International Children's Palliative Care Network (ICPCN) Position Statement on drug resistant TB (DR-TB) in children

Purpose	Policy statement
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Summary	This statement explains the need for palliative care for children and young adults with drug resistant TB.
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Introduction

The International Children's Palliative Care Network (ICPCN) is the only global network working to reach the estimated 21 million children worldwide needing palliative care who have a right to access such care. It is a network of individuals and organisations committed to the development of children's palliative care worldwide. The vision of ICPCN is to live in a world where every child and young person with a life-limiting or life-threatening condition and their families can receive the best quality of life and care regardless of which country they live in. We believe that the total needs of life limited and life threatened children should be met to encompass physical, emotional, spiritual and developmental aspects of care. To achieve this, children's palliative care must be acknowledged as a unique and specialist service.

ICPCN aims to:

- Assist services across the world to develop and meet the total care and support needs of life-limited children and their families.
- Advocate for and raise awareness of children's palliative care and the specific needs of life-limited or life-threatened children and their families.
- Campaign for the global development of children's palliative care services.
- Increase the international evidence base for children's palliative care.

What is drug resistant TB (DR-TB)?

Drug resistant TB (DR-TB) refers to TB resistant to any of the first line anti-TB drugs. Multi-drug 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 source

of DR-TB in children is often a close contact whilst past treatment for TB is also an important factor. These forms of TB do not respond to the standard six-month treatment with first-line anti-TB drugs and can take up to two years or more to treat with drugs that are less potent, more toxic and much more expensive.[i] Extensively drug-resistant TB has a high mortality rate, especially among children and those infected with HIV.[ii]

TB is among the top ten causes of child mortality globally. TB mainly affects the young and vulnerable, 80% of child TB deaths occur in children younger than five years.[iii] In 2016, 6.9% of children under 5 years were reported to have TB.[iv] The Stop TB Partnership reports that of the estimated one million children who fall ill with TB every year, 32 000 are diagnosed with MDR[v]. However, the Lancet Report on Infectious Diseases (June 2016) warns that the identified cases of DR-TB in children are a tip of the iceberg and there is large unmet need for diagnosis, drug susceptibility and appropriate treatment.

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 care providers must evaluate the 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 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[vi].

The goal of palliative care is the relief of suffering and the improvement of quality of life. It is a holistic and professional approach to caring that includes pain and symptom management. Its provision is applicable throughout the lifespan from the peri-natal period, into childhood, adolescence and young adulthood and throughout adulthood.

DR-TB is one of the causes of serious health suffering (SHS) and The Lancet Commission report states that every year almost 2.5 million children with SHS die needing palliative care and pain relief, with more than 98% living in developing regions[vii]. This abyss in the provision of palliative for children must be corrected.

Palliative care in the context of Drug Resistant TB in children

Diagnosis of drug-resistant TB in children is difficult and it often takes a long time before it is made. When it is finally diagnosed it is the beginning of a long journey of treatment for close on two years. The treatment consists of multiple drugs which produce unpleasant side effects. Caring for a child with DR-TB is difficult due to its complex nature, heavily laden with medical and psychosocial issues. Palliative care provides a holistic approach for care, needed to be initiated right at the time of diagnosis and continued alongside curative treatment to improve the quality of life of the child and his/her family. Pain and symptom control forms the core of care and is directed at all types of pain, that is, physical, emotional, social, spiritual, cultural and educational. A team of health professionals including doctors, nurses, social workers, spiritual leaders and community caregivers exist to address the challenges facing children and families with DR-TB.

Due to late diagnosis of DR-TB in children and delayed treatment, many of them will die, especially those living in poor resource settings, hence end-of-life care forms an integral part of care provision. Where death is imminent, planning for such an event should take place well

in advance to ensure a dignified death and mitigate the impact of grief on family members including siblings.

Key challenges facing children and families with DR-TB

- Pain and other symptoms
- Long term treatment (up to two years)
- Unpleasant side effects from drugs
- Hospitalisation for long periods
- Stigma and isolation
- Missing out on education
- Lack of stimulation in young children
- Financial hardship

Palliative care a children's right to health

Children's palliative care is a basic human right for all children living with life threatening illnesses. The Convention on the Rights of the Child (General comments No.15 (2013) on Article 24 paragraph 1), states that *"Children are entitled to quality health services, including prevention, promotion, treatment, rehabilitation and palliative care services. At the primary level, these services must be available in sufficient quantity and quality, functional, within the physical and financial reach of all sections of the child population, and acceptable to all".*[viii] Furthermore no 27 of the General comment states that "*States should ensure an appropriately trained workforce of sufficient size to support health services for all children*".

Call to Action

In May 2014, the World Health Assembly (WHA 67.19)[ix] passed a resolution which called for member states to:

- Develop, strengthen and implement palliative care policies.
- Support palliative care initiatives including education and training, quality improvement and availability of medicines essential for the provision of palliative care.
- Provide support to caregivers.
- Include palliative care as a part of integrated training for all healthcare workers who routinely work with people with serious illness.
- Ensure access to essential medications.
- Foster partnerships between government and civil society to increase access to palliative care.

To ensure the best possible palliative care for children countries should:

1. Integrate children's palliative care into health care services for children.
2. Include children's palliative care in relevant health, welfare and educational policies.
3. Include palliative care in Universal Health Coverage, it is an essential component thereof.
4. Ensure training for health care workers in children's palliative care and the development of mentor programmes to support these professionals in their work settings.
5. Ensure equitable access to pain-relieving and other palliative medicines, including opioids. This may necessitate a review of the Essential Medicine Lists to include palliative medicines.

6. The Lancet Commission has developed and recommends the use of an Essential Package of palliative care. This essential package includes medicines, equipment and human resources which are affordable even in low-income countries.

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[i] ESPID Reports and Reviews. Multidrug-resistant Tuberculosis in Children: The Pediatric Infectious Disease Journal. Volume 31, Number 9, September 2012.

[ii] World Health Organization. Multidrug and Extensively Drug-resistant TB (M/XDR-TB): 2010 Global Report on Surveillance and Response. Geneva, Switzerland

[iii]Dodd PJ et al. The global burden of tuberculosis morality in children: a mathematical modelling study. Lancet Glob Health 2017;5:e898-e906.

[iv] World Health Organization. Global Tuberculosis Report. 2017

[v] 2018FEB_TB HLM ChildhoodTBmessages asks.

[vi] World Health Organization: 2002

[vii] The Lancet Commissions. Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage: Published online October 12 2017.http://dx.doi.org/10.1016/SO140-6736(17)32513-8

[viii] Convention on the Rights of the Child. General comments No.15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health (Art.24):2013.

[ix] Sixty Seventh World Health Assembly: Strengthening palliative care as a care component of comprehensive care throughout the life course. Geneva. 2014