

# **Spirituality in Children and Families Facing Serious Illness**

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The artwork in this presentation was created by the true experts and teachers of this topic – the children cared for by Trinity Kids Care Hospice. We are grateful to them.

# Introduction

Caring for seriously ill children is a spiritual experience for the child, the family and the health care professionals involved.

Previous literature has documented the spiritual needs of children and families; often these needs have not been assessed or addressed.

# Children and Spirituality

- Fowler's Faith Development Theory, 1981: In children, faith and spirituality develop in stages. (Mueller, 2010; Neuman, 2011)
- "Children have spiritual life, they have spiritual capacities and experience – profound moments that shape their lives in enduring ways. They are sometimes stunning, often tender and reveal a remarkable spiritual world." (Tobin Hart, 2005)





# Children Have Spiritual Curiosity and Spiritual Needs

- Children have spiritual curiosity, and like adults, seek the meaning of life and God. (Coles, 1990)
- All children, both healthy and the seriously ill have thoughts and feelings about prayer and God. (Coles, 1990; Pehler, 1997; Smith & McSherry)

# The Spiritual Needs of Dying Children

- D.R. Sommer recognized dying children's spiritual needs; to love and be loved; to know that God loves all people and that he is not punishing them; that what lies ahead is positive, i.e. reuniting with loved ones; and that they will be remembered. (Sommer, 1989)
- Unlike physical symptoms which are visible, a dying child's spiritual distress is harder to recognize and to treat. (Heilferty, 2004; Pehler, 1997)





# Children's Spirituality Defined

“Children have the capacity for wonder, wisdom, compassion, deep questioning and seeing beneath the surface of the physical world...finding meaning, purpose and connectedness.” (Tobin Hart)





# Research

- The following narratives were collected through the End of Life Nursing Education Consortium (ELNEC) Pediatric courses, as nurses shared their experiences in the spiritual needs of children.\*
- Four major themes emerged from the qualitative analysis:
  - Why?
  - The afterlife
  - Hearing God's call
  - The roll of caretakers

\*Findings published in the Journal of Palliative Medicine, 2016.

# Theme 1 - Why?

“I remember working night shift at the bedside, on an adolescent unit. These teenagers were often alone at night with their nurse (me) as company. This was often the time when these kids asked the big questions, about God, faith, their place in the universe...these kids had an extra element of time-limitedness to their questions.”









## Theme 2 -The Afterlife

“...children and their families have crossed what I like to refer as the *thin grey line*. That almost imperceptible line between worlds...the place where we leave one and enter the next...a permeable membrane...a place of passage...an open door...a fraction of an inch. I have learned that each child's spirit takes that step.”

“...help them across the river as gently as we can. “





## Theme 3 - God's Call

“She had told her daddy she was so very tired because they all wanted to talk with her. It was a little rude she thought. *She was trying to rest.* But in her dreams, she was carrying on lovely conversations with her friends on the other side of things. She felt that she should not tell her parents yet what they were saying. Then one evening before her death she awoke...

## Theme 3 - God's Call (cont.)

“Daddy, Daddy, can you see it? It’s so beautiful, it’s so beautiful...I feel like I am floating just like they told me I would...this is fun.” Her father looked up to the ceiling and said softly, “I don’t know who you are but I think you are here to help my daughter not be afraid through this process. Thank you, please take care of her.”







# Theme 4 - Nurse's Presence and the Importance of Addressing Spiritual Needs

“[Maria’s] Dad had prayed many prayers to our ‘Lady of Guadalupe’ as he was so grieved that Maria did not have a mother in these final days. On the last evening before she left us, it was difficult. Symptoms were escalating, she needed holding and bathing and loving...

# Theme 4 - Nurse's Presence and the Importance of Addressing Spiritual Needs

“Dad asked me to do these things. He asked me to pray the rosary with her and continue in prayer until she died, which seemed moments away. I had never prayed a rosary in my life, so I asked dad to pray and I would repeat. He spoke mostly only Spanish and I don't speak Spanish. Amazingly, I could 'understand' what he was saying and repeated that rosary so many times. He was finished, but sweet Maria was still with us. He went to check on the younger brother asleep in the back of the garage.”

# Theme 4 - Nurse's Presence and the Importance of Addressing Spiritual Needs

“Without thinking, I began to sing hymns to her...rocking her, keeping her safe, weeping for her, wiping her forehead with a cool towel, telling her all would soon be well...and that she was not alone, the angels were coming. Dad came back and stood gazing at us there on that small old couch...he, too, began to weep. ‘Madre, madre, Maria has madre.’ In the moment, I thought he was referring to the Lady of Guadalupe for some reason. Then he softly said, ‘You, senorita, Maria’s madre. Glory a dios.’

# Theme 4 - Nurse's Presence and the Importance of Addressing Spiritual Needs

I do believe we are often the answers to someone else's prayers. I was not just Maria's nurse, for that little time I was an answer to her father's prayer....what holy work..."

MY FAMILY



# The Care of Parents

- A child's spiritual needs should be assessed in the context of the parents'/family's spiritual care needs. (Hart, Schneider, 1997)
- Nurses rendering care to children with cancer should focus on the "child as a whole spiritual being". (Hart, Schneider, 1997)
- Kari Hexem and colleagues studied how parents of children with serious illness use religion, spirituality or life philosophy (RSLP) as coping mechanisms. (Hexem et al., 2011)



# The Care of Parents

Increased diversity of the patients and families we serve requires attention to a range of cultural, religious, and spiritual factors.

Spiritual care is essential to any patient centered, quality care. Failure to respond to spiritual needs impacts the patient's experience of illness, symptoms, death, and the bereavement of families.



# The Care of Parents

- The following narratives were collected through the End of Life Nursing Education Consortium, (ELNEC) Pediatric courses as nurses shared their experiences in the spiritual needs of families.\*
- Four major themes emerged from our qualitative analysis:
  - Anger
  - Blame & regret
  - Forgiveness
  - Rituals and cultural traditions

\*Findings published in the International Journal of Palliative Nursing, 2016.

# Summary

Seriously ill and dying children have spiritual experiences to share with their families and clinicians.

Caregivers need support to enhance their communication skills including listening, presence and language to respond to spiritual needs.

Caregivers, working collaboratively with their interdisciplinary colleagues including chaplains as spiritual care experts, can provide patient and family centered care.

The care of all seriously ill children is sacred work and we are fortunate to support them through this journey. All children – those who will be cured of their disease , those who will survive for many years, and those who will die – deserve quality care including spiritual care.

