City of Hope

Compassionate Person Centered Care of the Dying: An Evidence Based Palliative Care Guide for Nurses

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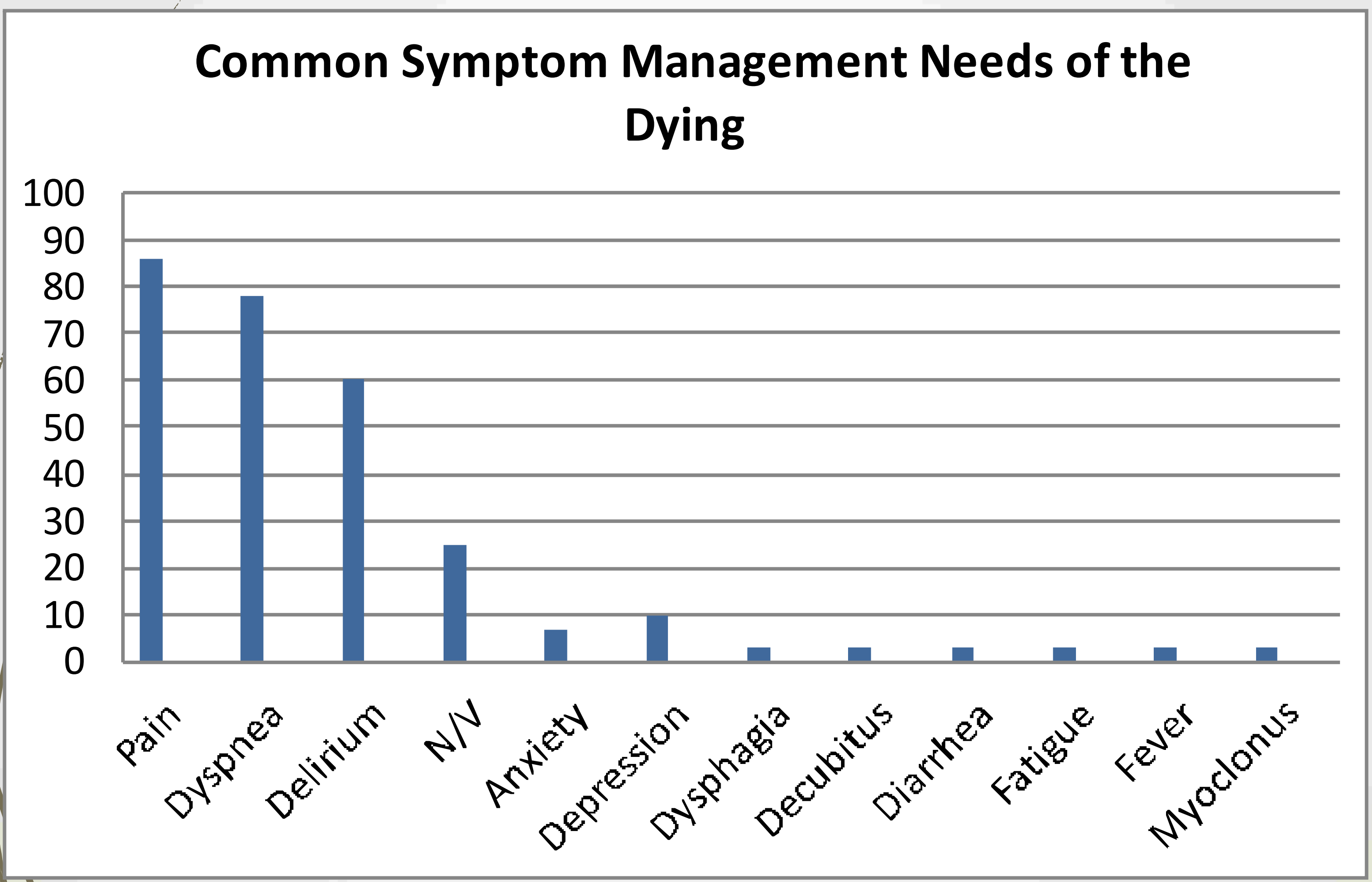
Objectives

- Share History and Development of CARES Tool.
- Explore applications of CARES Tool.
- Discuss barriers to learning and providing EOL care.
- Future plans to share and promote the CARES Tool.

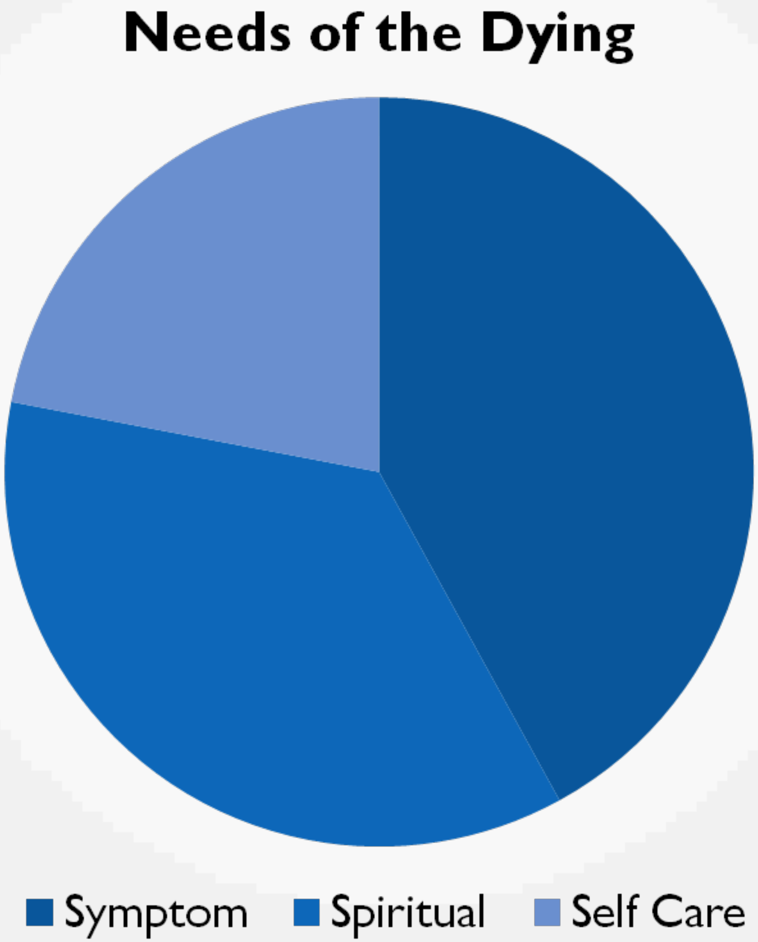
Statistics

- 85%of all deaths in the United States occur within the 65+ age group.
- 60% of Americans will die in a hospital.
    - 40% will occur in the ICU
- 80% to 90% of their deaths will be expected.
- Average amount of time expended on end-of-life care education in medical and nursing programs is 15 hours.
- Healthcare professionals considered their basic education on care of the dying to be woefully inadequate.
- Currently practicing healthcare providers often do not possess any end-of-life training, and they are the individuals who are now providing care for dying patients (Sanchez-Reilly & Ross, 2012).

92 Abstract and Title Review



Review of 68 Evidence Based Research Studies



Cares Tool

The CARES tool is an acronym organized educational guide that addresses the most common symptom management needs of the dying:

- **C**omfort
- **A**irway
- **R**estlessness and delirium
- **E**motional and spiritual support,
- **S**elf-care.

CARES Tool

- **Intended to supplement end-of-life care education.**
- Provides suggestions and prompts on individualized patient and family-driven evidence-based care of the dying.
- Identifying common teaching and communication needs.
- Encouraging holistic support during the last few days to hours of a patient’s life.

Face Validity

Débuted in October, 2012 as a poster presentation at the 19th International Congress on Palliative Care in Montreal, Canada.

- 125 expert palliative care providers:
  - Could utilize CARES tool to educate healthcare staff.
  - Could integrate CARES tool into standards of care.
  - CARES tool could effectively prompt the obtaining of orders and supportive measures for a dying patient and the family.

A positive approval rating of 98% .

- The only rationale given for not using the CARES tool was the existence of an already implemented protocol or pathway (*n* = 3, or 2%).
- Usually implemented too late or not at all.

Face Validity

A peer reviewed article:

CARES: An Acronym Organized Tool for the Care of the Dying

- Published in the May, 2013 (volume 15, issue 3)
- *Journal of Hospice and Palliative Nursing.*
- Received the highest number of downloads for the Journal in the month of May.
- Featured on Medscape.com.

Face Validity

Formal requests were received to implement the CARES tool as part of education or research projects in:

- United States
- Taiwan
- Canada
- New Zealand
- Saudi Arabia
- Australia

CARES TOOL

Comfort – Pain Management

- Pain was the most common symptom management need of the dying.
- Individuals do not fear death as much as how they will die.
- 90-50% of patients will die in pain (LeGrand & Walsh, 2011).
  - Lack of education
  - Fear of euthanasia
  - Cultural factors
  - Fear of addiction
  - Fear of speeding up dying process

Pain Management Considerations for the Dying

- If an individual was in pain before became unresponsive they are probably still in pain.
- There will always be a last dose.
- Intent
- A person is more likely to die of their disease than from the opioids.
- There is no maximum dose of opioids for pain control (Quill, 1998; Byock, 2012).

Comfort Cont.

The focus of care is comfort.

Evaluate need for procedures, tests and activities

Provide as much time for the patient and family to be together as possible.

- Stop or modify vital signs.
- Stop nonessential medications.
- Clarify IV fluids.
- Stop or reduce tube feedings.
- Turn off monitors and alarms.
- Stop or decrease labs.
- Discontinue isolation.

Comfort Cont.

Never underestimate the power of a washcloth (Hutchinson, 2011).

Explain the difference between a normal dying process and suffering.

- Mottling/cyanosis vs being cold.
- Hunger and thirst.

A is for Airway

- Use of supplemental oxygen is more for the family.
- SOB can be reduced with use of a fan.
- Control death rattle.
- Explain agonal breathing vs. suffering.
- Morphine is still the gold standard.
- Emphasize use of touch and talking to patient.

R is for Restlessness and Delirium

Also called terminal or agitated delirium.

Can result from pain, bladder distention or stool impaction.

Consider:

- Trial dose of opioids.
- Assess for bladder distention.
- Assess for impaction if appropriate.
- Consider antipsychotics: haloperidol or chlorpromazine.
- Consider benzodiazepines: Lorazepam or Midazolam.

Delirium and Restlessness Cont.

- Address possible unfinished business.
- Importance of saying good-bye and to give permission to stop fighting.
- important family event or anniversary.
- Educate the family:
  - Patient lacks awareness of behavior.
  - Possible to be peacefully confused.

E is for Emotional and Spiritual Support

- **Caring for the soul.**
- Know your resources.
- Focus on retaining the patient’s dignity and feelings of value.
- Every family is unique and grieves differently.
- Good communication is essential.

Emotional and Spiritual Support Cont.

Just be with patient and family.

Work with family to provide favorite activities, smells, sounds, etc.

Support rituals.

Your humanity is needed the most.

Always be available.

The **family** becomes your focus
- Be sure families are getting rest and breaks.
- Provide coffee, water, etc.
- Continue to be available to answer questions.

Emotional and Spiritual Support Cont.

Celebrate the Person.

They are NOT their disease.

(Cobb, Puchalski, & Rumbold, 2012)

S is for Self-Care

- Allow yourself to be human.
- Professional grieving: Its okay to cry.
- Importance of debriefing

  Tea for the Soul

  Hope Rounds
- Development of moral distress

  And death anxiety.

Self-Care Cont.

- Challenges and privilege of assisting a fellow human being through the dying process.
- Acknowledging the spiritual impact of witnessing death.
- Exploring how your care made a difference.
- Reviewing effective communication techniques, available resources and support (Lang, Thom, & Kline, 2008).

Self-Care Pearls

- Don't believe the pedestal you were placed upon.
- A power greater than you will determine your patient's fate.
- Find comfort in knowing you did your very best.
- Review actions and explore feelings daily.
  - Stay in the present.
  - Separate personal issues from actual events.
- Do not fear feelings of sadness or grief.
  - They are normal human emotions.
  - It will be worth the journey.
  - The experience will make you a better person.

Never avoid the opportunity to be compassionate and to share your humanity.

(Wicks, 2006)

CARES Tool Applications

- Sunnybrook Science Health Centre, Toronto, Canada end of life care initiatives.
- Book through Springer Publishing.
- Novel picked up by Tate Publishing called Resilient Hearts.
- Lecturing nationally and in Canada
- Invited to attend the IOM Conference in Washington D.C.
- To release a Supportive Care Personnel and a Friends and Family version of the cares Tool.

COMFORT Nursing Initiative

Communication

Orientation and opportunity

Mindfulness

Family

Oversight

Reiterative and radically adaptive messages

Team

(Wittenberg-Lyles, Goldsmith, Ferrell, & Ragan, 2013)

CARES Tool Web Site and Smart Phone Link

- Http://www.carestool.com
- Springer publishing web site: Http://www.springerpub.com/compassionate-person-supplrmental-materials

Barriers to Training and Implementing the CARES Tool

- Staffing and organizing meetings.
- Hospice/palliative care services are poorly understood.
- Changing a culture.
- Denial of death.

Meir, 2010; NHPCO, 2011

CARES
TOOL

> "It is the power of our own humanity that can make the difference in the lives of others. We must value this as highly as our own expertise."

(Puchalski & Ferrell, 2010)

“….there are worse things than having someone you love die. Most basic, it is having the person you love die badly, suffering as he or she dies. Worse still is realizing later on that much of his or her suffering was unnecessary.”

(Ira Byock, 2012)

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