

# **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 in this topic children cared for by Trinity Kids Hospice. We are grateful to them.**

# Introduction

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

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

Nurses are the professionals most often at the bedside, across all settings of care, providing opportunity to address spiritual needs.

# Spirituality

**“Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.”**

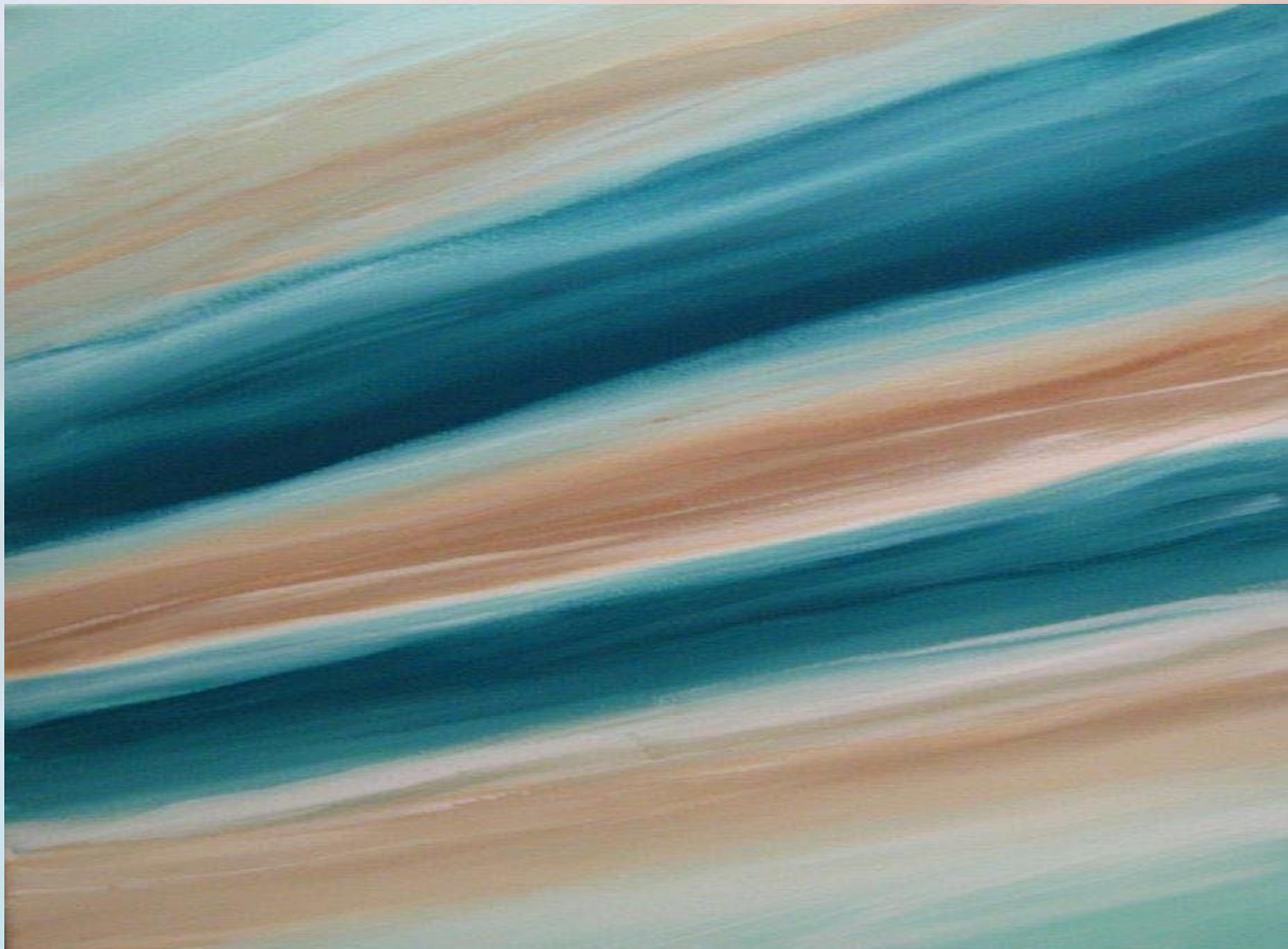


# Early work in pediatric spiritual care

- In 1998, a subcommittee of the Children's International Project on Children's Palliative/Hospice Services began work to improve the care of dying children by encouraging research in pediatric hospice and palliative care. (Davies et al. 2002)
- Recognizing the importance of spirituality to this population, one subgroup worked to create guidelines for spirituality assessment of pediatric patients. (Davies et al. 2002)

# Children and Spirituality

- Fowler's Faith Development Theory, 1981: In children, faith and spirituality develop in stages (Mueller 2010; Neuman 2011)
- Children "may be conscious or unconscious participants in a spiritual life"; their presence alone provides spirituality to the world. (Mueller 2010)



# Children have a spiritual curiosity and spiritual needs

- Kubler Ross's early work in the early 1970s identified the butterfly as an image used by many dying children. (Davies et al. 2002)
- Children have spiritual curiosity, and like adults, seek the meaning of life and God. (Coles)
- All children, both healthy and those who are seriously ill, have thoughts and feelings about prayer and God. (Coles, 1990; Pehler, 1997; Smith & McSherry)



E.R.

# The spiritual needs of dying children

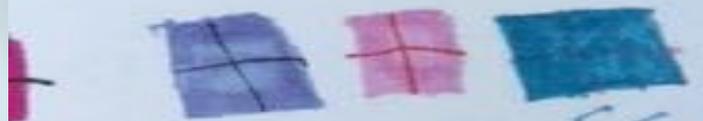
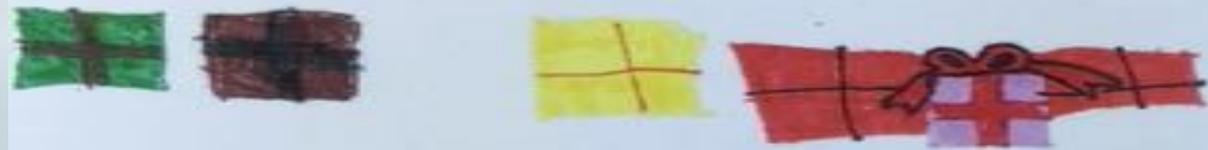
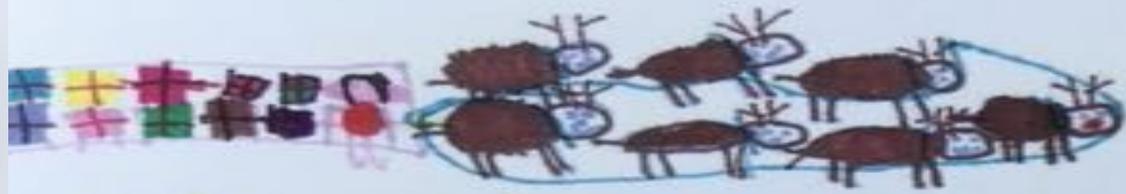
- D.R. Sommer recognized dying children's spiritual needs: to love and be loved; to know that God loves all people and that he is not punishing them; that what lies ahead is positive (e.g., reuniting with loved ones); and that they will be remembered. (Sommer 1989)
- Unlike physical symptoms which are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



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# Seriously ill children in the context of family

- 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)



# The Care of Parents

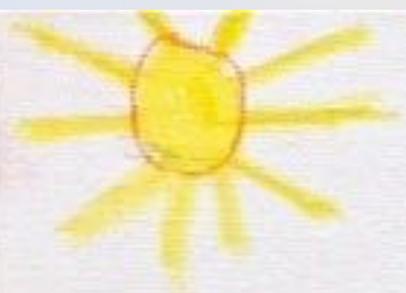
- Based on Feudtner's and Mack's early survey work on the spiritual needs of parents of seriously ill children, Knapp and colleagues found that more empirical research was needed to identify gaps in care of parents of children in palliative care programs. (Knapp et al. 2011)
- Kari Hexem and colleagues studied how parents of children with serious illness use religion, spirituality or life philosophy (RSLP) as coping mechanisms. (Hexem et al. 2011)



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.

MY FAMILY



Sandra  
Mommy  
DARIE  
MOM



# Stories of Spiritual Communication with Children



These narratives were collected by the presenters (Ferrell, Walker, Battista) through the End of Life Nursing Education (ELNEC) Pediatric courses as nurses shared their experiences in the spirituality of children and families.

# 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 Other Side/Heaven

“...children and their families who 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...and 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: Jesus and Angels

“There is much to tell about dreams. Those of the children, the parents, the grandparents. Several times, a child has told me that they ‘almost went to God (Jesus etc.) but came back.’ They met grandparents, friends, siblings (some they did not know had existed.

# Theme 3: Jesus and Angels

“Kyra is the only 5-year-old I know who has ever asked for a harp for their Make-a-Wish. According to her parents, her heart’s desire was to be able to ‘play like the angels’. She got her harp. Her parents told us the first song she wanted to play was *Amazing Grace*. She learned it quickly – I would venture to guess that she knew her time was precious.”



# Theme 4: Joining Others in Heaven

“Garrett was 14 years old when we met and had CF. He weighed 40 lbs, an adolescent in his mind, a small boy in his body. Garrett loved trains and had a pretty awesome set of tracks going throughout his home when we first met. As he became less mobile, the train set got smaller – his sphere of influence diminishing, room by room...

# Theme 4: Joining Others in Heaven

...When Garrett was bedbound the tracks went around his bed and when he lay dying – he had the caboose in his hand – all other evidence of the train set was gone at Garrett’s request. When his mom asked “why the caboose and not the engine – he said I’m the engine – I’m leading the way – I’m saving you the caboose so you can follow me later.”

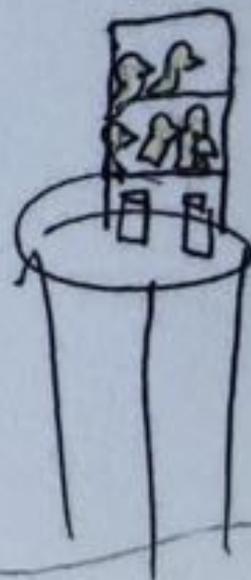
# My family

Dad

mom



birds



# Theme 5: 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 5: God's Call

“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.”



Mina  
2004

## Theme 7: 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 7: 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 7: 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 7: 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..."

Angel



## Theme 7: Nurse's Presence and the Importance of Addressing Spiritual Needs

“Truong’s parents were extremely anxious to take him home from the hospital. They spoke halting English, as Vietnamese was their main language, and let the team there know they “had to get him home NOW.” When I went to assess his condition and speak with them I realized that transport home may be too traumatic for Truong as he was very near death. ..

## Theme 7: Nurse's Presence and the Importance of Addressing Spiritual Needs

They were aware he could very likely die on the ride home and that could make his last moments more difficult than being here in the safety of the hospital. They would not hear it and began to pack up his things to go home...”

## ...Theme 7: Nurse's Presence and the Importance of Addressing Spiritual Needs

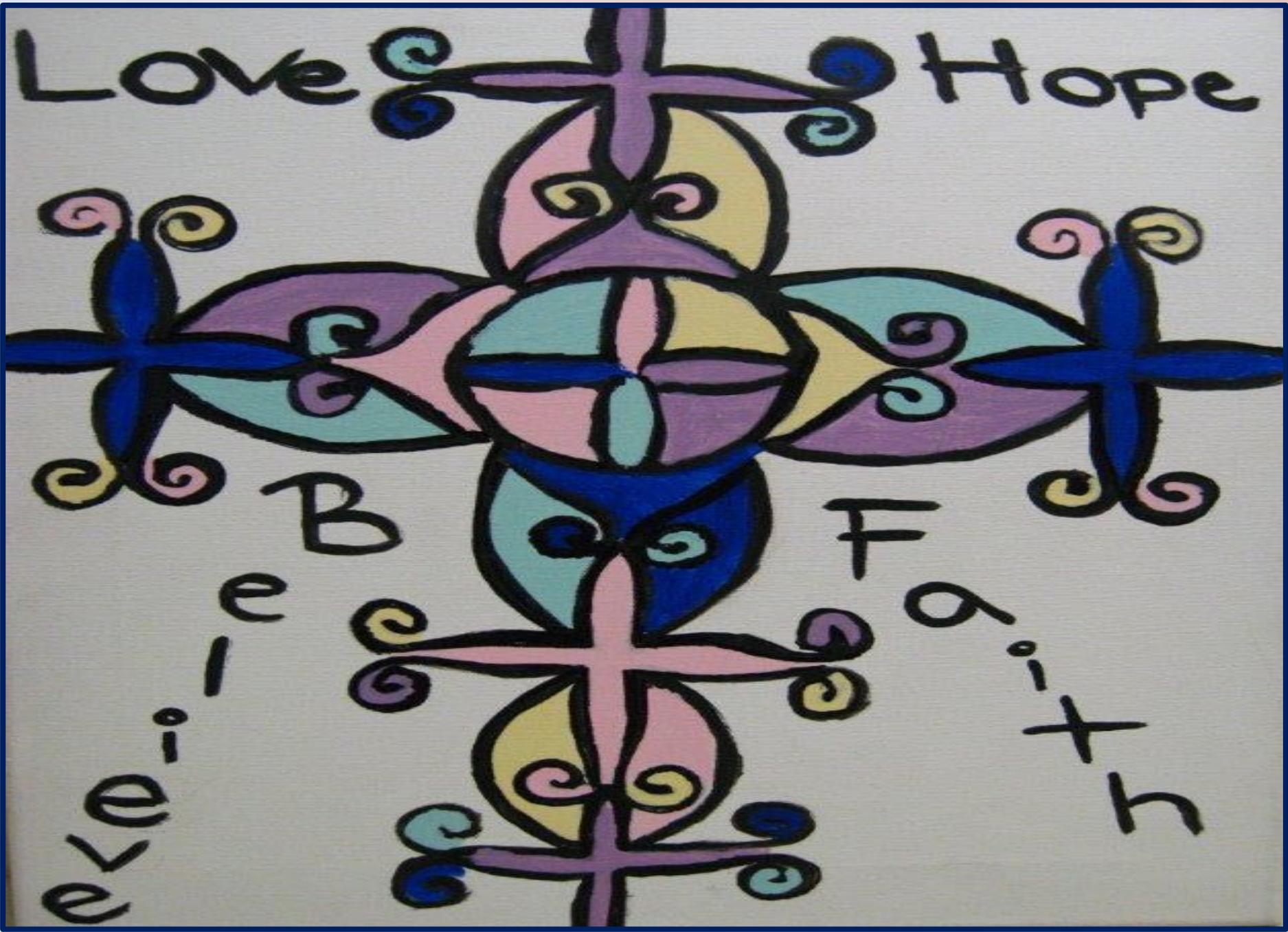
“But he was still with us when we laid him in his own bed. Symptoms had not changed only escalated. I began to do all the technical things. Hook up oxygen, prepare meds, etc. The father came into the room. I was soothing Truong with some gentle touch and he asked me to stop. Oh dear was there a cultural side I had not even been thinking about in the flurry of things?”

## ...Theme 7: Nurse's Presence and the Importance of Addressing Spiritual Needs

“I stopped and his mother entered the room with a beautiful, single pearl in her hand. I stepped aside. They gently covered him in a saffron colored prayer robe. And after lighting the incense, began their chants. They were not crying, they were now not distressed, and not nervous. Lastly, they placed the pearl in his mouth. It was just a little while until Truong left. I returned the next day to their home.

## ...Theme 7: Nurse's Presence and the Importance of Addressing Spiritual Needs

“I returned the next day to their home. They were almost serene. They were so grateful that I had gotten their son home. Had they not placed that pearl (they have one for each member of the family when the time comes) he would not have had passage to get to the other world that is waiting and that he would be wandering aimlessly for the rest of time. They believed they could not have performed these rituals in the hospital because no one was listening. I will never forget the lessons they taught me.”



Love

Hope

Peace

Faith

Peace

Faith

“As an example – no NICU nurse would ever let an infant die in a bed. We believe that it is every baby’s right to die in someone’s arms – if it’s not the family member, a nurse will be that someone, and I believe that is the ultimate expression of our spiritual care for neonates.”

# Stories of Spiritual Communication with Families



# Theme 1: Anger

“Dad was a very large black man, very angry and being labeled as a ‘difficult parent’. We were finally able to converse with him about his goals, fears, beliefs. His true spirituality was Voodoo. We facilitated his speaking with his mother in Jamaica for spiritual support and counsel. He softened to be a big teddy bear and was able to be with his family and to be present.”



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## Theme 2: Blame/Regret

“One experience I had in the hospital was when a very young couple came into the emergency department bringing a small child in their arms who had diarrhea for the past eight days and was in respiratory distress. The child was wrapped with a blanket and had several types of leaves on her. I asked why is this and the couple responded that they took the child to a bush doctor. The child died about an hour after admission, while still being evaluated by the pediatrician. Relatives regretted not bringing the child earlier to the hospital for medical attention.”



# Theme 3: Forgiveness...

“We had a 21-year-old drug overdose, in our ICU. His mother had no idea he used. We were able to locate how he injected drugs, but they were not noticeable to his family, “friends”, and team mates – he was a football player. We showed his mother his thumbs, he was injecting under his fingernail. This is when forgiveness began. As his friends lined the ICU to say goodbye – his mother apologized to the staff for denying he used and OD’d.”

## ...Theme 3: Forgiveness

“After his friends cleared, his mother told him she forgave him for what he had done, told him it was ok – and within minutes, he went systole with us having to withdraw treatment – the decision she knew she would have to make later that evening – needless to say – there was not one staff member in the ICU that day that did not have to go to the break room for a moment.”



-Michelle M.  
9-25-15

# Theme 4: NURSE'S ROLE

“My role – listen, reflect, listen some more. And of course, prayer – lots of it.”



# Theme 4: Nurse's Role...

“I was on call and a mother delivered her newborn, by a physician on call, not her regular OB, who left the room upon delivery. Upon review of the records, the child had congenital anomaly incompatible with life. She had seen genetics and nephrology and was aware of the prognosis. When I spoke to the mom she was crying and cradling her newborn. Though she knew, she was obviously unprepared, so I also called the chaplain to prepare this mom to say goodbye to her newborn.”

## ...Theme 4: Nurse's Role

“Together the mom, the chaplain, myself, and the pediatrician prayed and cried together. Her usual OB was not there and since the prognosis of illness was dismal, she had not chosen a pediatrician. We all prayed at the bedside, held this mom and baby, and I witnessed the child’s color turn to ashen grey slowly.”



## Theme 5: Rituals and Cultural Traditions

“Attending the death of a 4-day-old child. Mom’s belly was anointed by the hospital priest prior to baby’s birth. At time of death, family wanted baby anointed. It’s 1 am, 2 hrs to nearest (rural) town – minimal chance of a priest though I attempted to reach the parish priest. I offered to have the family (siblings, grandparents, parents, uncles...) anoint their baby.”

## Theme 5: Rituals and Cultural Traditions

“We went through the home looking for vessels for oil. Mom had her mother’s set of individual butter plates. Every family member had their own vessel with olive oil. They told stories of their family and their love for their baby, what had been added to their lives by having her in it, and each family member there anointed this child.”



# Summary

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

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

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

“For who but children can show us so much about the reality of human life? Their skin is thin, like plastic wrap, revealing a delicate system of vital tissues beneath it. Their breathing is shallow and frequent, revealing the primordial struggle that all living things have to receive the breath of life. Their hands and feet are fashioned with tiny details, revealing their dependence on other, stronger hands for survival. Their hearts beat with a powerful incessancy, revealing that even though they appear weak, they have a great will to live. Their faces have wonderful details displayed in countless expressions, revealing the uniqueness of each individual and the potential that each has to have a long and abundant life.

Their spirit is alive, revealing an immediate ability to respond to love and offer love in return, revealing that each is an incarnation of God's love. Who but children can show us so much about what it means to be human, revealing that all of us are rather fragile creatures, struggling for life, trying to fulfill our potential, expressing our uniqueness, living in relationship with God.

And who but children can so easily reveal how the fragile balance of life can be disrupted?”.

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.

