

Palliative care for children with Rare Diseases

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International Children's Palliative Care Network

Need for children's palliative care

More than 21 million children need palliative care worldwide annually

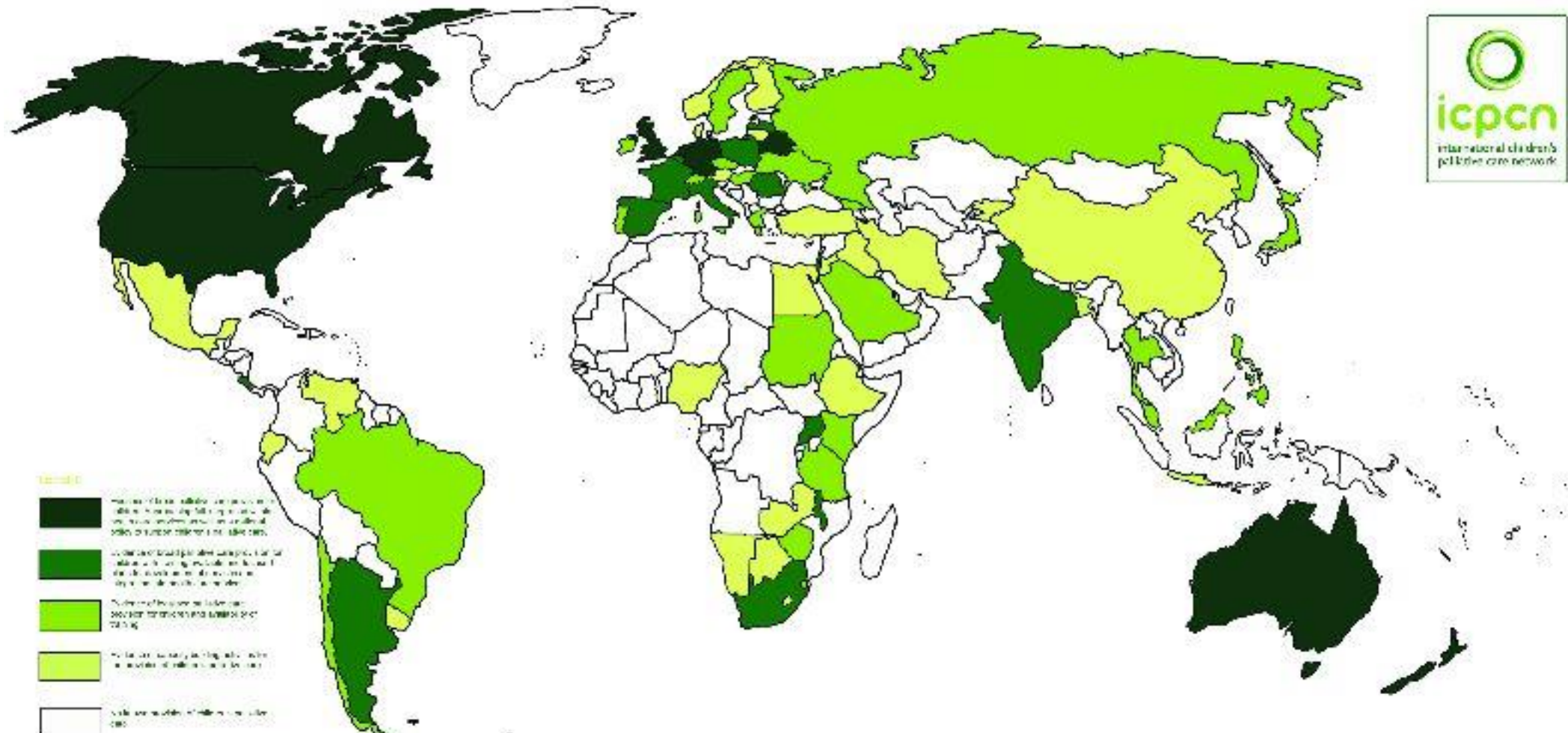
More than 8 million in need of specialised palliative care

Provision is less than 1%

Estimating the global need for CPC: Journal of pain and symptom management

Children in need of palliative care at end of life almost 1.2 million

WHO and WHPCA, Global atlas of palliative care at end of life: January 2014



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Lancet Commission

- More than 5.3 million children < 15 years experience Serious Health-related Suffering (SHS) each year.
- 1/3rd children who died in 2015 had SHS.
- Every year at least 2.5 million children die in SHS >90% in LMICS

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Source: Knaul FM, et al.
Alleviating the access abyss
in palliative care and pain
relief—an imperative of
universal health coverage:
the Lancet Commission
report. The Lancet. 2017

[http://www.thelancet.com/
commissions/palliative-care](http://www.thelancet.com/commissions/palliative-care)

www.miamledu/lancet

- Serious health-related suffering (SHS) is associated with illness or injury of any kind that could be ameliorated by palliative care and pain treatment¹.
- More than 5.3 million children aged 15 years or younger experience SHS each year worldwide.
- Children and their families have specific and intensive palliative care needs that can easily be overlooked because the absolute number of paediatric patients is low compared with adults².
- Children account for 9% of patients who experience SHS, 5% of total days with SHS days, and 6% of days in pain.
- One third of all children who died in 2015 experienced SHS.
- Every year nearly 2.5 million children die needing palliative care and pain relief and more than 98% of these children are from developing countries.
- Over 90% of all paediatric deaths associated with SHS in low-income countries are avoidable.
- In low-income countries, childhood deaths account for more than 30% of all deaths associated with SHS, compared with less than 1% in high-income countries.
- More than 50% of the burden of SHS in children in low-income countries is associated with HIV disease.
- At best international medicine prices, the cost of covering the unmet need for opioid analgesics in all children with SHS in low-income countries is just over 1 million USD per year, which is only 63 cents per child in need.

¹The most common SHS health conditions are: atherosclerosis; cerebrovascular disease; chronic ischaemic heart disease; congenital malformations; degeneration of the CNS; dementia; diseases of the liver; haemorrhagic fever; HIV disease; inflammatory disease of the CNS; injury, poisoning, and external causes; leukaemia; lung disease; cancer; musculoskeletal disorders; non-ischaemic heart disease; premature birth and birth trauma; protein energy malnutrition; renal failure; and tuberculosis. The common SHS physical symptoms are: pain, weakness, fatigue, shortness of breath, nausea and vomiting, constipation, diarrhoea, dry mouth, itching, and wounds and bleeding. The most common psychological SHS is anxiety and worry, depressed mood, delirium or confusion, and dementia.

²Connor SR, Bernedo MCS. Global atlas of palliative care at the end of life. Geneva: World Health Organization, Worldwide Palliative Care Alliance, 2014.

Why palliative care for children with Rare Diseases?

- 95% of Rare Diseases have no treatment
- 30% of children with rare diseases will not live to see their 5th birthday
- Rare diseases are responsible for 35 % of deaths in the first year of life
- Sometimes there is a need for 24 hour care
- Parents and siblings suffer emotionally and socially
- Depression and anxiety

Definition of Palliative Care for Children

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.

SPIRIT

MIND

BODY



FAMILY



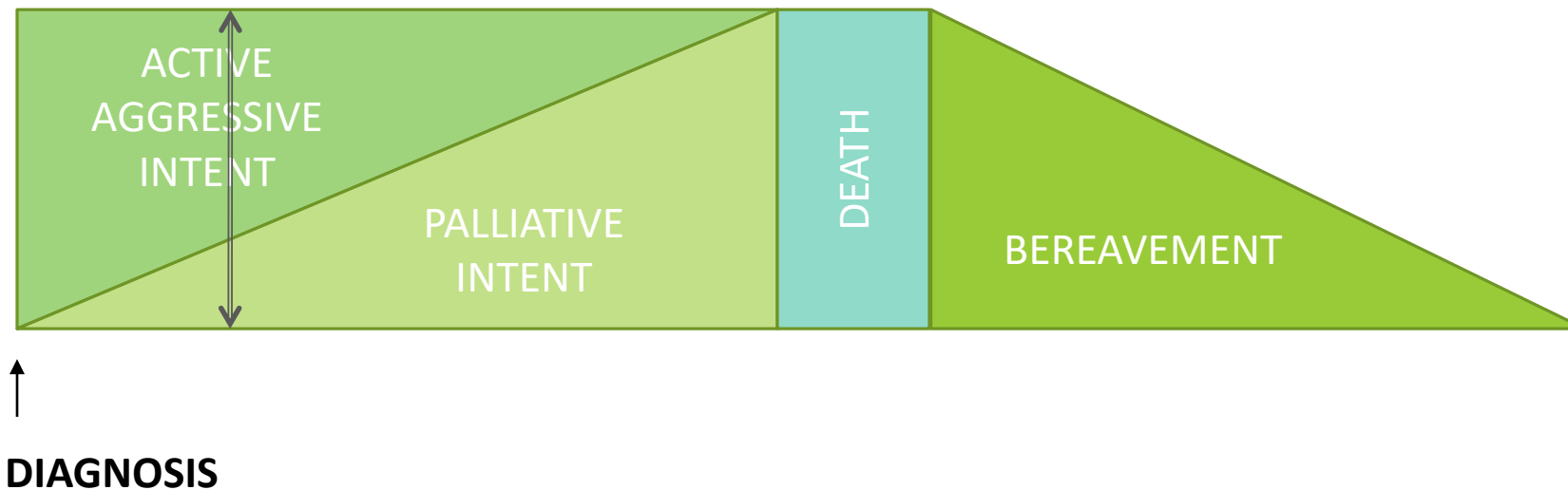
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Definition

It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.

Figure 2: Modified integrated palliative care services model (Forager, 1997)



Definition

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... even at the patient's home!

World Health Organization 2002



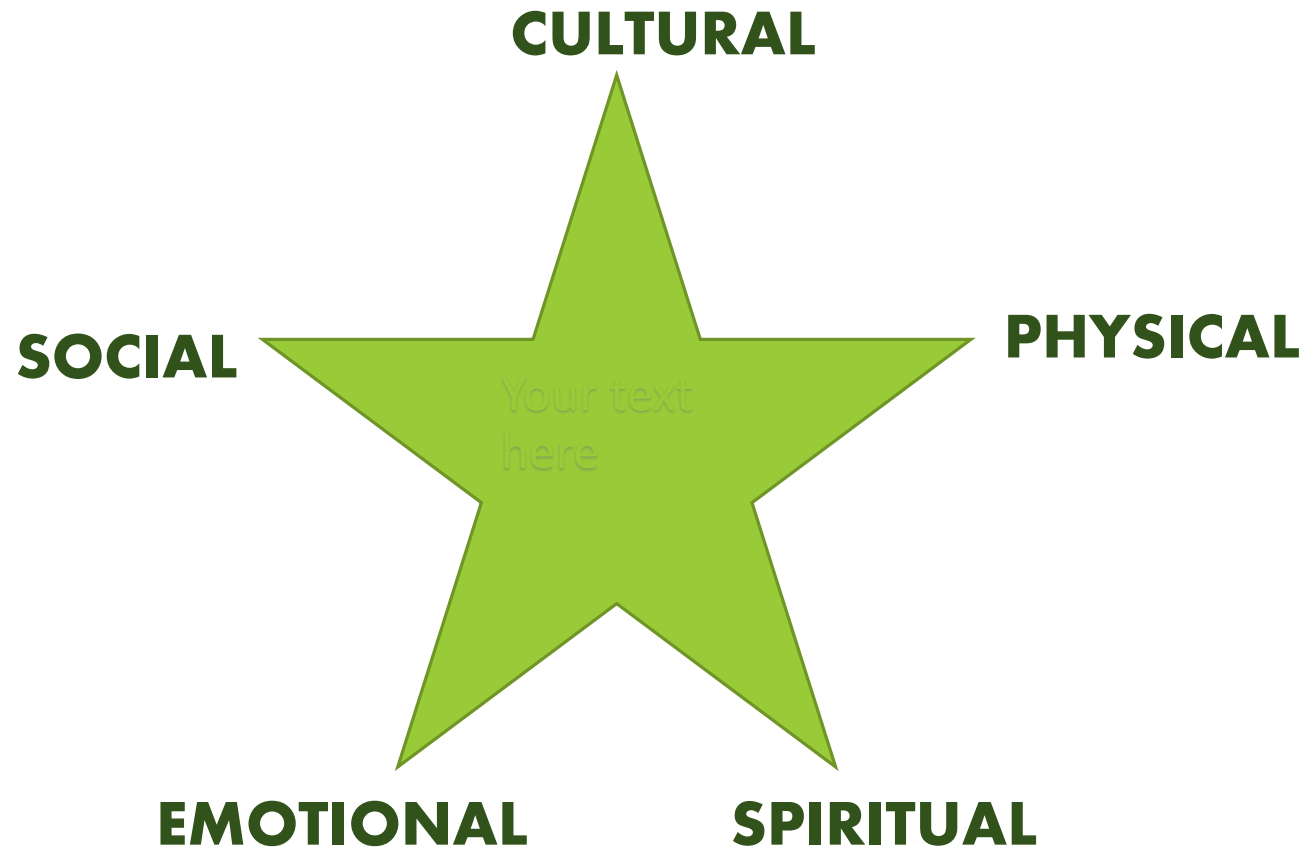
Palliative Care...

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death.

Goal of Palliative Care

- Relieve suffering
- Improve quality of life
- For the patient and family

PAIN IS NOT JUST PHYSICAL: IT IS TOTAL

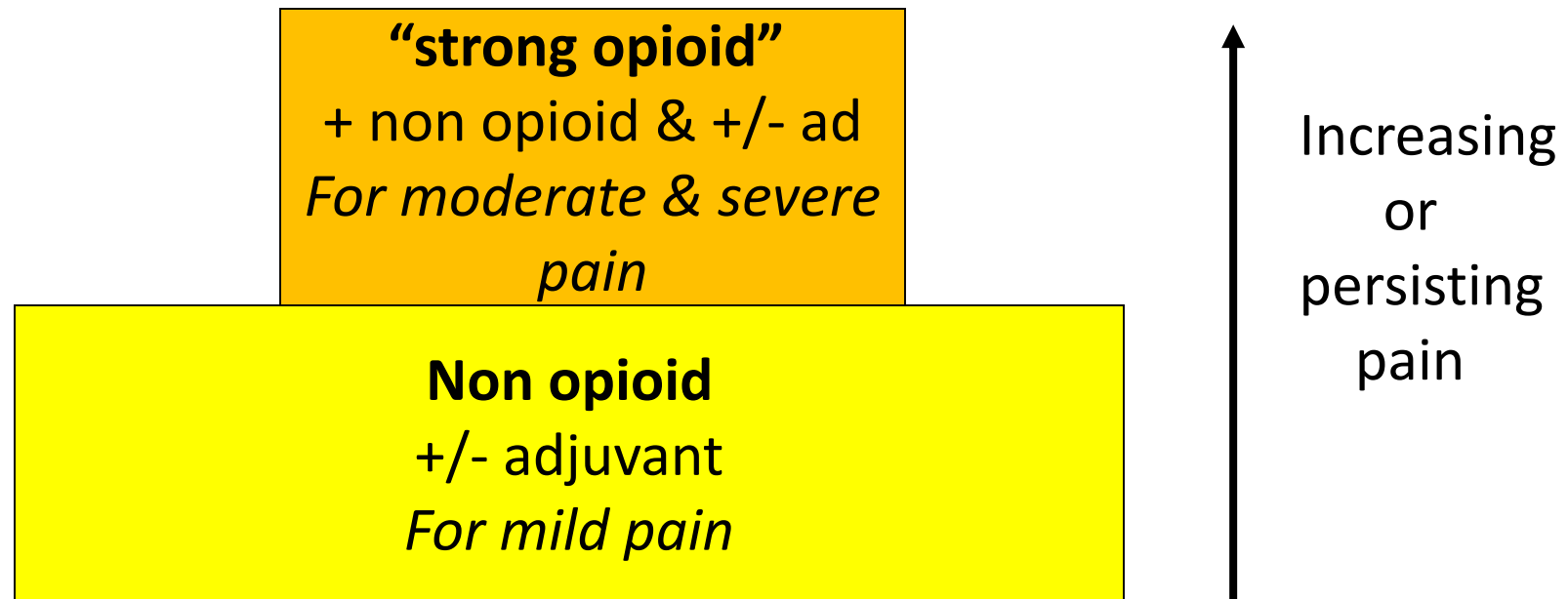


Why children continue to suffer pain?

- Children express pain differently to adults particularly children who are not verbal such as premature and term babies, infants and severely disabled children;
- Training and education of health care professionals in the evaluation and treatment of pain in children is poor;
- Many, if not the majority, of health care professionals are not competent or lack confidence in prescribing analgesic medication for children, especially opioids;
- Opioids are under used due to unfounded fears, myths and misconceptions especially in regards to adverse effects and addiction;
- Acknowledgement and support of spiritual pain and emotional conflict is mostly ignored in children as is the impact of culture and language.

WHO 2-step analgesic ladder

NO PAIN



Lancet Commission Report

‘Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage’

Examples of Key messages (5 in total):

- 1. Alleviation of the burden of pain, suffering, and severe distress associated with life-threatening or life-limiting health conditions is a global health and equity imperative.*
- 2. An affordable, Essential Package of palliative care and pain relief interventions should be made universally accessible*

“Developing and presenting an Essential Package specifically for pediatric palliative care should be high priority.”

(Knaull et al 2017)

A Human Right

“Relief of suffering is a common
goal of medicine and human
rights”

Margaret Somerville, eminent scholar
of medical law
1992

UN Convention on the Rights of the Child

Ratified by all but one country:

- In every situation regarding a child , the best interests of the child shall be the primary consideration
- Right to Life
- Right to best attainable state of health
- Health includes physical, mental and spiritual health

Report of UN Special Rapporteur on the right to the highest attainable standard of health

“Palliative care for young children is an obligatory part of health services...[They] have the right to receive the necessary physical, social, psychosocial and spiritual care to ensure their development and promote their best quality of life... Health systems must have adequately trained professionals to assess and treat pain in children of different ages and developmental stages and ensure the availability of paediatric diagnostic procedures and palliative care medicines in paediatric formulations...”

World Health Assembly (WHA) Palliative Care Resolution 67.19 (2014)



WHA Palliative Care Resolution 67.19 (May 2014)

- 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.

Hats on for Children's Palliative Care

www.hatson4cpc.org



SHOW YOU CARE - WEAR A HAT TO WORK OR SCHOOL FOR CHILDREN NEEDING PALLIATIVE CARE

Please HELP US help them.

1. Wear a hat on Friday 12 October
2. Post a picture on social media using #HatsOn4CPC
3. Donate to ICPCN or a children's hospice or palliative care service.

Thank you



References

1. WPCA and WHO, Global Atlas of Palliative Care at the End of Life, London, 2014.
2. WHO. 2012. WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses
3. Knaul et al on behalf of the Lancet Commission on Palliative Care and Pain Relief Study Group. (2017) Alleviating the access abyss in palliative care and pain relief – an imperative of universal health coverage: the Lancet Commission report. *The Lancet*. Published online October 12, 2017
4. Report Of the Un Special Rapporteur on the right to highest attainable standard of health , Dainius Puras, A/70/213,30 July 2015, [Http://ohchr.org/EN/Issues/Health/Pages/SRRightHealthIndex.aspx#para52](http://ohchr.org/EN/Issues/Health/Pages/SRRightHealthIndex.aspx#para52)

References

4. WHA Resolution "Strengthening of palliative care as a component of comprehensive care throughout the life course", WHA67,19 9th plenary meeting, A67/VR/9, 24 May 2014, https://apps.who.int/gb/ebwha/pdf_files/WHA67//A67_R19-en.pdf