A Good Death: It Takes A Village

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Learner Outcomes

• Recognize the importance of “presence” as a bedside provider supporting families of a dying child.
• Identify strategies and tasks that occur simultaneously while a child is actively dying.

A Good Death: A Nurses Perspective

Presented by: Anna Marie Borich, RN
Once patients and their families enter the medical world, their actions are guided by the values and pervasive practices of that world. Kaufman (2000)

Dying may be an important part of living. Framing it as an unnecessary part of life may have damaging consequences for individuals, for families and for society. Cottrell & Duggleby (2016)

Denying dying may preclude families from creating significant moments and from forming important memories to carry into subsequent generations. Cottrell & Duggleby (2016)

Mindfulness in Death and Dying

- Dignity
- Preparedness
- Physical suffering
- Community

Four Key Elements Influence Quality of Death Experience
Clinically Relevant Factors

- Communication
- Pain and symptom management
- Clinical expertise
- Palliative care service
- Patient goals match prescribed treatments

MAKING A DIFFERENCE

- Stay informed on current best practices
- Communication on end of life matters
- Bedside compassion
- Manage pain
- Attend to non-medical needs, coping and social support
- Tailor treatment to patient wishes
- Timely referrals to Hospice and Starshine
Denying dying may destroy individuals' opportunities to grow, to find meaning, hope, and joy, and to live fully until they die.
Cottrell & Duggleby (2016)
What are the components of a good death?

- Clear communication
  - Patients and families know death is coming
  - Time to process and ask questions
  - Opportunities to express hopes and fears

- Symptom management
  - Pain
  - Dyspnea
  - Delirium/agitation
  - Anxiety
  - Depression

Guilt is perhaps the most painful companion of death.

Coco Chanel
Pain

- Opioids do not have a "ceiling effect"
- The correct dose is that which provides adequate analgesia with acceptable side effects

Dyspnea

- Treat the underlying disease
- Opioids are the mainstay of management
- Oxygen has not been shown to be beneficial
- Non-pharmacological therapies

Delirium/agitation

- Antipsychotics (i.e., haloperidol, olanzapine)
- Benzodiazepines
What are the components of a good death?

• Education and managing expectations around normal dying process

A Good Death:
A Social Workers Perspective

Presented By:
Wanda Merleweather, SW
Being involved with a social worker may be new to some families. Sometimes having social work involved can have a negative connotation, i.e. (there must be a problem).

Patients and family’s can have social work involvement throughout their medical journey. Relationship may start due to a emergent need.

Social Work Support

- Maintaining a relationship with patient and family becomes key during discussions regarding treatment, progression/relapse, and end of life concerns.
- Patient and family start to feel comfortable to share with social worker concerns and fears regarding end of life decisions.
- Discussions start early on with young adults and adolescents regarding decision-making and advance directives (over the age of 18 years old).

Multidisciplinary Team Approach

- Providing support to the patient and family at end of life becomes a multidisciplinary team approach.
- Social Workers work closely with the primary oncologist/ medical team, palliative care, child life, chaplains, behavioral medicine, nursing, music and holistic therapy.
Key Elements to a Multidisciplinary Model

- Honor the wishes of patient/family
- Provide comfort care and coping support
- Address issues of anxiety/depression
- Assist in memory making
- Address spiritual needs
- Provide clarity regarding end of life issues.

Addressing Difficult Decisions

- Social Worker often acts as a sounding board for families as they process end of life concerns that have been discussed with the medical team. Often the family feels that the team has given up hope when addressing end of life concerns.
- Families can experience judgment from extended family members/community regarding decisions. Viewed as giving up on love one.
- Being able to provide supportive listening allows families to not feel judged by their decision, and be able to come to terms with impending death.

Preparing for Death

- As end of life approaches, social worker’s assist patient and family in making decisions regarding being at home with the support of hospice or in the hospital.
- Discussions can also include making special memories (visits or outings), how much information to share with family/friends, and funeral expenses.
During the Death

• Peaceful death includes the family coming together for the patient.
• Having time after the death to be alone as a family.
• Allowing parents, caregivers, spouses, and extended family to participate in cleaning the body.

After the Death

• Social Work role continues after death with family.
• Along with Bereavement Coordinator, social worker maintains contact with family after death by making a phone call two to three weeks after death.
• Phone call is provided to let know family know that they are not forgotten.
• Social Worker will often schedule a meeting with primary medical team and nursing staff that provided care to patient when family is ready to visit.

A Good Death:
THE ROLE SPIRITUAL CARE
Religion vs Spirituality

In this question, spirituality is a noun that means concern with matters of the soul. Spirituality has to do with the spirit, not as in ghosts, but as in the essence of being human—your soul or your inner life.

spirituality - Dictionary Definition : Vocabulary.com
www.vocabulary.com/dictionary/spirituality

Chaplain

Spiritual care is an essential aspect of the delivery of palliative care. The diagnosis of a life-threatening illness often results in the person reflecting on the meaning of life with concomitant spiritual, religious and existential questions. In fact, spiritual and religious needs and concerns may be equally, and sometimes more, important than those physical in nature.

http://www.professionalchaplains.org/files/publications/chaplaincy_today_online/volume_24/number_2/24_2scott.pdf

Why Spiritual Care at End of Life?

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A GOOD (SUPPORTED) DEATH: SPIRITUAL CARE

- Assessment
- Empathetic Presence
- Normalization of Patient/Family Experience
- Exploration of Sources of Hope & Meaning
- Affirmation of Sources of Strength & Comfort
- Reframing
- Diversional & Life-Affirming Activities
- Prayer, Rituals & Observance of Religious Practices

EndLink: An Internet-based End of Life Care Education Program
http://endlink.lurie.northwestern.edu
PART IV: BASIC SKILLS AND TECHNIQUES IN PROVIDING SPIRITUAL CARE
http://endlink.lurie.northwestern.edu/religion_spirituality/part_four.pdf

A GOOD (SUPPORTED) DEATH: SPIRITUAL CARE

RELIGIOUS BELIEFS AND TRADITIONS AT END OF LIFE

Keep in mind...

- Everyone is unique, so be sure to ask and verify
- Usually different expectations of or exceptions for children
- Sensitivity and respect matter more than expertise

Islam – Beliefs & Rituals

- God’s plan – “Life and death is in God’s hands.”
- Reading verses from the Koran and praying for peaceful departure of the soul very important.
- May want to position the body in direction of Mecca.
- Gathering memories, such as handprints or footprints as well as photographs of the baby may cause distress to a Muslim family. This may be considered a desecration of the body.
- Muslim practice is to bury rather than cremate the dead.
- Postmortems are not agreed to unless required by law.
- Preparation for burial involves ritual washing of the body by next of kin (and same gender as deceased) then wrapped in white cotton.
Hindu – Beliefs & Rituals

• Things happen because they are predestined, actions in the present life are the result of sins in a past life. Death is viewed as rebirth, the transition to another phase of the life cycle.
• After a death, readings from the Bhagavad Gita (holy scriptures) are conducted by Brahmin priests of elders from the upper caste community.
• A relative then bathes and anoints the body, males washing males and females washing females.
• After a tulasi (basil) leaf is placed in the mouth, the body is dressed in white cloth and is faced north with the feet facing south in preparation for rebirth.
• These preparations are vital to ensure purity surrounding rebirth and the final transmigration of the soul.

Jewish – Beliefs & Rituals

• When a Jewish patient dies, nurses should always try to contact the patient's rabbi or the Jewish chaplain designated to the hospital. If they are not available, staff are permitted to carry out basic procedures immediately. These include closing the eyes and mouth, with strapping if necessary. Any external catheters and medical equipment attached to the body may be removed and all incisions should be dressed.
• It is essential that the body is laid flat, with hands open, arms parallel and close to the body, and the legs stretched out straight. There is no need to remove identification bracelets or wash the body as the Jewish Burial Society will prepare it for burial.
• It is traditional for relatives or friends to keep vigil by the body and recite prayers. If possible, their wishes should be accommodated. Although the recital of prayers is encouraged, there is no concept in Judaism of last rites.
• A Jewish burial should take place as soon as possible after death and arrangements for the release of the body should be made without delay. Even if the patient had not been a particularly observant Jew, he or she would want to hasten the burial. But if death occurs on the Sabbath or a festival, there is little that the Jewish community can do to prepare for a funeral.

Christian – Beliefs & Rituals

• Usually no preference for same-gender care
• May want their own clergy/faith representative present
• May request baptism or blessing or prayers
• Roman Catholic Catechism recognizes ‘In case of necessity, anyone, even a non-baptized person, with the required intention, can baptize, by using the Trinitarian baptismal formula.’
• Roman Catholic “last rites” encompass several sacraments, including penance (confession of sins), viaticum (holy Communion given as food for the journey to eternal life) and the anointing of the sick.
• Autopsy and cremation or burial are personal choices
A Good Death:
A Child Life Perspective

Presented By:
Rachel Franklin, MS, CCLS
Overarching Goals

• Psychosocial care: whole family system
• Individualized: reflect beliefs, preferences, communication styles, defined as meaningful
• Ongoing collaboration with psychosocial and medical team
• Grief support: education, play, emotional support
• Legacy-building and memory-making

Preparation for the Child or Adolescent

• Education, preparation and emotional support tailored to cognitive and emotional level
• Anticipation of developmentally-appropriate questions, concerns, misconceptions
• Involvement or presence of trusted adults/caregivers
• Information about physiologic and physical happenings
• Promoting control, choice, and comfort

Medical Play
Support for Siblings

- Follow guidelines for talking with and supporting patient
- Impact of situational factors
- Teach positive coping behaviors
- Double loss created, social isolation, own health concerns
- Cognitive, emotional, behavioral changes or difficulties

Guidelines for Interventions with the Child and Siblings

- Provide creative outlets for difficult emotions
- Create open communication but do not force it
- Allow children and adolescents time to say good-byes
- Allow them to decide when and with whom they want to share feelings of grief
- Promote routine, normalcy, and play or age-appropriate activities

Therapeutic & Expressive Activities
Therapeutic & Expressive Activities

Keepsake Boxes

Support for Caregivers

- Encourage self care
- Provide support and education focused on assessing and promoting patient and sibling coping
- Assist in facilitating family conversations
- Support caregiver in having opportunities for continued, familiar caregiving or parenting roles
Involvement in Decision-Making

- Help the child live their available days
- Allow patient to engage in age-appropriate decision-making surrounding details related to death event (partnership with team, caregivers)
- Helping a child know what to expect with treatments and body changes
- Expressing wishes, giving items, post-bereavement planning
- Preparation for funeral or memorial events

Building Legacy and Memories

- Beads of Courage
- Photographs
- Storytelling, special routines, and comfort items
- Ink Prints
- Lock of hair
- Canvas printing
- Plaster hand molds

Beads of Courage
Photographs

Storytelling, Special Routines, and Comfort Items
A Good Death: 
A Music Therapist's Perspective

Presented By: 
Alexa Economos, MMT, MT-BC

Music Therapy 
is the clinical and evidence-based use of music within a therapeutic relationship to address physical, emotional, cognitive, and social needs of individuals.
In the best case scenario, there has been a music therapy relationship established prior to the days and hours before dying.

- Relationship with the patient
- Relationship with the family
- Assessment of goals and wishes for music therapy process

(Economos, 2015)

Legacy Music

- Songwriting or original compositions
- Heartbeat Recordings (Schreck, 2015)
- Song dedications
- Musical autobiography

(O’Callaghan, 2013)

Songwriting Piece

(Rut & storm is negociat-ed open life)
What does music therapy look like during the dying process?

- Complementary pain and anxiety management (Bradt & Dileo, 2010)
- Shifting focus to family's needs (Krout, 2003)
- Facilitating meaningful shared experience
- Music as a catalyst for difficult conversations (Hogan, 2003)

In defense of beauty

- Transforming the experience and the environment
- Creating something beautiful from something painful
- Facilitating final moments of connection
- Connecting with spirituality through music (Potvin & Argue, 2014)
  (Economos, 2015)

References

References


Mertz, et al. (2005). The spiritual needs of parents at the time of their child's death in the pediatric intensive care unit and dying processes: A qualitative study. Pediatric Critical Care Medicine, 6(4), 420-427.


