The Relief of Suffering and the Community of Caring

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Disclosure

Dr. Ferrell has no financial disclosures
Objectives

1. Describe the opportunities for interdisciplinary approaches to the relief of suffering.

2. Recognize the role of palliative care as a privilege and sacred work.
Those who scream in pain and suffer in silence

• Mute Suffering
• Expressive Suffering
• New Identity

William Reich
Palliative Care Clinicians as Spiritual-Scientific Practitioners
“Under this new medical covenant, a spiritual-scientific practitioner would affirm that the transcendent is made manifest at the edge of the surgeon’s knife, at the tips of the palpating fingers of the pediatrician, in the firm handshake of the internist, in the birth of the child whose unwed mother has AIDS, in the tears of the woman who feels a hard lump in her one remaining breast, and in the vacant stare of the elderly man with dementia.”
Rebirth of the Clinic (cont.)

“A spiritual-scientific practitioner would affirm that the transcendent is there when disease and suffering are recognized together, when the hand that performs the spinal tap distills compassion into the needle’s point, the objectivity of science with the subjectivity of God’s healing will; the particularity of the case at hand with the universality of a profession under oath; the finitude of the moment and the infinity of a life lived in the service of love. Thus might the clinic be reborn.”

(Sulmasy, 2006)
The Spiritual Crisis of Fatigue

“Fatigue wastes time and time is precious.”

BR Ferrell, M Grant, GE Dean, B Funk, J Ly
From “Bone Tired: The experience of fatigue and its impact on quality of life” 1996. Oncology Nursing Forum
Specialist and Generalist Spiritual Care Providers

“The Face of God”
The Role of Witness and Moral Agent

• Firsthand Observation/Providing Voice
• Ceremonial Role/Ritual
• Expert Witness
• Visionary

(Kahn and Steeves, 1996)
Forgiveness

Beyond “simple acts of pardoning, excusing, forgetting, or denying”

(Ashby, 2003)
The Essential Role of all Clinicians and Volunteers
Showing Up

Sometimes we can only witness. We cannot fix or do the work of creating meaning. This family responds to support, to ideas, to reframing, but ultimately they have to wrestle with the guilt themselves. We can provide a container, a holding environment of safety so they don’t have to do this in isolation. We can keep showing up, even when it’s messy and ragged and uncomfortable.
Death is awful, demonic. If you think your task as comforter is to tell me that really, all things considered, it’s not so bad, you do not sit with me in my grief but place yourself off in the distance away from me. Over there, you are of no help. What I need to hear from you is that you recognize how painful it is. I need to hear from you that you are with me in my desperation. To comfort me, you have to come close. Come sit beside me on my mourning bench.

(Wolterstorff, 1987)
Spirituality in Children and Families Facing Serious Illness

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Vanessa Battista, RN., MS, CPNP
Gay Walker RN, CHPPN
Children and Spirituality


• Children “may be conscious or unconscious participants in a spiritual life”; their presence alone provides spirituality to the world. (Mueller 2010)
The Spiritual Needs of Dying Children

• 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)
Stories of Spiritual Communication with Children

Jocelyn and I together
united with other fighters
and their brothers and sisters
These narratives were collected (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.
My family
Theme 6: 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 6: (cont’d) 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...
"...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.’
Angel
“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 Nature of Suffering and the Goals of Nursing
Betty Ferrell & Nessa Coyle
Oxford University Press, 2008
The Nature of Suffering

1. Suffering is described as a loss of control which creates insecurity. Suffering people often feel helpless and trapped, unable to escape their circumstances. Those who suffer feel vulnerable and uncertain about the future.
The Nature of Suffering

2. In most instances, suffering is associated with loss. The loss may be of a valued object or relationship, or of some aspect of the self, whether a role or loss of some aspect of the physical body. The loss may be evident only in the mind of the sufferer, but it nonetheless leaves a person diminished and with a sense of brokenness.
Breaking Bad News... Breaking a Heart
The Nature of Suffering

3. Suffering is thoroughly individual and intensely personal.
The Nature of Suffering

4. Suffering is accompanied by a range of intense emotions. Sadness, anguish, fear, abandonment, despair, and a myriad of other emotions may occur. This range of feelings is sometimes referred to as emotional pain.
5. Suffering can be deeply linked to a recognition of one’s own mortality. When threatened by serious illness, people may fear the end of life. Conversely, for others, living with chronic illness may cause a yearning for death.
The Nature of Suffering

6. Suffering often involves asking the question “why?” Illness or loss are often seen as untimely and undeserved threats. Suffering people seek to find meaning and answers for that which is unknowable.
7. Suffering is often an expression of the angst associated with separation from the world. Individuals often express intense loneliness and yearn for connection with others. This may be a highly ambiguous and confusing concern, since the same suffering person may also feel intense distress about dependency upon those who are present.
8. Suffering is often accompanied by spiritual distress. Regardless of religious affiliation, individuals experiencing illness, injury, or threat often feel a sense of hopelessness. When life is threatened, there may be a self-evaluation of what has been lived and what remains undone. Becoming weak and vulnerable and facing mortality causes one to reevaluate his/her relationship with a higher being.
9. Suffering is not synonymous with pain but is closely associated with it. Physical pain is closely related to psychological, social, and spiritual distress, which intensifies the physical experience. Pain which persists without meaning becomes suffering.
The Nature of Suffering

10. Suffering occurs when an individual feels voiceless. This may occur when the person is mute to give words to their experience or when their screams are unheard.