Palliative Care for HIV Infected and Affected Children and Adolescents

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The Teresa Group: Children How; Children Now Symposium

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Children and HIV/AIDS in Africa

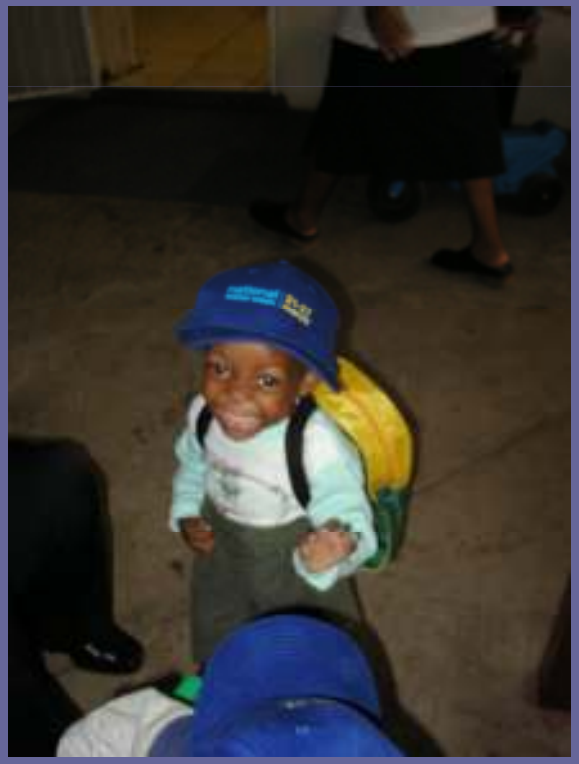
Statistics as at November 2007

- **33.2 million** people infected with HIV worldwide – 68% of these live in Sub-Saharan Africa
- In 2007 32% of all new infections occurred in this region
- **2.1 million** children are infected worldwide – 90% live in Sub-Saharan Africa

- **290 000** children died of AIDS in 2007.
- 10 children die of an AIDS related illness every 15 minutes
- In this region, **less than 10%** of pregnant women testing HIV positive receive services to prevent transmission to their children.

Orphans

- **11.4** million children have been orphaned by AIDS in Sub-Saharan Africa



ALL OF THESE CHILDREN WILL BENEFIT FROM PALLIATIVE CARE INTERVENTIONS

Sources of information

- 2007 AIDS epidemic update
- Global epidemic: Save the Children
- Childinfo.org: Statistics by Area

In this workshop we will look at :

Palliative care for HIV+ children and adolescents – Joan Marston: Hospice Palliative Care Association of South Africa & the International Children's Palliative Care Network

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Challenges to providing palliative care in sub-Saharan Africa – Eunice Garanganga: Hospice Association of Zimbabwe & the African Palliative Care Association

Discussion around these issues

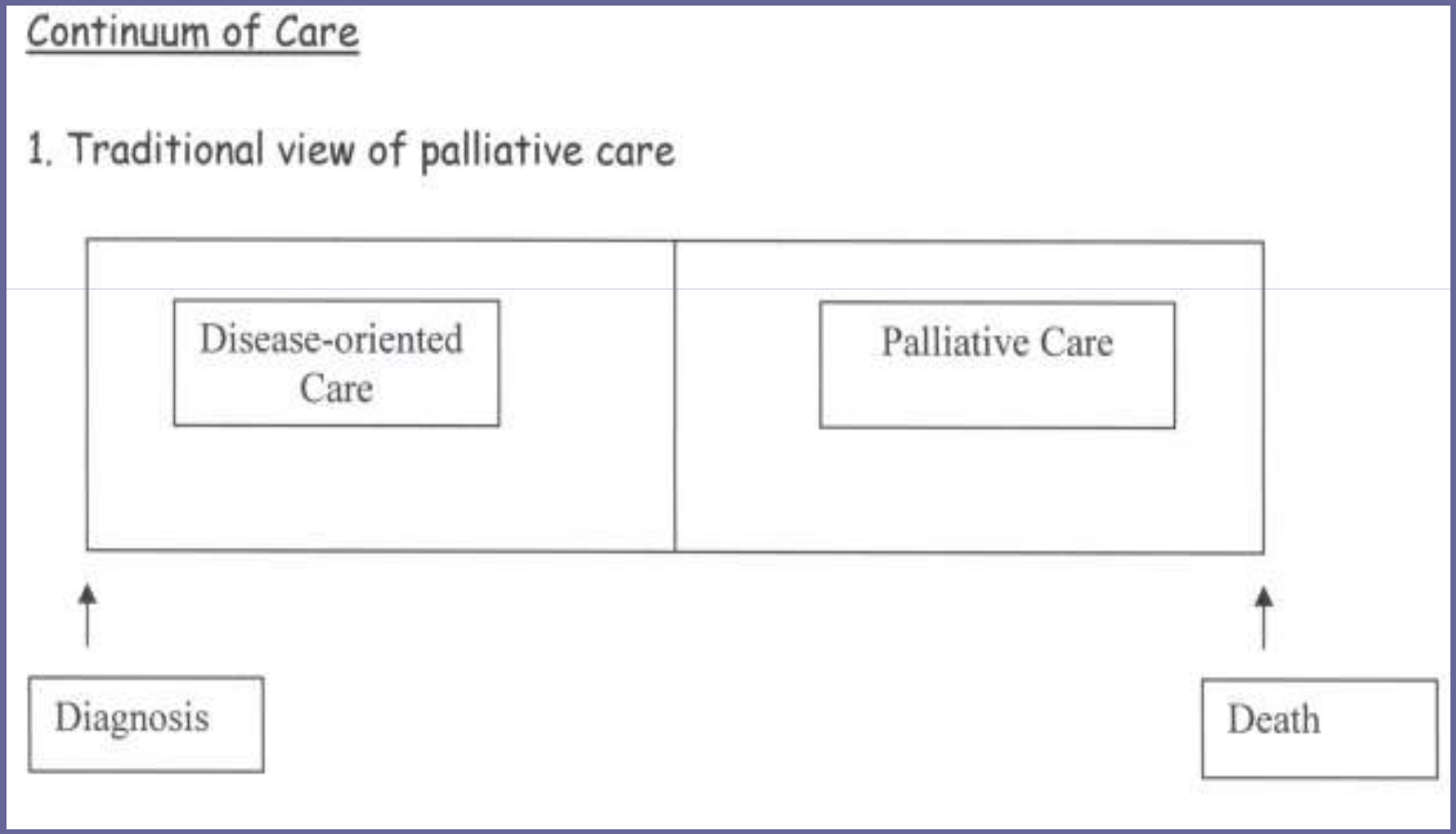
WHO Definition of Paediatric Palliative Care

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 centres and even in children's homes.

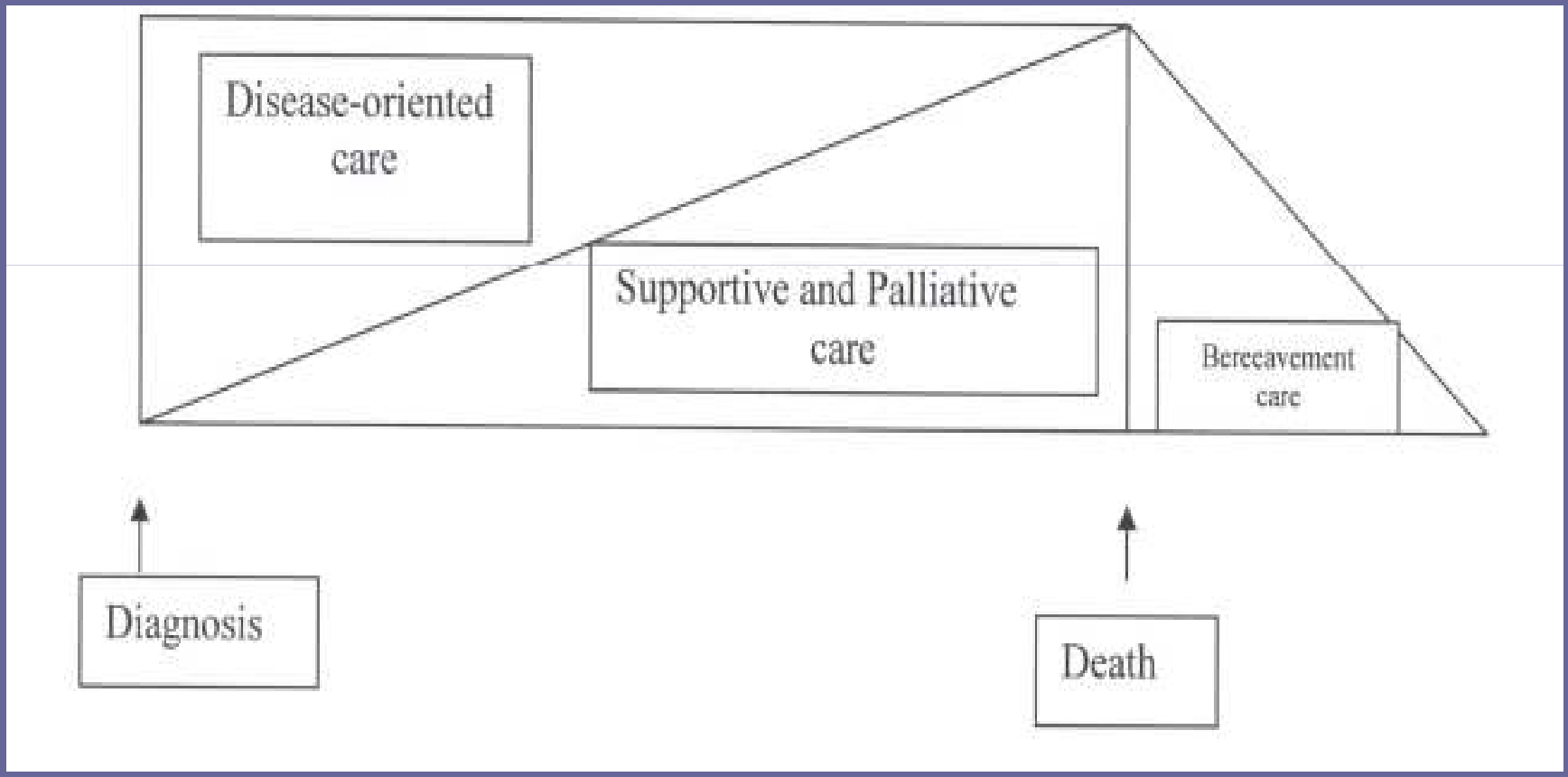
The aim of palliative care is

TO RELIEVE SUFFERING AND TO IMPROVE QUALITY OF LIFE OF CHILDREN WITH LIFE-LIMITING; LIFE-THREATENING AND CHRONIC CONDITIONS, THROUGH EXCELLENT ASSESSMENT, PAIN AND SYMPTOM MANAGEMENT AND SUPPORTIVE CARE

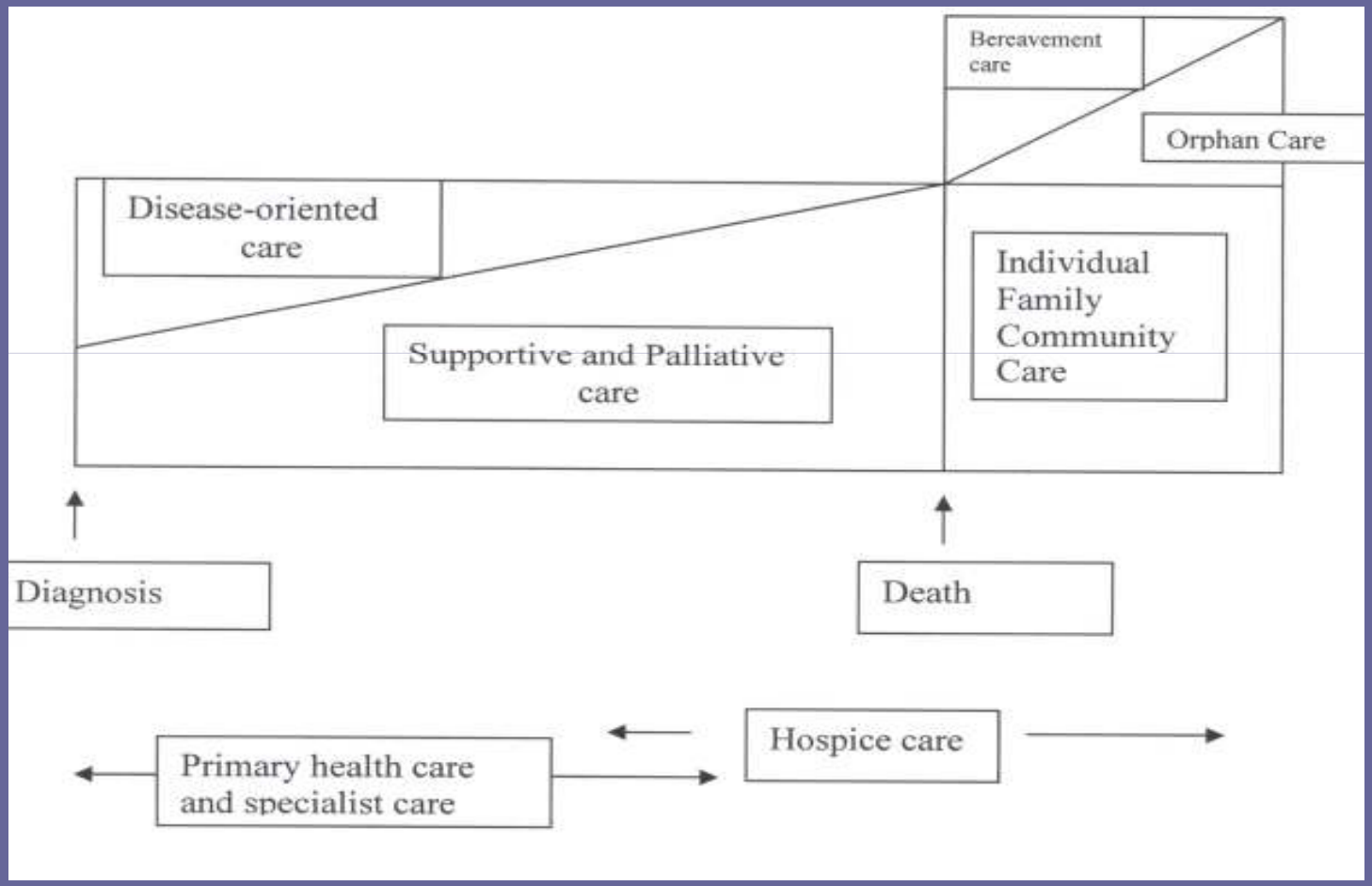
Palliative care



Palliative Care in the developed world



Palliative care in the developing world



ONLY

Excellent assessment

+

Pain and symptom control

+

supportive care into bereavement

=

Palliative Care

Palliative Care for Pain and Suffering

How does it differ from adult PC?

- Often a matter of degree
- Vulnerability
- Some conditions never found in adults
- Some children never live to adulthood
- Chronic conditions
- Severe disabilities
- Impact of development
- Impact on family, community and care team

In this time of HAART – why palliative care ?

- Still limited access to ARVs in developing countries
- HIV is a Chronic condition with HAART
- Children still experience pain and symptoms on HAART
- Compliance issues
- Other pre-existing conditions before initiation of HAART
- Improves quality of life, and promotes dignity in death

HAART

+

Palliative care

=

Best quality of life

It includes preventative and curative care

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

GOOD NUTRITION; EDUCATION; TREATMENT OF INFECTIONS; CO-TRIMOXAZOLE

A children's palliative care programme shoud have

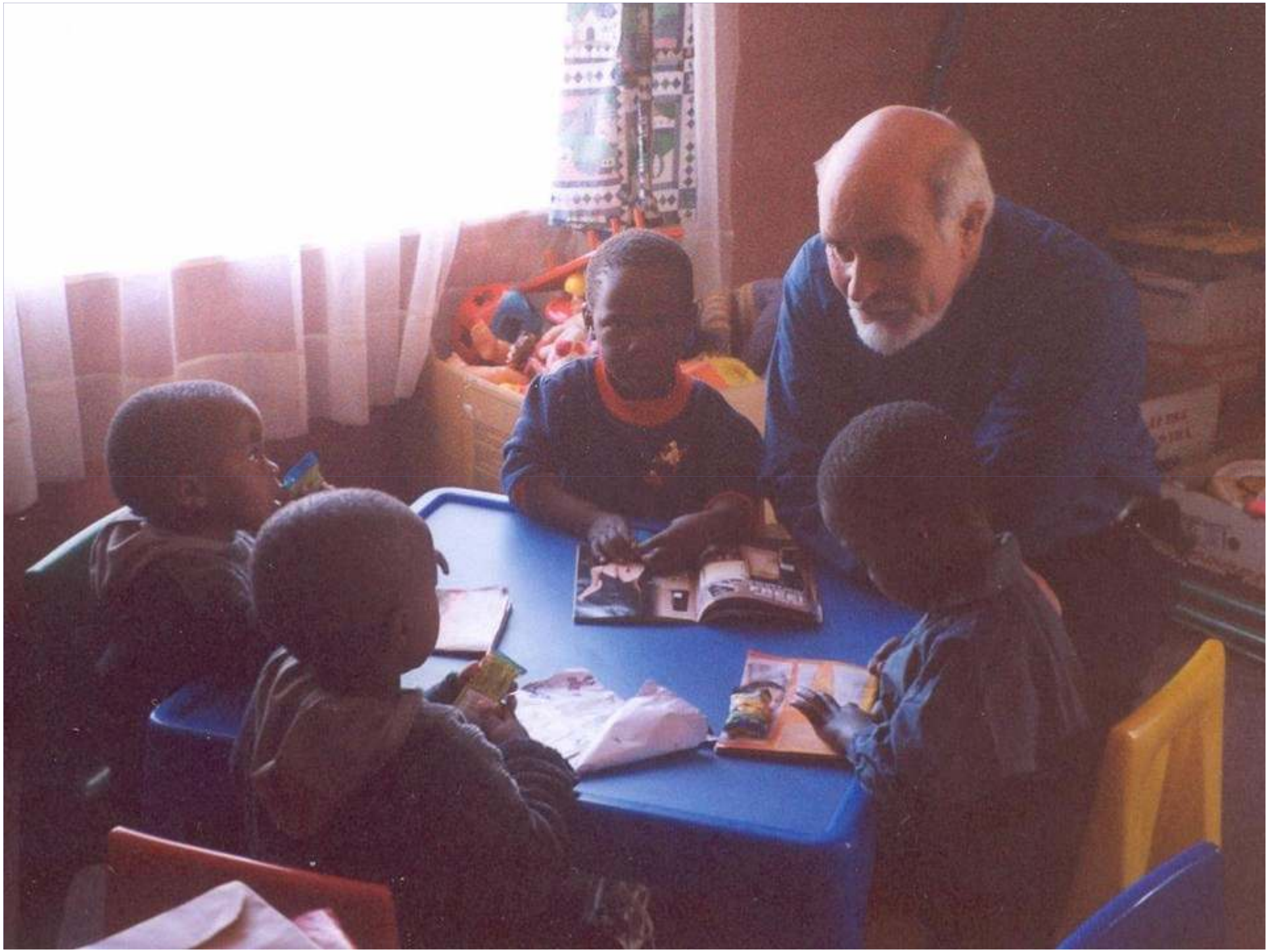
- Interdisciplinary team trained in palliative care
- Community workers trained in palliative care
- A multi-disciplinary approach – varies according to circumstances
- Access to medications including opioids – varies
- Ability to assess and manage pain and symptoms

Will be where the children are

Will preserve the family through home visits

Will include psycho-social care

And Spiritual Care

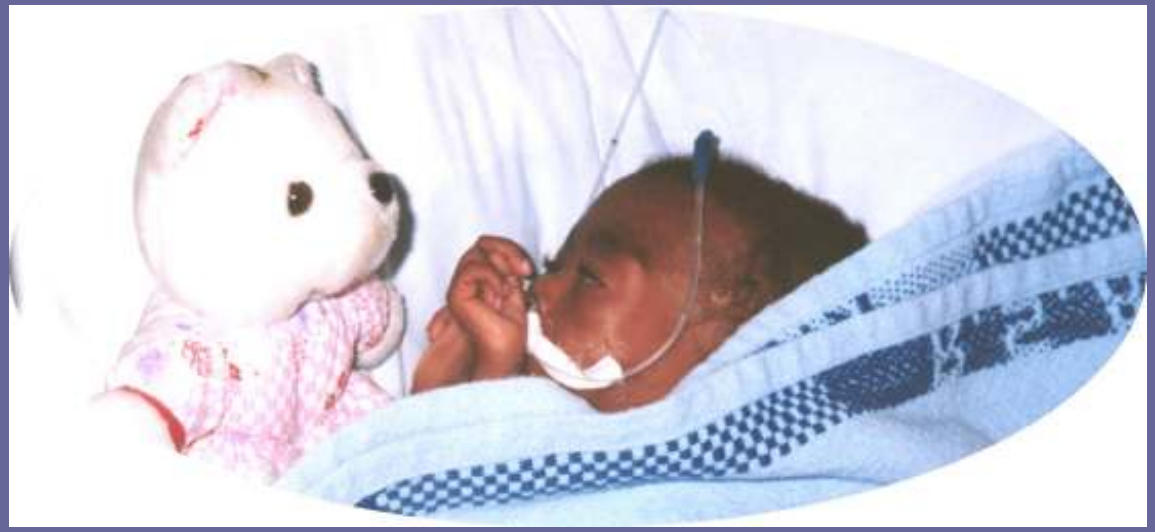


Developmental support

END OF LIFE CARE

The dilemma

TERMINAL IS “FLEXIBLE”

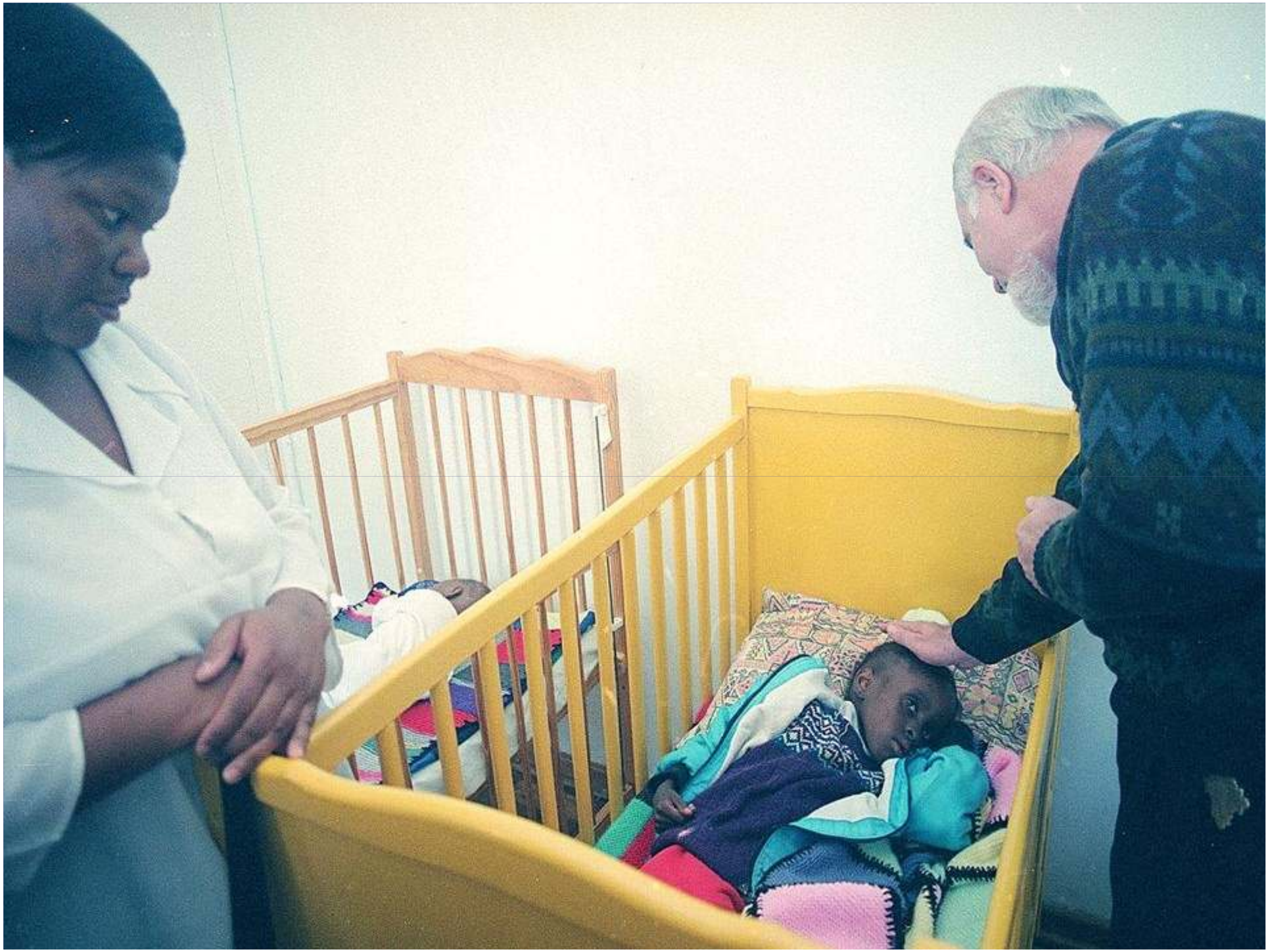


END OF LIFE CARE

- Decision making
  - Family, where possible, involve early
  - Team
    - include surrogate “mothers” and hospital
  - Consider “timeline” “allow natural death”
  - Quality of life
    - past, now and future
  - Place of death
    - Home/hospital? Admissions, interventions, support available

END OF LIFE CARE

- Clear decision about interventions
  - Discuss with IDT paediatricians/hospital
- Keep children “normal”
- Honest communication
- 24 hour presence
- Respect for autonomy
- Feeding and O2
- Pain and discomfort
- Encouraging intimacy of family



Palliative care for children is

QUALITY OF LIFE

DIGNITY IN DEATH

SUPPORT INTO BEREAVEMENT

Thabo: 9 months

Thabo: 4 years

What we need to do

- Increase the knowledge and evidence base for PPC.
- Develop standards for PPC relevant to the particular setting
- Increase the palliative care content of under and post graduate students
- Dispel the myths about what palliative care is about
- Dispel the myths about childhood pain
- Dispel the morphine myths and teach about dosing
- Involve doctors & nurses in the palliative care of their own patients in their own settings: bed - side teaching
- Provide opportunities for research and study

www.icpcn.org

You matter because you are…You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, and to live until you die."

Dame Cecily Saunders,

founder of the modern hospice movement

Challenges to providing palliative care to the Children of Africa

Eunice Garanganga HOSPAZ

Why the focus on children?

Children represent the future
Children are unique and have complex palliative care needs that differ from those of adults

These require a multi-sectoral and multidisciplinary approach and an understanding of paediatrics

SERVICES FOR CHILDREN

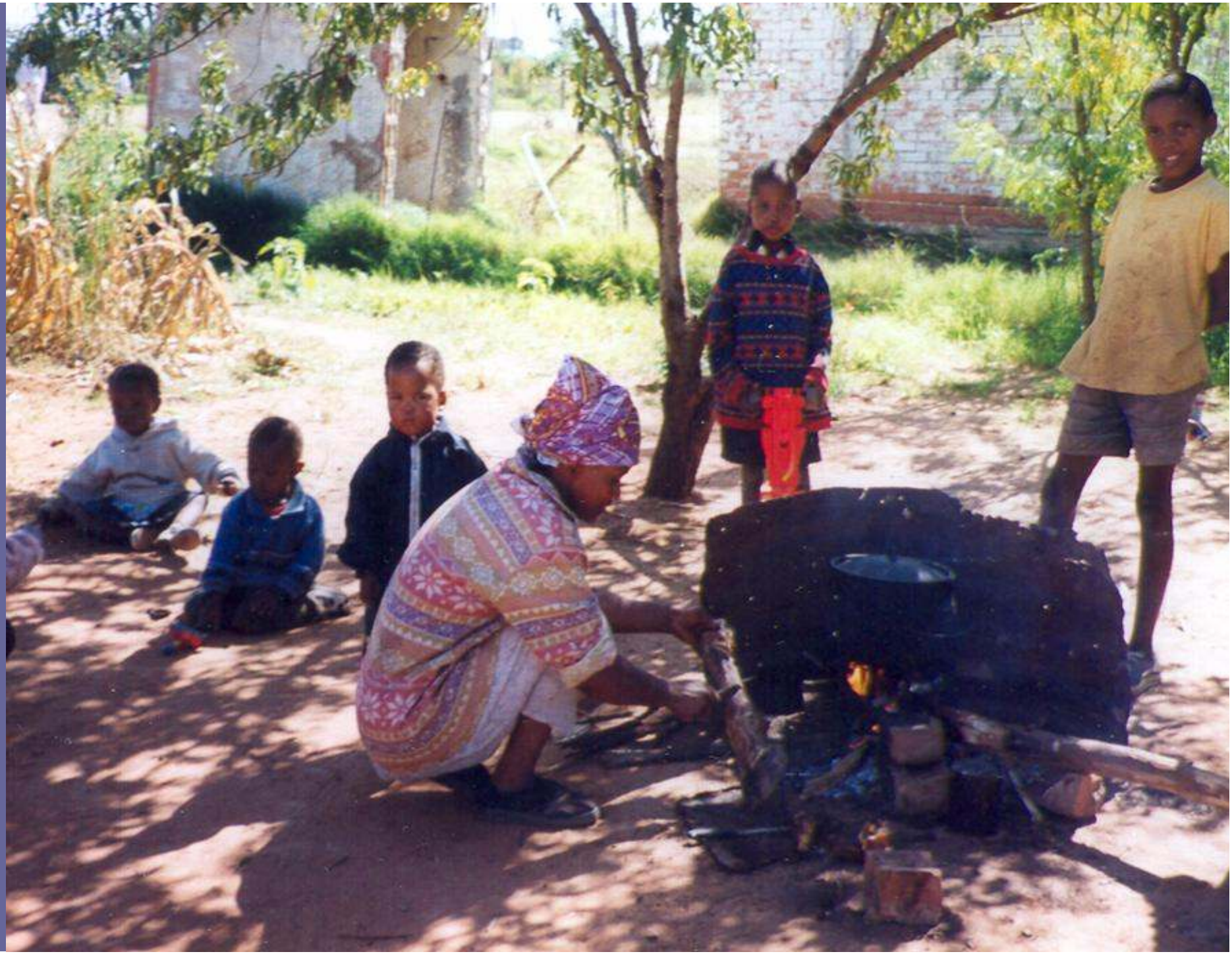
- Few programmes providing paediatric palliative care in Africa
- Poor understanding of paediatric palliative care
- Few training courses and no qualified health professionals in PPC in Africa
- Little African literature on children
- PPC programmes developing in isolation

Lack of Resources

- Paediatric palliative care drugs
- Paediatric formulations
- Poor access to medication
- Trained personnel
- Policies and standards
- Lack of relevant tools that are culturally appropriate

The impact of poverty

- Malnutrition
- Breakdown of families
- Lack of adult support and supervision
- Child-headed households
- Granny-headed households
- Children living alone
- Unable to get to health care resources
- Susceptible to abuse



Developmental needs

- Children's palliative care must be delivered in line with developmental stages and changes
- Requires assessment skills for each age
- Special skills in communication at different ages and stages of development
- Requires a flexible approach which is unique to each child


THREE BLIND MICE

Bereavement Issues

- Children are living with multiple and ongoing losses – hopelessness and psychological effects, behaviour of adolescents
- Compounded by HIV and AIDS
- Adults not comfortable with speaking of death and dying with children
- Often not included in burial rituals
- Children need support throughout the parent/sibling's illness
- Requires a skilled and compassionate approach aimed at building strength and resilience in each child

Communication and cultural issues

- Children are seen not heard
- Idea of consulting children not heard of
- Adults do not know how to communicate with children – language difference/barrier
- Cultural influences e.g. attending funerals, talk through somebody
- Breaking bad news
- Empowering children to make decisions about their health care
- Parents being ashamed to ask for help when faced with a sick child
- Multiple levels of communication – including family

Why are we not providing palliative care for children?

- Fear of dealing with children
- The idea that children should not die
- Fear of using opioids in children
- Lack of knowledge, skills, training
- Lack of resources
- People working in isolation

Advocacy

- Children are voiceless and not listened to
- Little advocacy for paediatric palliative care
- UN Convention on the Rights of the Child makes advocacy for children an obligation for health professionals
- Advocacy needs to influence policies to benefit the child

Challenges faced by orphans overwhelm services

- Missing out on schooling
- Less food security
- Suffer anxiety and depression
- High risk of exploitation
- Lose inheritance
- Live in vulnerable households

All these issues overshadow palliative care

Beacons of Hope !

- Zimbabwe
- South Africa
- Zambia
- Kenya
- Uganda
- Tanzania
- Malawi
- Other countries developing programmes
- Partners abroad – sharing skills

What we are striving to achieve

- Commitment to the children.
- African Children's Palliative Care Network
- Collation of all available materials
- Children's Palliative Care Textbook for Africa
- African Children's Palliative Care Toolkit
- Standards
- Monitoring
- Mentoring
- Develop African materials


THANK YOU!