Caring, Comfort, and Compassion at the End of Life

Deborah Klein MSN, RN, ACNS-BC, CCRN, CHFN, FAHA
Clinical Nurse Specialist
Coronary ICH, Heart Failure ICU, Cardiac Short Stay/CARU
Cleveland Clinic

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Death and Dying in America

- Unprecedented number of older Americans with chronic illness
- Technology is prolonging but not restoring life
- Exploding healthcare costs
- Many uninsured
- Rising drug/device costs
- Failure to treat pain
Death and Dying in ICUs Across America

• In ICUs annually
  – ~40,000 deaths
  – 28% of Medicare patients in last 6 months of life
  – 59% inpatient deaths
  – Accounts for 80% of inpatient costs

McAdam & Puntillo, 2010
Angus et al., 2004
What Constitutes Good Quality Care at the End of Life?

• For Healthcare Team:
  – Providing symptom management
  – Discussing emotional aspects of the disease

• For Patients:
  – Achieving a sense of control
  – Attaining spiritual peace
  – Succeeding in having finances in order
  – Strengthening relationships with loved ones

Grant & Dy, 2012; Jacobsen et al., 2011
Illness/Dying Trajectories
Sudden Death, Unexpected Cause

< 10% (MI, accident, etc.)

Field & Cassel, 1997
Illness/Dying Trajectories
Steady Decline, Short Terminal Phase

Field & Cassel, 1997
Illness/Dying Trajectories
Slow Decline, Periodic Crises, Death

Field & Cassel, 1997
Toll of Death and Dying on Patients and Families/Caregivers

- Fear being a physical and financial burden

- If “nothing more can be done,” will healthcare providers abandon them?

- Adjustment to role changes

- Draining life savings and/or bankruptcy to cover medical costs

- Caregiver may be aged spouse who is also ill

- Older children/ caregivers with acute or chronic illness

Egan-City & Labayak, 2010; Given et al., 2012
Barriers to Quality Care at the End of Life

- Failure to acknowledge the limits of medicine
- Lack of training for healthcare providers
- Hospice/palliative care services are poorly understood
- Rules and regulations
- Denial of death

Meier, 2010; NHPCO, 2011
Palliative Services

• Goal is to prevent and relieve suffering

• Focus is symptom relief to support the best possible quality of life

• Initiated at any stage of illness including life-prolonging treatment

• Provided by an interdisciplinary team

• Addresses physiological, psychosocial, and spiritual needs
Hospice Services

• Palliative care for patients with limited life expectancy
• Supports patient through dying process
• Supports family through dying and bereavement process
• Provides comprehensive medical and supportive services (psychosocial, spiritual)
• Multiple settings: home, residential facilities, hospitals and nursing facilities
Current Practice of Hospice and Palliative Care
Continuum of Care

Disease-Modifying Treatment

Palliative Care

Hospice Care

Bereavement Support

Terminal Phase of Illness

Death
End-of-Life Care Across Settings and Specialties

Critical Care Nurses are a valuable resource to improve and address the needs of patients and families facing life-threatening illness in a variety of settings

Nelson et al., 2011
Strategies for Critical Care Nurses

• Effective communication
• Support through loss, grief, and bereavement
• Acknowledgement of cultural and spiritual beliefs
• Knowledge of ethics
• Management of pain and symptoms
• Care during the final hours of life
Effective Communication: Family Needs

- To be with patient
- Information and frequent updates for decision-making
- Permission to speak and be listened to
- Informed of changes in patient’s condition
- Assurance of comfort
- Open communication
Health Care Provider Barriers to Communication

- Lack of experience
- Avoidance of emotion
- Insensitivity
- Sense of guilt
- Assumptions
Barriers to Communication (cont.)

- Disagreement with decisions
- Lack of understanding of culture or goals of care
- Personal grief issues
- Ethical concerns
- Many consulting teams/too many people
Role of the Critical Care Nurse in the Communication Process

• The focus is the patient’s best interest
• Listen to and support patients and families
• Provide and clarify information to enable decision-making
• Be aware of body language, eye contact, gestures, tone of voice

Boreale & Richardson, 2011; Buckman, 2001; Dahlin, 2010
Listening

• Our most precious gift is the gift of time
• Being present, being silent
• Attentive listening
  —allows flow of conversation without interruption
  —encourages talk
Presence

- Comfortable with self
- Know the person/family be able to connect (who is at the bedside?)
- Affirm and value
- Be vulnerable
- Empathize
- Be in the moment
- Provide serenity and silence
Team Communication

• Intra-team communication is vital, especially between RN and MD
• Family meetings
• Should be collaborative
• Should be effective and frequent
• Document
• Expect conflicts
Resolving Conflict

• Try to take a step back
• Identify your own emotions
• Talk about it. Get other person’s perspective – “Help me understand…”
• Identify your feelings – “This makes me feel…”
• Agree on patient care issues

Jeffrey, 2010
Loss, Grief and Bereavement

- Patient, family and nurse all experience losses
- Each person grieves in his/her own way
- An interdisciplinary approach is vital
Loss, Grief, Mourning, and Bereavement

• A loss may be a person, thing, relationship, or situation
• Grief is an emotional response to loss
• Mourning is the outward, social expression of loss
• Bereavement is the reaction of the survivor to the death of a family member or close friend; the adjustment to a life without the deceased
• All are strongly influenced by culture
Factors Influencing the Grief Process in Families

- Survivor personality
- Coping skills, patterns
- History of substance abuse
- Relationship to deceased
- Spiritual beliefs
- Type of death
- Survivor ethnicity and culture
What Do Family Caregivers Want When They Are Grieving?

- Loved one’s wishes honored
- Included in decision-making
- Practical help
- Honesty
- To be listened to
- To be remembered
- Know they did all they could possibly do

Northouse & McCorkle, 2010
Interventions

• Deal with need as presented
• Provide opportunities for family to be with the one who is dying
• Address concerns in manageable amounts
• Assist reconstruction, if appropriate

Humphrey & Zimpfer, 2008
Completion of the Grieving Process: Is It Possible?

- Grief work is never completely finished
- Healing occurs when the pain is less
Ethical Issues in Critical Care Settings

• Advances in medical technology

• Landmark cases have influenced history

• Nurses are privileged to help patients and families make fully informed decisions
Ethical Principles

• Autonomy: respect another's right to self-determine a course of action
• Beneficence: desire to do good; compassion
• Nonmaleficence: avoidance of harm or hurt
• Justice: an equal and fair distribution of resources
Ethical Issues in End of Life Care

- Informed consent
- Decisional capacity
- Advanced directives
- Prolongation of life: balancing benefits and burdens
- Withholding/withdrawing medical interventions
- Code status (DNR-CCA, DNR-CC, DNR specified)
- Medical futility
- Assisted death
- Principle of double effect - “Last Dose Syndrome”
Preventive Ethics

• ANA Code of Ethics
• Nurses should focus on preventing the occurrence of conflicts
• Early identification of issues
• Understanding patient/family wishes
• Cultural and spiritual awareness
• Effective communication skills
• Bioethics consultation
Challenges in Pain and Symptom Management at End of Life

• Patients unable to report symptoms
• Medications may contribute to fears of worsened hemodynamics
• Clinicians are trained to resuscitate
• Symptoms create suffering and distress

• Priorities:
  • Symptoms which occur frequently
  • Symptoms which are most distressing to patients and families
Common Symptoms at End of Life

- Dyspnea
- Secretions
- Nausea/vomiting
- Nutrition/hydration
- Anxiety
- Delirium/agitation/confusion
- Intractable pain
- Seizures
- Fevers
Frequency of Symptoms Last 48 Hours

Harlos, 2010
Management of Dyspnea

• Treat symptoms or underlying cause
• Non-pharmacologic
  • Oxygen
  • Ventilator support
  • Balance rest with activity
  • Optimize positioning
• Pharmacologic treatments
  • Opioids
  • Bronchodilators
  • Diuretics
  • Steroids
Nutrition & Hydration

- Perception of “starving to death”
- Enteral feeding does not reduce risk of aspiration or mortality
- Enteral feedings usually are discontinued at imminent death secondary to malabsorption
- Hydration does not decrease “dry mouth”

Ersek, 2003; Ganzini et al., 2003; HPNA, 2003
Huang & Ahronheim, 2000
Medication Management of Pain and Agitation

• Morphine and Fentanyl IV
  — Can be used for both pain and anxiety
  — Morphine avoided in renal failure
  — IV infusion and/or prn IVP

• Benzodiazepines
  — Lorazepam (Ativan) or Midazolam (Versed)
  — IV infusion and/or prn IVP

• Haloperidol (Haldol) or Chlorpromazine (Thorazine) IV
  — For agitation if patient at risk for seizures
Non-Pharmacologic Techniques

• Modify environment
  – Reduce noise
  – Soft music
  – Limit light

• Consult other disciplines
  – Palliative Medicine
  – Art Therapy
  – Healing Services
  – Pastoral Care
Optimum End-of-Life Care in Critical Care

- Advocate for patient/family
- Provide supportive physical environment for patient and family
- Avoid changes at final stage
- Provide privacy for family away from bedside
- Respect culture and spiritual beliefs (death rites and rituals)
Open, Honest Communication

• Convey caring, sensitivity, compassion
• Provide information in simple terms
• Prepare patient/family for dying process
• Maintain presence
Signs of Death

- Asystole, if monitored
- Absence of heart beat, respirations
- Release of stool/urine
- No response
- Pupils fixed
- Body color pale
- Temperature drops
- Eyes may remain open
- Jaw falls open
The Death Vigil

• Family presence
• Provide comfort
• Common fears
  – Painful death
  – Being alone with patient
  – Time of death
Pain During the Final Hours of Life

- Diminished ability to self report
- Behavioral cues – grimacing, muscle tension, clenched fists, moaning, “silent scream” when intubated
- Dosing of opioids in last hours
- Titration of opioids
- Intractable pain and palliative sedation
Cleveland Clinic Resources

- Comfort Care order set
- Nursing End of Life Comfort Care Protocol
- Tool Kit
- Bereavement Cart
- Code Calm
Code Calm

• Purpose is to limit conversation and noise outside patient’s room (speak quietly and as needed)
• All personnel are expected to be respectful of the patient and family
• Address alarms and answer telephones in a timely manner
• Symbol posted on door of patient’s room or nurses station
• Share purpose with family
White Rose Program
Hillcrest and South Pointe Hospitals

Placed outside the patient’s room to signify end-of-life and promote quiet, respect and comfort to patient and family.
Withdrawal of Life Support

Decisions are made when:

- The capable patient requests withdrawal
- Prognosis for recovery to acceptable baseline is poor
- Death is near and inevitable
- Coma is expected to persist
Ventilator Withdrawal

• Multidisciplinary
• Critical Care Nurse prepares, supports and reassures patient and family
• Provide education for staff regarding withdrawal of ventilator support
• Prepare family/patient in advance
• Pre-medicate
Cardiac Deactivation Procedures

• Deactivation of any of these devices is legal and ethical, when patients/families request it

• It is important to talk with patients/families about the possibility of deactivating cardiac devices when treatment is no longer successful and/or when it is no longer needed

• No need to wean

• Extubation before or after stopping cardiac devices and vasopressors is patient dependent

• Pacemakers are not turned off

• Implantable cardiovascular defibrillator (ICD) are deactivated with a magnet over the device

• Ventricular assist devices (VAD) are turned off
The Critical Care Nurse: Compassion Fatigue

- Nurses witness medical futility
  - Prolongation of suffering
  - Denial of palliative care services
- Critical Care Nurses experience moral distress
- Cumulative effect
Stages of Adaptation

• Nurses new to working with the dying need to emotionally and spiritually adapt

• Stages of adaptation
  – Intellectualization
  – Emotional survival
  – Depression
  – Emotional arrival
  – Deep compassion
  – The “doer”
Factors Influencing the Nurse’s Adaptation

- Professional education
- Personal death history
- Life changes
- Support systems
Systems of Support

• Find meaning in your work
• Find balance
• Assess your support systems
• Spiritual support
• Education in end-of-life care
• Self care strategies
Conclusion

Family members will always remember the last days, hours, and minutes of their loved one’s life. Nurses have a unique opportunity to be invited to spend these precious moments with them and to make those moments memorable in a positive way.