficiency anaemia (low Hb, low mean red cell volume, high red cell distribution width)
Intracranial hypertension and hydrocephalus	Nurse at incline 30° head up Ensure euvolaemia Dexamethasone reduces oedema around ring-enhancing lesions CT scan if available to diagnose hydrocephalus or tuberculoma Acetazolamide, frusemide if hydrocephalus identified Consider ventriculoperitoneal shunt Oxygen and mannitol if acute deterioration
Contractures and wasting	Ideally physiotherapists will design a programme of exercises, and teach the parents, ensuring a full range of joint movement Early mobilisation in wheelchair Nutrition Baclofen and gabapentin for severe spasticity (low-dose diazepam if baclofen not available)
Electrolyte imbalance	Avoid prolonged use of intravenous fluids Avoid hypotonic intravenous solutions Regular checking of serum [Na ⁺] when patient on intravenous fluids Nasogastric or oral soup feeding
Prevention of hospital-acquired infections	Hand washing Intravenous site care Pulmonary suctioning Avoid prolonged bladder catheterisation Avoid unnecessary antibiotics
Seizure prevention and control	Phenobarbitone Distinguish cortical seizures requiring anticonvulsants from dystonia or athetoid movements Avoid oversedation
Pressure areas	Regular turning, massage, daily inspection of bony prominences
Dental and oral hygiene	Chlorhexidine mouth wash Cleaning of teeth regularly, dental review Oral nystatin for prevention of mucosal candidiasis
Gastric ulceration	H2-receptor antagonist to reduce gastric acid production (when on corticosteroids) Feeding protection
Constipation and gastrointestinal health	Regular lactulose/Movicol (macrogol) Fruits and vegetables in diet Consider probiotics
Urinary retention	Intermittent catheterisation if needed Prevention of urinary tract infection
Monitoring	Glasgow Coma Score Oxygen saturation using pulse oximetry Temperature Weight twice weekly, plus MUAC Head circumference
Diagnostic issues	Diagnostic specificity, when there is limited neurological recovery due to established brain injury, multidrug resistance, or other causes Where GeneXpert test available, CSF can be tested to investigate for drug-resistant TB
Adverse treatment effects	TB drug side effects—check for jaundice Pyridoxine for INH-related peripheral neuropathy Monitor for ethambutol eye toxicity Monitor for hearing loss if on aminoglycosides for MDR TB
Staff infection protection	P2 masks Hand washing

CNS, central nervous system; CSF, cerebrospinal fluid; Hb, haemoglobin; INH, isoniazid; MDR, multidrug resistant; MUAC, mid-upper arm circumference; TB, tuberculosis.

and cerebral cortex is compressed with loss of normal spaces around the sulci and gyri. With ventriculomegaly due to cerebral atrophy, sometimes called ‘ex-vacuo hydrocephalus’, the sulci

of the cortex are typically more spacious than the normal and the cerebral cortex is thin, with more extra-axial fluid spaces (around the brain). Children with ex-vacuo hydrocephalus will not have macrocephaly, and depending on the age may have failure of head growth or microcephaly. Children with hydrocephalus will have macrocephaly if their sutures are not fused, and a lateral skull X-ray may show a copper-beaten appearance to the bone, and widely split sutures (figure 2).

Diuretics, particularly acetazolamide (50 mg/kg/day) and/or frusemide, are often used as medical treatment for TB-related communicating hydrocephalus. This will benefit some children, but a proportion will fail medical therapy and require a ventriculoperitoneal (VP) shunt.^{16–18} Complications of diuretic therapy need to be monitored.

In TB-related hydrocephalus a VP shunt can be effective in improving outcome, especially if done early. Studies suggest that surgical placement of a VP shunt has a role even in advanced hydrocephalus, but that children less than 3 years of age may do worse than older children.¹⁹ Hydrocephalus can be associated with other brain lesions such as areas of vasculitis causing ischaemia or stroke, or a compressive tuberculoma, and this influences outcome. Complications of VP shunts, especially shunt blockage, shunt infection and hospitalisation with suspected infection are common.¹⁸

Monitoring and interpreting rates of improvement

The expected rate of improvement depends on the depth of unconsciousness and the types of neuropathology present at the commencement of treatment, and the presence of comorbidities such as HIV and malnutrition. Improvements require opportunity, and are less likely if a child is bed-bound and malnourished. Physiotherapy helps; putting weak or contracted joints and limbs through a full range of movement, sitting upright in a chair, mobilisation out of a ward in a wheelchair or with other supports, having age-appropriate stimulation, natural light and a day–night sleep–wake cycle are all important.

Some children with CNS TB require anticonvulsants for seizures, or medications to reduce dystonia, such as baclofen or gabapentin. The interaction of these drugs and TB treatment, and their effects on conscious state and ability to cooperate with rehabilitation need to be considered, and balanced.

Sometimes, difficult treatment decisions arise when children are slow to improve. If there has been no objective improvement



Figure 2 Lateral skull X-ray of a child with tuberculosis with raised intracranial pressure.

in the 2 months of intensive phase of TB treatment, MDR TB should be strongly considered. Some questions in the assessment of improvement and in considering MDR TB as a possible cause of failure to improve are listed below.

Key questions in the assessment of improvement

- ▶ Adherence issues
- ▶ Has there been sufficient time for improvement?
- ▶ Have the objective markers of inflammation, including fever, improved?
- ▶ How deep was the unconsciousness or how severe were the neurological findings on commencing treatment? In this context, has there been sufficient time for improvement?
- ▶ Have there been sufficient opportunities for rehabilitation?
- ▶ Have there been iatrogenic complications that would slow the rate of improvement?
- ▶ Have other comorbid conditions such as malnutrition, anaemia and HIV been addressed?
- ▶ Are there any drug interactions that may affect improvement?
- ▶ Are there untreated complications, such as hydrocephalus, or epilepsy, or established brain injury as a complication of CNS TB?
- ▶ Is there any risk of exposure to MDR TB?
- ▶ Is the diagnosis of CNS TB likely to be correct? Could there have been pre-existing neurological or developmental problems?

CHRONIC TB-RELATED LUNG DISEASE

Pulmonary TB can progress to complicated chronic lung disease in children. This is especially the case in late presentation, relapsed TB, extensive lung disease, poor adherence, MDR TB or HIV.²⁰ The chronic lung pathologies may include cystic, emphysematous lung disease, pulmonary fibrosis, restrictive pleural disease or bronchiectasis. Higher bacterial load,^{20 21} coinfection with HIV²² and exposure to indoor air pollution from burning of biomass fuels appear to be risk factors for more severe TB-related lung disease.²³

Table 2 lists other diseases which can mimic or complicate TB-related chronic lung disease, and distinguishing clinical features. Chest radiograph can help distinguish between these types of chronic lung diseases. Chest CTs, if available, provide clear definition of bronchiectasis, pleural thickening and other chronic changes (figure 3).²¹ A miliary pattern (figure 4) is pathognomonic, but radiology is rarely conclusive. The working diagnosis will usually be based on a combination of clinical features, radiography and laboratory investigations.

Adjunctive treatments

Table 2 also outlines some of the adjunctive treatments that may help in some cases of specific chronic complicated TB and its differential diagnoses. In most cases, mobilisation, deep breathing exercises and physiotherapy are useful. Prolonged bed rest leads to dependent atelectasis, lobar collapse and reduced sputum clearance. Mobilisation, even if in a wheelchair, helps reinflate posterior collapsed lung segments and induces cough and aids sputum clearance. Many of the supportive care requirements listed in table 1 also apply to children with chronic TB-related lung disease.

Therapeutic trials and monitoring improvement

Sometimes, based on likely clinical diagnoses in table 2 or as adjunctive treatments for chronic lung disease, therapeutic trials are needed. These may be of bronchodilators, corticosteroids,

nebulised hypertonic saline, diuretics, medications to reduce pulmonary hypertension, judicious use of prophylactic antibiotics and other therapies. Where possible such trials should have an objective assessment of effect, and treatments should be discontinued if there is no objective effect. A standardised 1–3 min walking or step exercise test,²⁴ modified for the child, with measurement of respiratory rate, heart rate, oxygen saturation and spirometry or peak expiratory flow rates if the child is capable, at baseline and following exercise can be useful (see box 1). This can guide decision about the effectiveness of interventions, the need for oxygen for mobilisation and the safety of hospital discharge.

Nutrition in all complicated forms of TB

Almost all children with TBM, chronic pulmonary TB and other forms of disseminated TB have weight loss, many have severe wasting and stunting. Malnutrition is a significant risk factor in turning latent TB into active TB,²⁵ and a body mass index (BMI) <16 is associated with significant higher mortality in adults with TB.²⁶ Patients with active TB have decreased blood concentrations of micronutrients, including retinol, vitamins C and E, zinc, iron and selenium.²⁷ If not addressed, the protein-calorie malnutrition worsens even after children commence treatment, because of chronic inflammation, anorexia (loss of appetite because of medications and general illness) and poor food intake.

Nutrition should be instituted as soon as possible, either orally or through nasogastric tube, according to WHO guidelines for the level of malnutrition,³ together with the TB drugs. Children with TB should be weighed regularly, given a nutritious diet, daily micronutrients and have their food intake monitored. Children on isoniazid should be on pyridoxine. Iron supplementation should be given to children with iron deficiency,²⁸ as manifest by a low haemoglobin, low mean cell volume and a high red cell distribution width.

Administering nutrition to all those with malnutrition in a busy children's ward is a full-time job, so it is important to a well-functioning nutrition unit and nurses who are informed and enthusiastic about nutrition. Plotting weight, mid-upper arm circumference and BMI in older children helps monitor progress.

Identifying and treating comorbidity

All children with TB should have an HIV test, and if positive commenced on antiretroviral therapy (ART) in a staged fashion. TB treatment should be started first, followed by ART as soon as possible thereafter, at least within 8 weeks of the start of TB treatment. Where a CD4 count can be done, if below 50 cells per mm³, ART should be commenced within 2 weeks of the start of TB treatment. WHO has detailed guidance for national TB programmes on the management of TB and HIV in children.²⁹

Risk assessment and understanding the patient's journey

Understanding the patient's journey, from the time of first symptoms to presentation and effective treatment is important. For many children, this can involve a family member having TB, multiple presentations to health professionals, previous courses of antibiotic treatment or truncated courses of TB treatment, non-adherence or defaulting from treatment, premature discharge from a health facility and relapse with a more severe form of TB. Understanding the timeline and journey can help in risk assessment at the time of discharge planning, and it can help understand families' experiences with health services.

Risk assessment is needed at milestones in the treatment. The risks are different on admission, in acute and chronic stages, and when contemplating discharge. Early risks include acute medical and nutritional complications, including nosocomial infections,

Table 2 Differential diagnostic and treatment considerations in chronic lung diseases in children, including chronic and complicated pulmonary TB

Diagnosis	Clinical and X-ray features, investigations in favour of diagnosis	Treatment*
Persistent or recurrent pneumonia	Rapid onset or worsening of tachypnoea, hypoxaemia, fever New changes on chest X-ray Consider recurrent viral infections as a cause, rather than chronic respiratory disease	Broad-spectrum antibiotics trimethoprim–sulfamethoxazole for PjP if HIV positive Oxygen if SpO ₂ <90%
Bronchiectasis	Purulent sputum Halitosis Clubbing Localised signs on chest X-ray	Chest physiotherapy Treatment of intercurrent infections (base antibiotics on sputum culture if possible) Erythromycin daily dose Oxygen if SpO ₂ <90% Oral hygiene
Chronic airways disease: may be reactive or non-reactive/asthma	Wheeze Chest X-ray may define focal (such as endobronchial lymph node obstruction) or diffuse nature of airflow obstruction Low PEF ₁ or low FEV ₁ (on spirometry)	Trial of salbutamol (measuring PEF ₁) Trial of prednisolone or inhaled corticosteroid/ long acting beta-2 agonist
Bronchiolitis obliterans	Chest X-ray air-trapping and atelectasis	Oxygen
Pulmonary hypertension	Examine for signs of heart failure—tachycardia, raised jugular venous pressure, loud pulmonary second sound Cardiomegaly on chest X-ray	Furosemide Sildenafil Enalapril if systemic hypertension Oxygen if SpO ₂ <90%
Additional diagnoses to consider if HIV positive		
<i>Pneumocystis</i> pneumonia	Rapid onset or worsening of tachypnoea, hypoxaemia, fever New changes on chest X-ray—fine reticular interstitial or perihilar pattern, no effusions	Broad-spectrum antibiotics, trimethoprim–sulfamethoxazole for PjP Oxygen
Lymphoid interstitial pneumonitis	Generalised lymphadenopathy Clubbing Chest X-ray: multiple nodular densities throughout the lung fields	Prednisolone Bronchodilators may be useful
IRIS	Paradoxical worsening in signs weeks—months after starting ART, lymphadenopathy, parotid gland swelling, X-ray consolidation, fever	TB treatment Prednisolone for severe IRIS
<i>Aspergillus</i> (can also occur in HIV-negative immune-suppressed children)	Exposure to building dust Immune suppression (eg, long-term steroids) Septated hyphae on sputum wet smear Chest X-ray nodular consolidation or cavitation	Amphotericin Voriconazole
Other complications to consider if there is poor response to TB treatment		
TB non-adherence/relapse	History of likely non-adherence to TB treatment Changes consistent with TB on chest X-ray GeneXpert MTB/Rif positive on gastric aspirates or sputum Strongly positive Mantoux test	Recommence TB treatment and hospitalise or supervise closely
MDR TB	Deterioration or no improvement despite good adherence to TB treatment Changes consistent with TB on chest X-ray History of exposure to MDR contact GeneXpert MTB/Rif positive on gastric aspirates or sputum Strongly positive Mantoux test	MDR TB treatment, for example, Ciprofloxacin Amikacin or kanamycin Ethionamide Cycloserine

If the initial diagnosis is uncertain, or no improvement after one of supervised TB treatment: Take a detailed history of treatment and adherence to TB and other medications, MDR contact, check for signs of HIV, check for effusion, wheeze, loud pulmonary second sound, signs of heart failure, clubbing, anaemia, lymphadenopathy, do an HIV test, cardiac Echo, sputum smear for GeneXpert, AFB stain, TB culture, sputum wet preparation for fungal elements and Mantoux test. Do spirometry or PEF₁ if the child is old enough, a standardised exercise tolerance test, and do a chest CT if you can.

*Treatment includes ART if HIV positive.

AFB, acid fast bacilli; ART, antiretroviral therapy; FEV₁, forced expiratory volume in 1 s; IPT, isoniazid preventative therapy; IRIS, immune reconstitution inflammatory syndrome; MDR, multidrug resistant; PEF₁, peak expiratory flow rate; PjP, *Pneumocystis jirovecii* pneumonia; SpO₂, cutaneous oxygen saturation using pulse oximetry; TB, tuberculosis.

and chronic phase risks include being the potential for non-adherence if discharged too early, or risks of chronic adverse health and developmental outcomes.

Psychological support to the child and family, providing a child or adolescent friendly and stimulating environment and education opportunities are important for recovery and optimising outcome.

For children who present too late to be cured and even for those in whom cure is uncertain or possible, providing palliative care is an important component of management. Sources of pain include raised intracranial pressure, pleuritic inflammation, bony infiltration or erosion, neuropathic pain from nerve compression in Pott's disease or from isoniazid and chest wall muscle ache from coughing. Nausea and vomiting from drugs or

gastrointestinal TB, the distress of breathlessness and coughing and night sweats are other symptoms that may need treatment. Following a pain ladder for appropriate use of paracetamol, oral morphine and codeine, using ibuprofen, amitriptyline or gabapentin for neuropathic pain and being aware of drug side effects and interactions are all important.³⁰ Many families prefer palliative care to be provided in their homes, successful examples exist of community-based palliative care for TB patients.³¹

Discharge planning and follow-up

Since at the time of admission the outcome for children with severe complicated TB is often unpredictable, the parents should be advised of a realistic range of functional outcomes for their



Figure 3 CT chest of a child with chronic cystic lung disease and bronchiectasis due to tuberculosis.

child. They should also be advised that it takes time to determine the prognosis and outcome, that everyone in the ward will do their best to optimise the outcome and that they—the parents—have a large role in helping the child improve, by adhering to medicines and providing supportive care, love and encouragement. Parents should be informed that the hospital treatment is long; 2 to 9 months of hospitalisation depending on the rate of recovery. Such information puts parents and staff in a much better position to accept positive or negative outcomes. It is important not to raise unrealistic expectations, but also important not to take away hope, which is essential for parent's mental health and the recovery of the child.

Families should be fully informed early of the steps that are needed prior to discharge, including nutrition and physical rehabilitation. Some of the steps prior to discharge are outlined in [box 2](#). These steps can be worked towards steadily during the child's time in hospital, so that the parents and the child understand that progress is being made. Depending on the family's social circumstances and how far they live from the hospital, and if certain community healthcare services are available ([box 2](#)), much of the treatment and rehabilitation can occur closer to

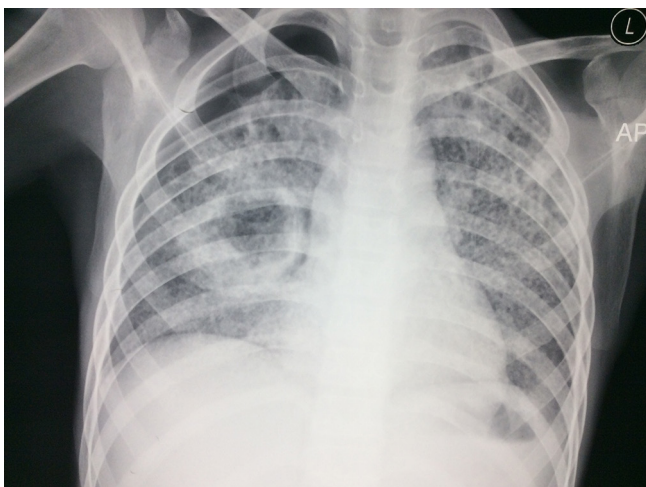


Figure 4 Severe miliary tuberculosis with cavitation and pneumothorax.

Box 1 Simple exercise test

Start with a 1 min walking test, between cones separated by 10 m

Baseline measurements:

1. Respiratory rate (breaths per minute)
2. Heart rate
3. Oxygen saturation at rest
4. Self-assessment of respiratory difficulty
5. Peak expiratory flow rate or spirometry if it can be done (best of three attempts).

Ask the child to walk as fast as they can for 1 min, and then measure

1. Respiratory rate
2. Heart rate
3. Oxygen saturation
4. Self-assessment of respiratory difficulty
5. Peak expiratory flow rate or spirometry if it can be done (best of three attempts).

Do this test weekly. Progressively increase the exercise duration to 2 and then 3 min and the distance between cones to 20 m as tolerated.

Graph progress so that the child can see improvement. Point out to the child and the family the type of activities that can be done safely, if they can walk for 1 min without getting breathless or needing oxygen.

home. Transition from hospital to outpatients and community requires services to be in place, and good communication to occur. Most countries have national TB programmes and WHO has guidance on integrating childhood TB management into national programmes, and family and community follow-up.²⁹ A roving outreach TB nurse who visits families in their homes can greatly assist in follow-up.³² Understanding the environment to which the child is being discharged, the resources of the family and their vulnerabilities can help assess the risks of receiving adequate care after discharge.

There are a number of barriers to care for children with chronic complex healthcare needs, including access to services if they live in rural areas, lack of chronic disease programmes, perceived competition for hospital beds and the ethics of setting limits on escalation of care. However, the gains that can be made in health and quality of life if children are provided with holistic comprehensive care by hospitals within their community and the support this can be to their families are immense.

Watt³³ speculated that addressing the inverse care law in deprived communities required a personal doctor, who knew his or her patients well, could see their problems in the family and community context and worked with patients over a long time to reverse risks and prevent complications. A personal doctor or child health nurse who takes responsibility for providing, coordinating and monitoring care is also needed for the best outcomes in complicated childhood TB and other chronic paediatric illnesses. In the era of the Sustainable Development Goals children with chronic conditions deserve this, wherever they live.

Box 2 Steps prior to discharge of children with complicated tuberculosis

The child is clinically well, and the original symptoms have resolved:

- ▶ Not in severe respiratory distress
- ▶ Not requiring oxygen
- ▶ Not febrile
- ▶ Eating well and gaining weight
- ▶ Ascites or plural effusions resolving
- ▶ Mobilising
- ▶ Swallowing treatment well
- ▶ Exercise tolerance test suggests the child can cope outside hospital with required daily activities.

The child and their parents or guardians understand about their condition:

- ▶ Understand they have tuberculosis (TB)
- ▶ Understand the duration of treatment required
- ▶ Understand the need to take treatment daily, even if they are feeling well
- ▶ Understand the consequences of stopping or interrupting their treatment
- ▶ Understand the importance of nutrition, fresh air and activity to recovery.

HIV test done

- ▶ Understand the result
- ▶ Commenced on treatment if positive.

Family screening completed

- ▶ Family members with TB are on treatment
- ▶ Siblings under 5 years of age who are exposed but asymptomatic are on isoniazid preventative therapy.

Registration and ongoing treatment properly organised

- ▶ Registered with the national TB Programme.
- ▶ The clinic in which the child will receive treatment has been identified, and it is certain that the clinic can provide the necessary therapy.
- ▶ A directly observed treatment, short-course provider is identified, and has undergone education about his/her role.

Community-based or outpatient TB and rehabilitative healthcare is organised and the child is linked with this

- ▶ Rehabilitation can continue in the community, with physiotherapy, growth monitoring, assessment of adherence and symptoms if services are in place.

An outreach nurse or health worker visits the child in their home

- ▶ Assessment of the environment and its suitability for the child in that phase of treatment and rehabilitation.
- ▶ Assessment of what else the family needs in terms of social, nutritional and financial support.

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