

Principle of Children's Palliative Care

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Objectives of the Session

- 1) What is Children's Palliative care (CPC)?
- 2) What are some things that can improve the quality of life for children and their families? (Principles of CPC)
- 3) What are the challenges that we face in providing CPC?

WHO's 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. **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 and alleviate 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 centers and even in children's [own] homes**.


Palliative care...

- Provides relief from pain and other distressing symptoms
- Affirms life and enhances quality of life
- Offers a support system to help children live as active as possible until death
- Helps the family cope during the child's illness and in their own bereavement
- It uses a team approach to address the needs of children and their families
- It is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life
- It is applicable wherever the child needs care

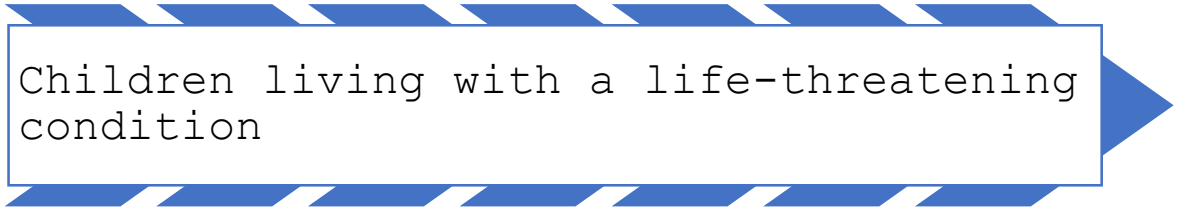
When is the best time for PC to begin for a child with a life-threatening disease?

- a) When there are no more curative treatment options available
- b) When the child has less than 6 months to live
- c) When the family can no longer afford treatment
- d) When the child is diagnosed with a life-threatening disease

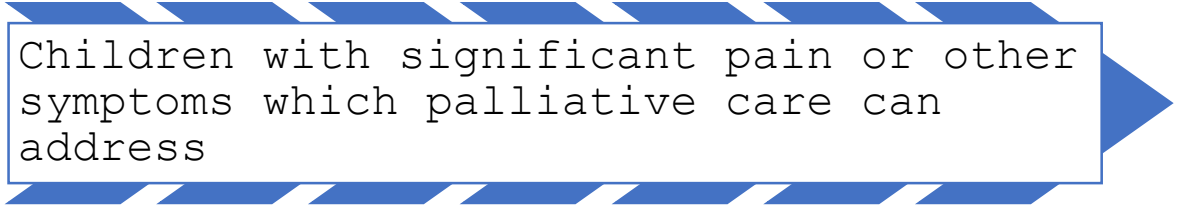
Which conditions need Palliative Care?



Children living with a progressive condition

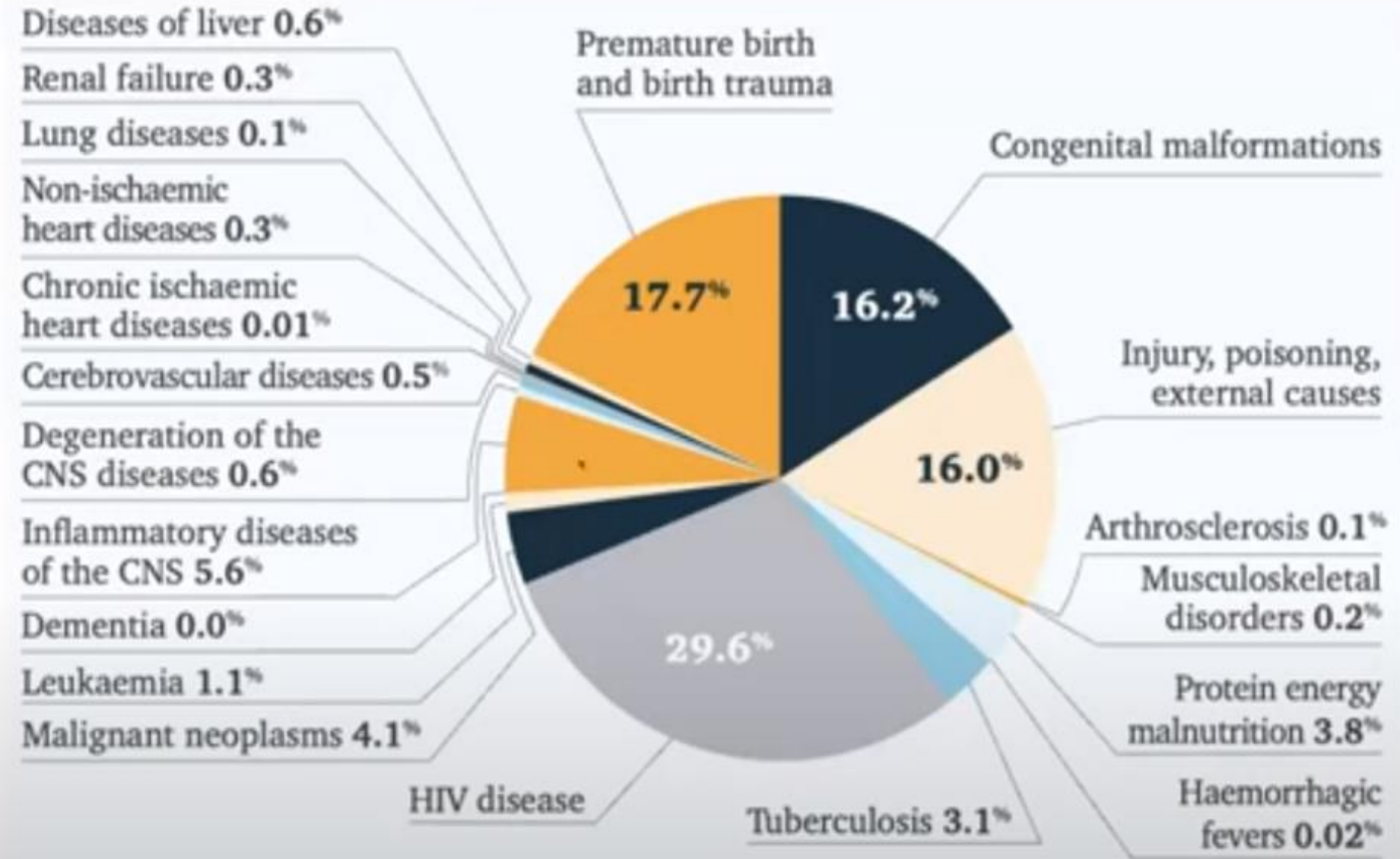


Children living with a life-threatening condition



Children with significant pain or other symptoms which palliative care can address

Those Needing PC...

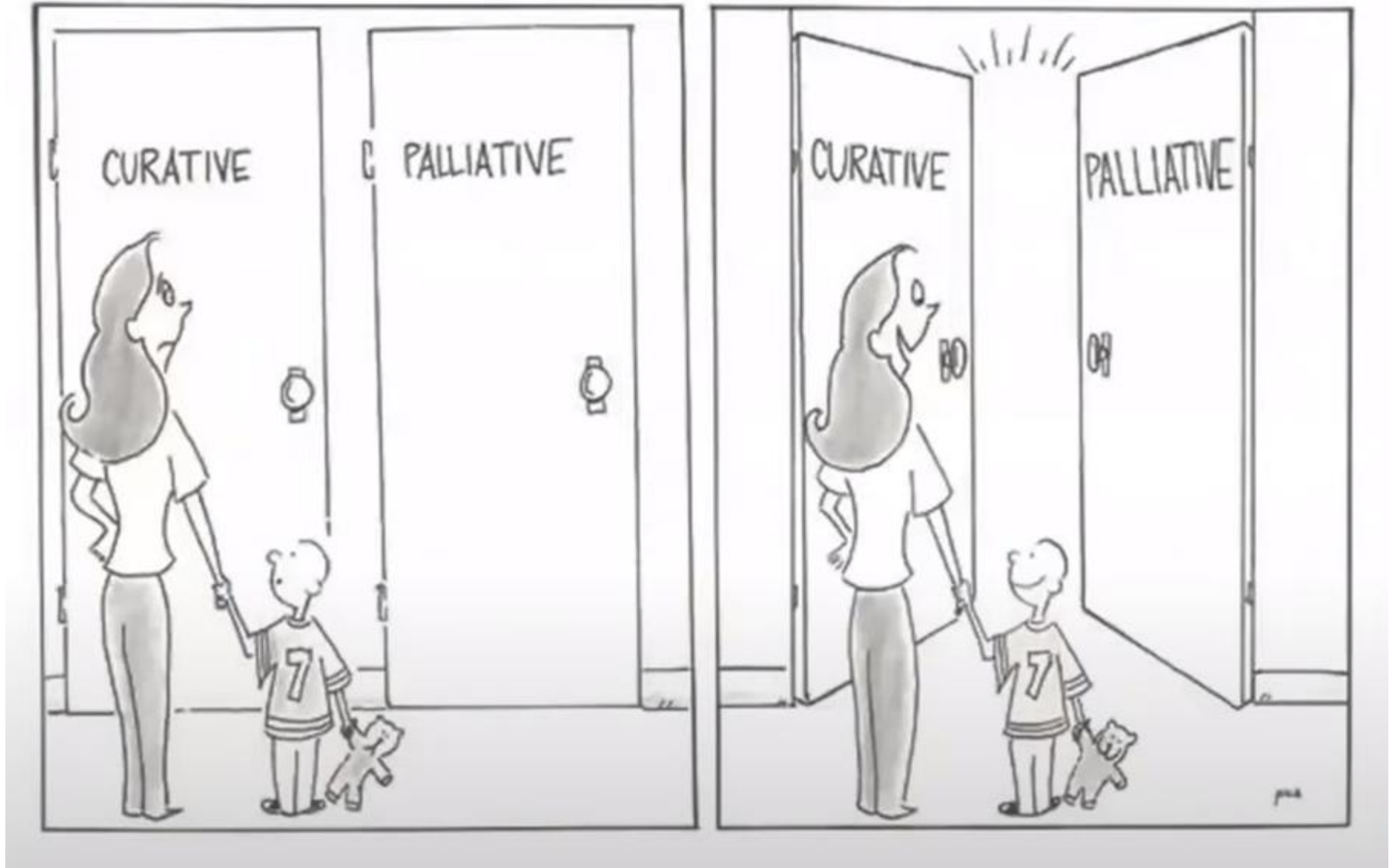


(Connor 2002)

Those Needing PC...

Category 1	<p>Life-threatening conditions for which curative treatment may be feasible but can fail.</p> <p>Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.</p> <p><i>Examples: cancer, irreversible organ failures of heart, liver, kidney.</i></p>
Category 2	<p>Conditions where premature death is inevitable.</p> <p>There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.</p> <p><i>Examples: cystic fibrosis, Duchenne muscular dystrophy.</i></p>
Category 3	<p>Progressive conditions without curative treatment options.</p> <p>Treatment is exclusively palliative and may commonly extend over many years.</p> <p><i>Examples: Batten disease, mucopolysaccharidoses.</i></p>
Category 4	<p>Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.</p> <p><i>Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event or episode.</i></p>

**Hoping
for the
best,
but
planning
for the
worst**





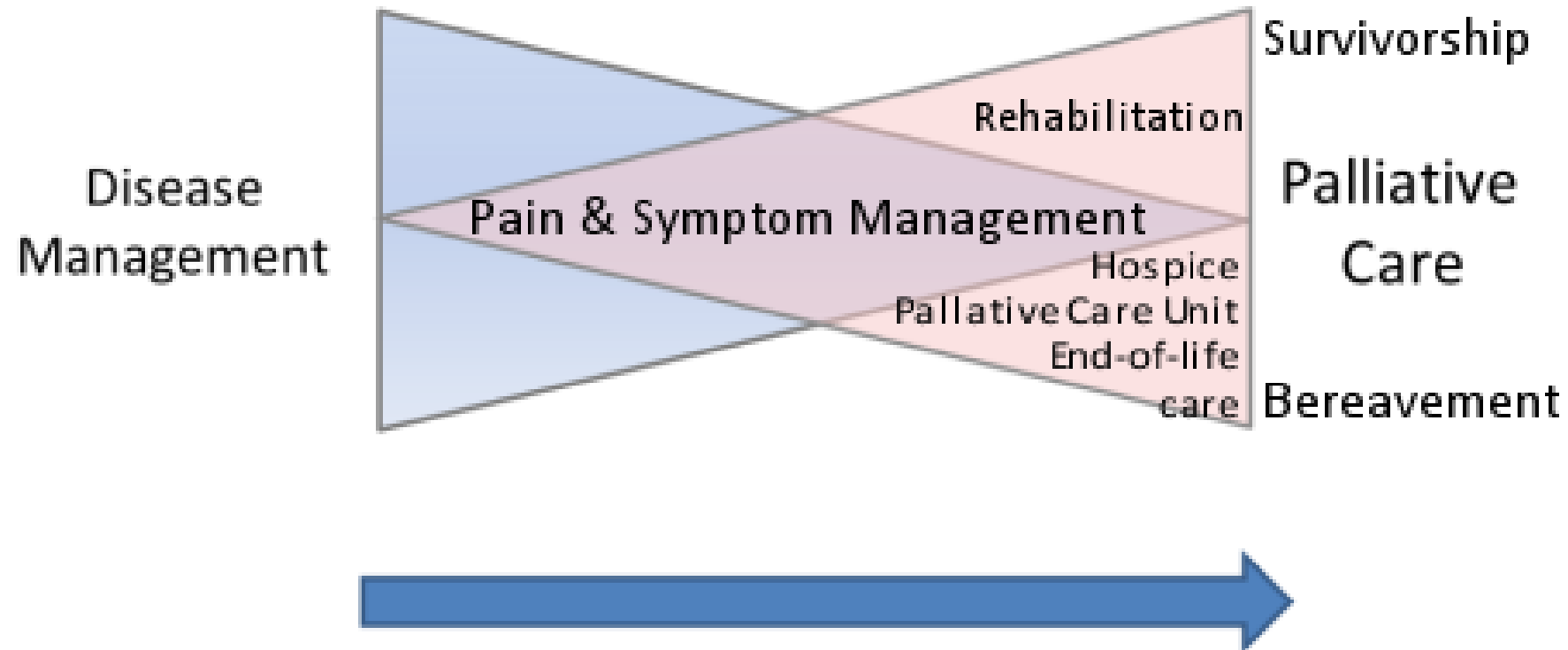
**What are some
of the
principles of
palliative
care in
children?**

1. Across the Continuum of Care

- From diagnosis through to death and into bereavement
- Across the variety of care settings
- Whenever the child and their family would benefit from it
- Should not be seen as a last resort but an essential component of care

The Bow-Tie Model

Palliative Care-Enhanced Model





2. Pain and Symptom Management

- An essential component of care
- Not just related to the child's condition, but to treatment as well e.g. procedural pain
- Pharmacological and Non-pharmacological
- Important from pre-diagnosis onwards
- Physical and Psychological



3. Emotional Support

- For all children, regardless of age
- “Friendship” groups with other children with similar conditions
- Important for the child and their family
- Need to be open and honest in our communication
- Address Collusion



4. Social Issues

- Important of peer support
- Loneliness and isolation
- “Stigma” and impact on the families
- Inability to continue with “normal” social activities
- Schooling is important



5. Spiritual Issues

- Existential issues are important in CPC
- Often hard for us to talk to children about such issues
- Useful concepts:
 - Hope
 - Transcendence
 - Meaning
 - Acceptance
 - Connectedness/Relatedness



6. End-of-life Care

- Dying in process
- Teamwork is essential in order to support the family
- Don't forget the siblings
- Encourage openness between members of the family
- Support decision making is key
- May have an advance care plan
- Think about where they will receive care e.g. at home, the hospital etc.



7. Grief and Bereavement Care

- Grief is a normal process and most families do not need specialist help
- Ideally team supporting the child and family can provide support in bereavement
- Volunteers can be trained to provide bereavement support
- Access to bereavement counseling should be available as part of health service provision to those who need it



8. Communication

- Good communication is key
- Open and honest
- Sharing bad news
- With children, siblings, families, h
workers
- Frameworks exist to help
- Need to try and develop trust

9. The family and Significant Others

- Need support throughout the course of the illness
- Particularly at the end of life and into bereavement
- Remember the whole family and significant others not just the parents
- Impact on relationships
- Siblings...





10. Financial Issues

- Often not thought about or discussed
- Many in vulnerable, fragile and conflict situations will have limited funds
- Cost of being with the child in hospital/clinic
- Out of pocket expenses
- Cost of caring for the child e.g.
 - Expensive equipment
 - Not being able to work
 - Care for sibling
- Spiral into poverty



11. Teamwork

- Essential
- Family (and child) as core member of team
- Shared care with oncologist, pediatrician, etc
- Volunteers in constant touch
- Home care teams
- Health workers
- Teachers

Integrating palliative care and symptom relief into primary health care

A WHO guide for planners, implementers
and managers

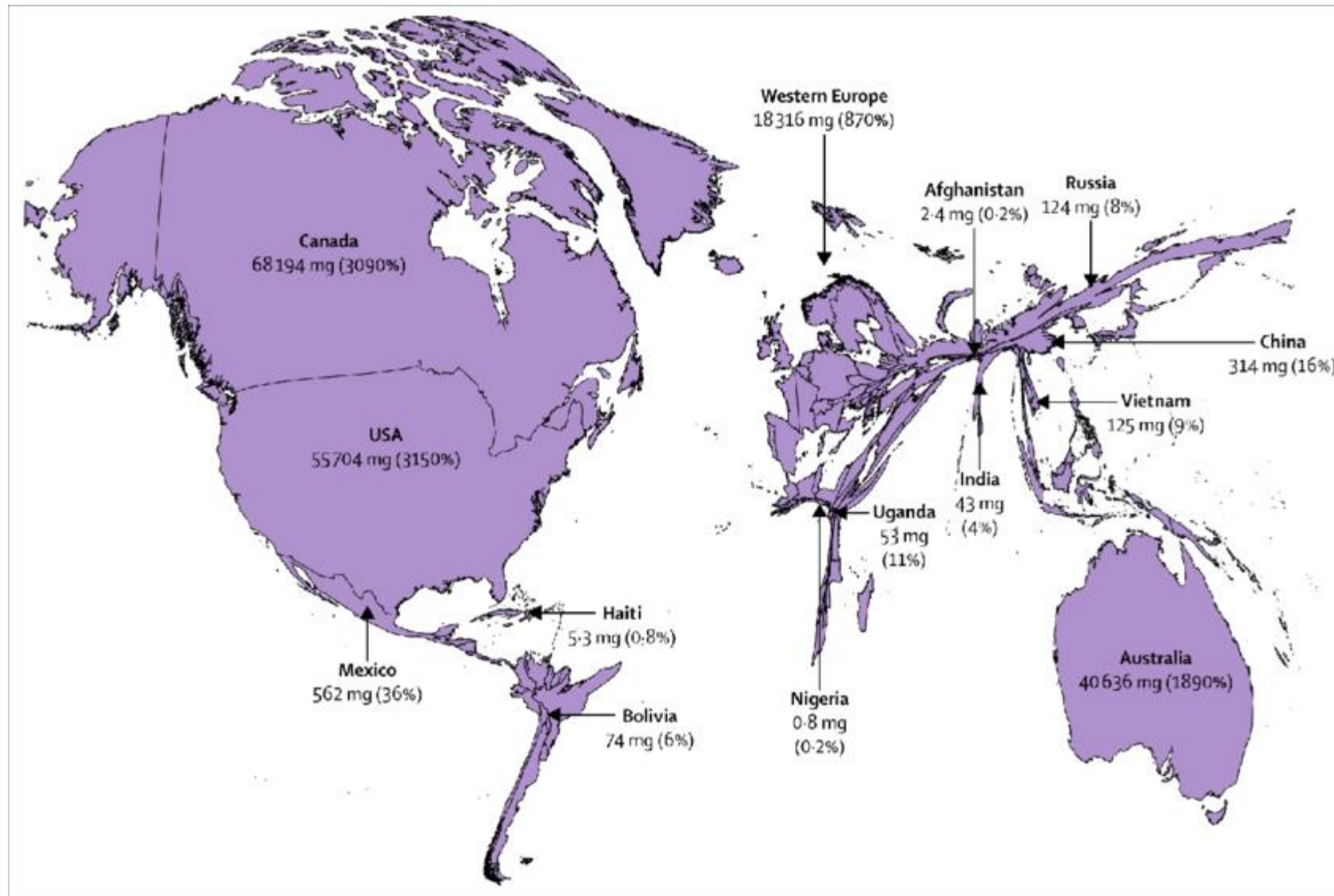


Challenges

- Lack of recognition of the need for CPC
- Lack of policies
- Lack of access to:
 - Education
 - Treatment
 - Trained professionals
 - Medicines and fear of opioids
- Lack of resources
- End-of-life care
- Decision making

Challenges cont...

- PC is not a priority
- Variety of models of care needed
- Lack of understanding of the need for CPC
- Traumatized population
- ...



Knaul FM, Bhadelia A, Rodriguez NM, Arreola-Ornelas H, Zimmermann C. The Lancet Commission on Palliative Care and Pain Relief—findings, recommendations, and future directions. *The Lancet Global Health*. 2018 Mar 1;6:S5-6.

