Before, During and After “The End”: End of Life Care

Jeannie Meyer, MSN, RN, CCRN, CCNS, PCCN, ACHPN
Clinical Nurse Specialist for Palliative Care
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The Beginning of the end...

- The prognosis, the treatment options and the plan.
  - Goals of care should be discussed with the physicians on the case prior to initiation of a discussion.
  - “How do we see this ending?”
    - (Just because we can, SHOULD we?)
  - Beyond the hospital setting: discharge and rehab expectations.
- Resuscitation realities:
  - If you’ve got a ventilator, pressors, antiarrhythmics and artificial pacing, you’re already “coding” the patient.
    - At that point, “no compressions, no defibrillation” may be the only other options.
  - It’s hard to arrest in a hospital!
  - Arrest = catastrophic event.
On national television, 75% of “cardiac arrest” patients survive.
Most have positive outcomes.
Little discussion of the real aftermath of a resuscitation effort.
- Ventilators
- Medications
- Downward trajectory
- Survival to discharge
- Quality of Life after discharge
Cardiopulmonary resuscitation: the grim reality

- For every minute that an individual is in arrest (no respirations or pulse) the chance of meaningful survival decreases 10%*.
- Even among previously healthy patients, only 15% survive after a resuscitation to be discharged from the hospital.
- Many patients have less than a 2% chance of survival:
  - Patients with pre-existing chronic medical conditions.
  - Those who do not live independently (such as nursing home patients or patients dependent on others for their care for medical reasons).
  - Those with terminal illness.
- These statistics do not address the long-term survival or quality of life.

*American Heart Association.
So why do it? The Original Intent of CPR

- For the reasonably healthy individual.
- Sudden, catastrophic event.
- Reversible condition (ex. Stroke that can be treated).
- Abnormal heart rhythm that can respond to electric shock and that has an underlying cause that can be treated.
In speaking to patients and their significant others...

- **Are you speaking to the person(s) who have the power to make the decision?**
  - If there is a Directive and a copy has not yet been provided, request it, and find out the gist of what it says.
  - Avoiding the “crazy daughter from Tuscaloosa”.
- “What have you been told about your own/your loved one’s condition?”
  - The physician update can help ensure that everyone is told the same thing (even if they may not all hear the same thing...).
- “Who is this person?”
- “Has he/she ever made any comments or expressed any wishes pertaining to the current situation?”
- “If he could speak to you now...”
“Not our goals, their goals…”

**However:** In cases where the healthcare practitioner believes that the patient’s wishes are not being honored, best interests are not being respected, or in cases of known or suspected medical futility, **get an Ethics consult!**

- As a professional courtesy, the primary and critical care physician(s) *should* be notified prior to the initiation of an Ethics consult by another healthcare team member.

- Even patients and loved ones with no specific belief system have spiritual distress and existential suffering. **Contact your chaplain** to offer support.

- Be aware of concerns outside of the dying process that may be contributing to suffering (financial concerns, questions about child custody, etc.) **Contact a Social Worker** if needed.

*When in doubt, Don’t Ask Just Call!*
And once the decision has been made...
Understanding death

- Death is holistic: Body .. Mind .. Spirit
- Signs and Symptoms can differ slightly depending on the type of death
  - The ‘usual road’
    - A gradual decline leading to unconsciousness then death
  - The ‘difficult road’
    - Complicated by distressing symptoms such as seizures, confusion, delirium, restlessness/pain
      - Seen frequently in setting that limit a peaceful/calm environment (hospital, nursing homes, Long-term Care, etc.).
- Nurses or care partners often are the first to notice when a patient is actively dying
Early stages ...

- Sensation/Perception
  - Impaired perception
  - Disorientation
  - Decrease visual acuity
  - Increased light sensitivity
  - Dulled senses
  - Hearing remains intact
Early stages ...

- Cardiopulmonary
  - Increase respiratory and heart rate
  - Cheyne-stokes respirations or periods of apnea
  - Difficulty clearing secretions
  - “Death rattle”
Early Stages

- **Renal**
  - Decreased urine output
  - Incontinence
  - Urinary retention

- **Musculoskeletal**
  - Gradual loss of ability to move
  - Starts in the legs
  - May lead to immobility-related pain and discomfort.
Late stages ...

- Sensation/Perception
  - Unconscious/obtunded
  - Loss of blink reflex
  - Dry/irritated eyes
  - Eyes remain half open
  - Hearing may still remain intact
Late stages ...

- **Cardio-Pulmonary/Renal**
  - Heart rate may double then start to decrease
  - Rhythm may become irregular, and strength minimizes
  - Cool to touch, diaphoretic
  - Mottling in extremities
  - Signs of cyanosis
  - Decreasing peripheral pulses followed by absence
  - Drastic decrease in urine output indicates near death
“First do no harm…” Misconceptions about End of Life Care

- “Care” is withdrawn or withheld
  - Withdrawal of Life Prolonging Treatment/Life Support
- Euthanasia is performed
  - Medications are given to alleviate symptoms
- Patients die more quickly
  - There is no literature supporting the belief that patients die more quickly who receive aggressive end of life care.
- “Can we get this over with?”
  - No. The patient is on his own journey.
- The patient is unresponsive, so there is no pain
  - We evaluate for presumptive pain indicators
- Minimal or no documentation is needed for End of Life Patients
  - Pain/agitation/dyspnea and other symptoms must be documented at least every 2 hours.
Support for the Dying

- Bereavement Packet (addresses concerns that may rise before, during and after the dying process).
- No One Dies Alone (NODA): a volunteer program to support the dying who have no one with them.
- Spiritual Care
- Integrative Therapies: music, pet therapy (Palliative Pups), Urban Zen
Choosing the right pain scale
- Numeric/Faces
  - ONLY use Faces if they can/will Point to the Face.
- Verbal Descriptors (a little, a great deal, or in the middle?)
- PAIN-AD
- CPOT/Non-cog

Pain versus............
- Anxiety
- Delirium

(Fink & Gates, 2006)
# PAIN-AD Tool

<table>
<thead>
<tr>
<th>Items</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative vocalization</td>
<td>None</td>
<td>Occasional moan or groan. Low-level of speech with a negative or disapproving quality.</td>
<td>Repeated troubled calling out. Loud moaning or groaning. Crying.</td>
<td></td>
</tr>
<tr>
<td>Facial Expression</td>
<td>Smiling or inexpressive</td>
<td>Sad, frightened, frown.</td>
<td>Facial grimacing.</td>
<td></td>
</tr>
<tr>
<td>Consolibility</td>
<td>No need to console</td>
<td>Distracted or reassured by voice or touch.</td>
<td>Unable to console, distract, or reassure.</td>
<td></td>
</tr>
</tbody>
</table>

(Warden, Hurley, & Volicer, 2003)
Table 4 Critical-Care Pain Observation Tool

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Description</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facial expression</td>
<td>No muscular tension observed</td>
<td>Relaxed, neutral 0</td>
</tr>
<tr>
<td></td>
<td>Presence of frowning, brow lowering, orbit tightening, and levator contraction</td>
<td>Tense 1</td>
</tr>
<tr>
<td></td>
<td>All of the above facial movements plus eyelid tightly closed</td>
<td>Grimacing 2</td>
</tr>
<tr>
<td>Body movements</td>
<td>Does not move at all (does not necessarily mean absence of pain)</td>
<td>Absence of movements 0</td>
</tr>
<tr>
<td></td>
<td>Slow, cautious movements, touching or rubbing the pain site, seeking attention through movements</td>
<td>Protection 1</td>
</tr>
<tr>
<td></td>
<td>Pulling tube, attempting to sit up, moving limbs/thrashing, not following commands, striking at staff, trying to climb out of bed</td>
<td>Restlessness 2</td>
</tr>
<tr>
<td>Muscle tension</td>
<td>No resistance to passive movements</td>
<td>Relaxed 0</td>
</tr>
<tr>
<td>Evaluation by passive flexion and extension of upper extremities</td>
<td>Resistance to passive movements</td>
<td>Tense, rigid 1</td>
</tr>
<tr>
<td></td>
<td>Strong resistance to passive movements, inability to complete them</td>
<td>Very tense or rigid 2</td>
</tr>
<tr>
<td>Compliance with the ventilator (intubated patients)</td>
<td>Alarms not activated, easy ventilation</td>
<td>Tolerating ventilator or movement 0</td>
</tr>
<tr>
<td></td>
<td>Alarms stop spontaneously</td>
<td>Coughing but tolerating 1</td>
</tr>
<tr>
<td></td>
<td>Asynchrony: blocking ventilation, alarms frequently activated</td>
<td>Fighting ventilator 2</td>
</tr>
<tr>
<td>OR</td>
<td>Talking in normal tone or no sound</td>
<td>Talking in normal tone or no sound 0</td>
</tr>
<tr>
<td>Vocalization (extubated patients)</td>
<td>Sighing, moaning</td>
<td>Sighing, moaning 1</td>
</tr>
<tr>
<td></td>
<td>Crying out, sobbing</td>
<td>Crying out, sobbing 2</td>
</tr>
<tr>
<td>Total, range</td>
<td></td>
<td>0-8</td>
</tr>
</tbody>
</table>

(Gelinas, Harel, Fillion, Puntillo, & Johnston, 2009)
Why bolus versus titration?

**Bolus**
- Max concentration
  - IV = 15 minutes
  - Sub-Q = 30 minutes
  - PO = 1 hour

**Titration**
- The full effect of a continuous IV infusion (or basal rate) will not be felt until steady state is reached (about 10-20 hours)

(Chris Pietras, MD)
Morphine IV Bolus Versus Continuous Infusion

- Bolus dose of 10mg
- Continuous infusion of 1.25mg/hr

Time in hours (4 hours = 1 half-life)

Percent of maximum plasma concentration

(Chris Pietras, MD)
What do doctors want RNs to know?

- RNs at the bedside know more
- Be confident in your assessments
- Ask the doctors for appropriate orders
References


