

PARENTS' PERCEPTIONS OF THEIR CHILDREN'S PARTICIPATION IN PAEDIATRIC PALLIATIVE CARE

By Penelope Mathe



NELSON MANDELA ON CHILDREN

Together as a nation, we have the obligation to put sunshine into the hearts of our little ones... They deserve what happiness life can offer.

Lunch for sponsors of his birthday party for children with life-limiting illnesses, South Africa, 4 July 1997

FINDINGS

- The empirical investigation of this study indicated that participants perceive it as their responsibility to decide what is in the best interest of their children.
- The parents feared that should children be given a voice in their treatment and care, children could make decisions, which might be detrimental to their health.

FINDINGS (CONT'D)

- It was found that the parents regard children's rights as a threat to their authority as parents.
- It was reported that parents are not supported by the health care system. Lack of proper systems and shortage of staff in the hospitals could be linked to poor communication channels.

CONFERENCES

- HPCA Conference (September 2015) Durban
- SWHPN Conference (March 2016) Chicago
- APCA Conference (August 2016) Uganda



FINDINGS FROM THE INTERACTIONS WITH THE HEALTH CARE PROFESSIONALS

- Despite the clear mandates for including children in participation:
 - “As a health care professional I know what’s best for the child”
 - “This right is not applicable in practice”
 - “My focus is on the parent not a child”
 - “I don’t know how to communicate with the child”

The UN Convention on the Rights of the Child (UNCRC) has 54 articles. Articles 42-54 are about how governments and adults should work together to make sure all children get all rights.

UNCRC, 1989 provided grounds for a child's right to participate in health care.

According to the South African Children's Act 38 of 2005, children have the right to participate in decision making regarding their lives.

BEST INTEREST OF THE CHILD

- The law requires and emphasises that anyone taking a decision that affects a child has to make sure that the best interests of the child are a key consideration.
- Section 7 and 9 of the Children's Act 38 of 2005 reinforces the importance of the best interest of the child.
- Child's best interests are influenced by many factors such as the child's age, experiences, opinions and wishes.
- Informed consent and assent
- Legal guide to age thresholds for children (Children's Institute, UCT, April 2011 ed.5)

PARTNERING WITH CHILDREN

Involves facilitating child participation in the health care context and it can be done in the following ways:

- Not only talking about children but also talking with children.
- Not only making decisions on their behalf but also including children in conversations.
- Informing children in a child-friendly manner what is going on, the benefits, risks, and social and other implications of the treatment.

RECOMMENDATIONS

The following are some of the recommendations directed at health care professionals:

- Share the best practices in paediatric palliative care.
- Education on children's rights in general and the children's right to participate in decision making.
- How to communicate with children.
- Child appropriate language-depending on the age of the child.

CONCLUSION

“I speak for those children who cannot speak for themselves, children who have absolutely nothing but their courage and their smiles, their wits and their dreams”

Audrey Hepburn

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Palliative Care – Relief of suffering
