

Book Title: Lerato learns about hospice care

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Abstract: Hospice care is generally an uncomfortable topic and the concept of hospice care is largely shrouded in mystery and associated with misery. Yet, patients and families who have accessed hospice care reflect positively on the benefits thereof.

As an off shoot of my PhD programme, I was struck by the lack of engagement of children in conversations and care plans of their terminally ill loved ones. It was not, in my opinion, a deliberate act but more an act of sparing the child from the emotional burden of palliative care. I also observed that some of the palliative care team members were not comfortable talking with children on a painful topic or did not consider it to be a culturally supported practice.

With this as a backdrop and having identified this gap, I conceptualized this book. Children are curious by nature. They like to be included and yet often the tendency is to protect children from sad/bad topics and incidents. Sadly, children will then go out to seek answers or obtain information from others or social media platforms which, if not contextually viewed, could be harmful to the child and his/her emotional and psychosocial well-being. Including children in the palliative care journey keeps the family closer, the child is aware of the care plan, the progression of the disease and will allow for the child to be heard and seen.

I want the book to be an educational tool for children whose loved one is faced with a terminal illness. Set in a semi-rural township just outside Cape Town, South Africa this book is a conversation between Tinus (10-year-old Coloured boy whose younger brother died of cancer recently) and Lerato (8-year-old Black girl) whose mother is terminally ill and is receiving hospice palliative care. Through this dialogue Tinus demystifies hospice care and brings about a sense of stability and predictability in an otherwise complicated situation.

The book could also be a tool for health care professionals navigating conversations with young children of palliating patients.

Presentation style: Oral presentation

Track fit: Track 2 (strengthening PC, training, leadership, advocacy) or
Track 4 (Psychosocial, spiritual and holistic approaches)