

# The Phenomenon of a Good Death



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# The Phenomenon of a Good Death



- **Objectives:**

- Define qualities of End-of-Life care that supports the phenomenon of a good death
- Describe the role of the patient and caregivers in defining and achieving a good death
- Describe how communication supports the phenomenon
- Discuss measurement of a good death

# Define “*Good*”



- **Personal experience**
  - Healthcare Professionals
  - Patients
  - Caregivers

# Definition of a Good Death



- **Sometimes difficult to define**
  - Who is defining what a “Good Death” is?
  - Based on current western normative expectations?
  - Diversity in definitions
  - How do you collect the data regarding a good death
    - ✦ **Time frame**
    - ✦ **Format**

# Defining a Good Death



- **Changes from person to person**
- **Requires effective communication to ensure patients are defining obtainable and meaningful goals**
- **Nurses role... MAJOR part of this phenomenon, the nurses' awareness of what their patient is experiencing**

# Institute of Medicine's Definition...



- A good death is “one that is free from avoidable distress and suffering, for patients, family, and caregivers; in general accord with the patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards.”

# A GOOD DEATH



- **My definition...**
  - The phenomenon of a good death is the integration of many concepts, including pain and symptom management, clear decision making, preparation for death, completion, experience of dignity and respect, closeness to people that care, and being at peace.
- **What is your definition? How have you experienced it?**

# Six domains



- **Six domains for measuring and modifying a good death**
  - Physical symptoms
  - Psychological and cognitive symptoms
  - Economic and caregiving needs
  - Social relationships and support
  - Spiritual and existential beliefs
  - Hopes and expectations

Emanuel, E. J., & Emanuel, L. L. (1998). The promise of a good death. *Lancet*, 351, 21-29.

# Patient Perspectives of a Good Death



- **Patient definitions:**
  - **Diverse and specific**
    - ✦ “dying in my sleep”
    - ✦ “Dying quietly”
    - ✦ “Dying without pain”
    - ✦ “Dying suddenly”
  - ✦ **TRANSLATION... Quick, painless, and peaceful.**

Hughes, T., Schumacker, M., Jacobs-Lawson, J. M., & Arnold, S. (2007).

# Health Care Professionals Perspectives of a Good Death



- **Health care professionals**
  - “pain free”
  - “peaceful”
  - “anxiety free”
  - “comfortable”
  - Family acceptance and cultural considerations included in multiple answers
- **Multiple domains highlighted in expert opinion papers, including physical, psychological, social, spiritual and existential experiences, life closure and death preparation.**

Payne, S. A., Langely-Evans, A., & Hiller, R. (1996); Emanuel & Emanuel, 1998

# Determination of Quality... was it Good?



- How do you determine the quality of a good death?
- Review of Literature:
  - Many studies have been done to describe what happens at the end of life, but do not clarify if it was considered “good” by those involved

Steinhauser, Clipp, & Tulsky, (2002); The SUPPORT Principle Investigators, (1995);

# Initiatives to Improve End-of-Life Care



- **American Medical Association's Education for Physicians on End-of-Life Care Project**
- **Open Society Institute's Project on Death in America**
- **Robert Wood Johnson Foundation's Last Rites Campaign**
- **End of Life Nursing Education Consortium (ELNEC)**

# Measurement of a Good Death



- **The Quality of Dying and Death Questionnaire (QODD)**
- **The Good Death Scale**
- **The Good Death Inventory**
- **The Quality of Dying in Longterm Care (QOD-LTC)**

Hales, S., Zimmermann, C., & Rodin, G. (2010) in their review of the literature highlighted the significance of clarifying the definition of a good death in order to ensure that when selecting a tool to measure the quality the concepts in the definition are addressed accordingly.

The characteristics and complex nature of the phenomenon of a good death is well published, the effectiveness of the ability to measure if it was good remains an aspect that still needs development.

# Communication... defining a good death



- **Variability of preferences**
  - Culture, religious beliefs
  - DO EVERYTHING... define everything
- **Goals of care/Patient “needs”**
- **Communication with patients about end-of-life requires HEACC:**

**Honesty, Expertise, Advocacy, Compassion,  
and Commitment**

# HEACC



- **Communication...**
- **Fear**
  - Process of death, helplessness, dependence on others, physical process, uncontrolled pain, leaving family behind, unfinished business
  - Stay with the patient
- **Patients may not have all the information or an accurate view of their prognosis**
  - Unrealistic patient and family expectations
  - If the expectations are not met... could change the opinion of patients and families on the quality of the death

# Communication



- **Gaining an understanding of the feelings, thoughts, and awareness of their experience invites the health care professional the opportunity to offer and facilitate a “good death”.**
- **Communication can facilitate successful movement of the patient and family through the stages, creating goals and meeting needs while supporting the transition**

# Kubler-Ross Model



- Model of Death and Bereavement
- A tradition of science that addresses patients and families concerns about the experience of a terminal illness and the experience of dying.
- *On Death and Dying*, Kubler-Ross
  - Discussions with 200 dying, critically ill patients
  - She taught us that terminally ill patients who are coming to terms with death deserve attention and respect
  - “Give up the conspiracy of silence”
  - Inspired a new approach to working with the terminally ill and believed that passing through the stages of dying would assist patients with acceptance and therefore facilitate the experience of a successful, or “good” death

Kubler Ross, E. E. (1975). *On Death and Dying*. New York, New York: MacMillian.

# Kubler-Ross Model



- **Stages of Death and Bereavement**
  - Stages of Dying
  - Stages of Grief
- **Stages**
  - Denial
  - Isolation
  - Anger
  - Bargaining
  - Depression
  - Acceptance

# Stages of Grief



- <http://vimeo.com/5419363>
- Not every patient manages acceptance, but in Kubler-Ross's writings she demonstrates that if communication occurs early on, even though the process is incomplete prior to death, transitions through the stages are therapeutic

- **MONK**



# Kubler-Ross Model



- Patients who are ill and dying have important needs during their journey
  - Facilitation of communication of concerns and thoughts related to the dying process may relieve some of the fear that patients who are suffering feel...  
They could experience PEACE instead of CHAOS
  - Communication with patients allows for discovery of the essence of their dying experience
- Kuczewski, M.G. (2004)

# Just to throw a wrench in...



- Walters (2004) approaches a good death, drawing on many sources, historical, literary, philosophical, and theological.
  - ✦ Premodern death – religious view, “to die well is to be at peace with God”
  - ✦ Modern Death – transformation that occurred with modern medicine
  - ✦ Postmodern... Euthanasia defines a good death, it is very procedural, offers control, can avoid suffering and loss of dignity

# End-of-Life Care for Research Participants



- Tension between the goals of medicine and the goals of science
- Tension between a good death and conducting clinical research in patients with a short life expectancy
- Addressing these tensions in order to provide a good death (as defined earlier)

# Research Participants



- **Hope**
- **Innovative therapies**
- **Economic demands**
- **Purpose**
- **Altruism**
- **Need to make sense of their illness**

# *A Good Death* in a Research Setting



- **Modify the informed consent discussion**
  - Use of technology – educational videos, computer, etc.
    - ✦ *What is “EVERYTHING”... the End-of-Life Video*
  - Ask the patient what do they understand about their disease and how do they feel about their illness and treatment options.
- **Build a Palliative Care component into clinical trial**
  - Provide standard of care in palliative medicine in the light of research
  - Would allow research to go on, while palliating symptoms and preparing patient and family for the end-of-life

Agrawal & Danis (2002)

# *A Good Death* in a Research Setting



- Attend to the needs of family caregivers of terminally ill research participants
- Arrange for continuity of care so that dropping out of research protocols does not effect care
- Train clinical investigators in end-of-life care
- Counseling program for patients

Agrawal & Danis, (2002).

# In closing...



- You have the perfect opportunity to have “good death” dialogue
- Education about end-of-life and goals of care is within your scope of practice
- HEACC... Communication
- Get involved, education necessary
- More research...
- We can make a difference!

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