Introduction

Tuberculosis (TB) in children has become a serious health issue worldwide and new estimates reveal that at least 67 million children have been infected by TB with 850,000 developing the active disease. This is compounded by the fact that two million of these children have been infected by multi-drug resistant TB, leading to 25,000 cases requiring expensive and toxic treatment. Drug resistant TB (DR-TB) refers to TB resistant to any of the first line anti-TB drugs. A report, published in The Lancet Infectious Diseases in June 2016, warns that the identified cases of drug-resistant TB in children are the tip of the iceberg and there is a large unmet need for diagnoses, drug susceptibility and appropriate treatment.¹

Defining palliative care for children

The World Health Organization (WHO) defines Palliative care for children as a special albeit closely related field to adult palliative care which includes:

- The active, total care of the child’s body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate a child’s physical, psychological and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources: it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children’s own homes.²

Drug-Resistant Tuberculosis (DR-TB)

There are two types of DR-TB, Multidrug Resistant TB and Extremely Drug Resistant TB. Multidrug-resistant TB (MDR-TB) refers to TB resistant to rifampicin and isoniazid which are the most effective anti-TB drugs. Extensively-drug resistant TB (XDR-TB) is resistant to rifampicin and isoniazid as well as the fluoroquinolones and injectable second line agents.

The need for palliative care for children with DR-TB cannot be overstated. DR-TB is associated with high morbidity and mortality. The child with this type of illness needs
hospitalisation for at least the first six months, which may be extended if response to treatment is poor or complications arise. Duration of treatment lasts from 18 – 24 months. Adherence is a challenge due to side effects, duration of therapy and pill burden. In low resource settings, poor adherence is exacerbated by long distances from health care facilities and transport costs.

The nature of DR-TB requires that the child and family should receive palliative care. Pain, dyspnoea, nausea and vomiting are often the main physical symptoms, whilst stigma and isolation bring about social and spiritual pain. Treatment for XDR TB may result in psychosis. Mortality in DR-TB is high, with 60% in XDR and 40% in MDR\(^\text{iii}\). The family needs support to care for child throughout the period of treatment and preparations made for end of life care where the prognosis is poor.

As cases of DR-TB are expected to rise in four countries (India, the Philippines, Russia and South Africa) by 2040\(^\text{iv}\), we can expect that morbidity and mortality will also rise in these countries. Children’s palliative care (CPC) services should be developed and strengthened to meet the needs of the sick and dying children in these and other countries.

**Challenges**

There are few or no palliative care services for children in most countries throughout the world, particularly in low and low middle-income countries. A recent study showed that over 21 million children globally need access to palliative care, with over 8 million requiring specialist palliative care services. In South Africa alone, there are approximately 801,155 children needing palliative care with over 304,400 needing access to specialist services. Yet the capacity to deliver palliative care is often limited, for example in South Africa less than 5% of the children needing care are receiving it\(^\text{v}\), which is as low as 1% in Zimbabwe\(^\text{vi}\).

There are many barriers to delivering palliative care to children and young people, including the fear of using opioids for children, a lack of palliative care knowledge in most healthcare providers, lack of integration of CPC into the health system, lack of policies on CPC and a lack of community awareness and understanding of CPC. Integration of palliative care into existing services e.g. those for children and young people with life-threatening and life-limiting illnesses, is essential to improve accessibility to those who need it. The provision of children’s palliative care is also a core component of the World Health Assembly (WHA) resolution on palliative care which also stresses the importance of palliative care within Universal Health Coverage.

**KEY POINTS**

- DR-TB is associated with high morbidity and mortality.
- 801,155 children in South Africa need palliative care with 304,441 needing specialised palliative care.
- Palliative care should be integrated into primary, secondary and tertiary health care services.
- Health and allied health workers should be trained in palliative care.
- There should be equitable access to pain relieving and other palliative medicines.
Recommendations

1. The Integration of children’s palliative care into primary, secondary and tertiary healthcare services.

2. Training of all health and allied health workers in children’s palliative care, ensuring that training is provided through basic training and continuing education, intermediate training and specialist palliative care training.

3. Ensuring equitable access to pain-relieving and other palliative medicines, including opioids in formulations suitable for children.

4. Ensure that care is provided in a holistic manner i.e. physical, psychological, social and spiritual.

5. Sensitise the community to the need for children’s palliative care, identifying individuals who may be local CPC champions.

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i University of Sheffield, Imperial College London (June 27, 2016) Revealing the global burden of drug-resistant tuberculosis in children. *The Lancet Infectious Diseases.*

ii World Health Organization, 1998 (a)

iii https://www.new-medical.net/news/20170511/study


