



The Role of Nursing in Palliative Care

*Todd Hultman, Ph. D., ACNP, ACHPN
thultman@partners.org*



Agenda

- ✧ How we suffer
- ✧ History and foundation of palliative nursing practice
- ✧ Current practice of palliative nursing
- ✧ The journey of Rufus



What is at stake

- ✧ Despite biomedical and technological advances, in tandem with the emergence of the hospice benefit, persons with terminal illness or chronic complex illness and their families continue to suffer needlessly. Palliative care is an effective model for relief of pain and suffering.



The Premise

- ✧ Given the complexity of medical and psychosociospiritual needs of patients and families and
- ✧ Given the necessity of an interdisciplinary team to meet these needs, with the nurse as a central member of the team
- ✧ And, given the trust and regard that nurses hold (Gallup poll)
- ✧ That optimizing the role of the nurse can strengthen the effectiveness of palliative care.



How we suffer...

- ✧ Like pain, suffering is what the person says it is
- ✧ Multidimensional-Cicely Saunders
- ✧ Reflects meaning/lack of meaning behind the experience
- ✧ Can occur at individual, group or population level-mediation



How we heal...

- ✧ Relief of symptoms
- ✧ The telling of the story
- ✧ Healing presence
- ✧ Locus of control
- ✧ The nature of hope
- ✧ Relief of burden on loved ones



What we know as caregivers

- ✧ Trust in the natural processes of healing
- ✧ The patient teaches us
- ✧ Witnessing takes time and energy



The Journey of Rufus

✧ Patient lives in Boston, MA with his female companion and her two daughters. He has five children of his own who are alive and well. He is currently disabled, having worked as an adult caregiver. He quit smoking and denies alcohol and illicit use. He notes financial concerns. He denies a spiritual practice.



Early Palliative Nursing

- ✧ Homes for the dying
- ✧ Religious societies and hospice care
- ✧ Cicely Saunders
- ✧ Florence Wald

(Buck, 2009; Buck, 2007)



Nursing Foundations

- ✧ Florence Nightingale
- ✧ Henderson
- ✧ Peplau
- ✧ Watson
- ✧ Travelbee

(Lynch, et al., accepted)



ANA Social Policy Statement

✧ Nurses “attend to the full range of human experiences and responses to health and illness without restriction to a problem-focused orientation; integrate objective data with knowledge gained from an understanding of the patient’s subjective experience; apply scientific knowledge to the processes of diagnosis and treatment; and provide a caring relationship that facilitates health and healing.” (1995)



ANA and HPNA

- ✧ The broad scope of palliative nursing practice
 - ✧ Holistic assessment of patient and family
 - ✧ Management of pain and other symptoms
 - ✧ Determination and optimization of functional status
 - ✧ Identification of goals, values and coping patterns



No one definition...as yet

✧ Palliative nursing is the assessment, diagnosis, and treatment of human responses to actual or potentially life-limiting illnesses within the context of a dynamic caring relationship with the patient and family in order to reduce or relieve suffering and optimize function

✧ (Lynch, et al., accepted)



The Nursing Team

- ✧ Nursing Assistant
- ✧ Licensed Practical/Vocational Nurse
- ✧ Registered Nurse
- ✧ Advance Practice Nurse



So it began

- ✧ Our first meeting-the experiment with a NYHA class III patient at MGH
- ✧ “I am not sure I can trust you, Todd.”



At the hospital and beyond-the APN

- ✧ Clinical judgment
- ✧ Advocacy and ethics at the systems level
- ✧ Research and Professionalism



The journey of Rufus

✧ The disease progresses...the need for subacute rehab

✧ "I just want to go home!"



At the nursing facility-the LPN

- ✧ Care of the patient with endstage disease
- ✧ Pain and comfort management
- ✧ Treatments and procedures
- ✧ Holistic care of patient, family and other caregivers
- ✧ Patient/family education and advocacy
- ✧ Interdisciplinary collaboration



The journey of Rufus

- ✧ The hospitalizations become more frequent...NYHA class IV
- ✧ "I can't do this any more, can't you just manage it!"



With each return to the hospital-the RN

- ✧ Pain management
- ✧ Symptom management
- ✧ Holistic care of the patient and family
- ✧ Education and advocacy
- ✧ Interdisciplinary collaboration



The journey of Rufus

- ✧ A change of heart-focusing on comfort for Rufus and his family
- ✧ "I can't stand to be alone!"



What the NA could do in the home

- ✧ Physical care of the patient and family
- ✧ Psychosocial and spiritual care of the patient and family
- ✧ Contributions to interdisciplinary team
- ✧ Professional practice issues



What the NA could do in the home

- ✧ Provide psychosocial and spiritual care of the patient and family
- ✧ Assist in identifying support needs of patient and family
- ✧ Assure dignity and honor choices at time of death
- ✧ Contribute to bereavement follow up



The Journey of Rufus

- ✧ In the end...inpatient hospice
- ✧ "When can I go home?"

- ✧ Lessons learned from Rufus
 - ✧ Advocacy
 - ✧ Being present with difficult news
 - ✧ Advanced care planning
 - ✧ Coordination of care



Advocacy

- ✧ Support congruency between plan of care and patient's and/or family's wishes/values.
- ✧ Empower patients through education in self-determination/informed consent
- ✧ Promote peaceful death



Discussing Difficult News

- ✧ Poor communication as a source of distress
- ✧ Unaddressed concerns lead to anxiety/depression
- ✧ Improved patient coping
- ✧ Promoting self-determination



Advanced Care Planning

- ✧ A timely topic...
- ✧ It starts in the primary care clinic
- ✧ An evolutionary process
- ✧ The ethics of communication
- ✧ Medical interpreter
- ✧ Anticipate the conflicts
- ✧ Healing the fears



Advanced Care Planning

- ✧ Help explore concepts of quality of life
- ✧ Help patients understand disease progression
- ✧ Explain benefits and burdens of life-sustaining treatment
- ✧ Advocate for care consistent with patient preferences



Coordination of care

- ✧ Where we may not have served Rufus well
- ✧ Where the nurse can be a key leader
 - ✧ Coordinating holistic care of patient and family
 - ✧ Transition arrangements
 - ✧ Medication reconciliation

(Prevost, et al., 2010)



Conclusion...

- ✧ When the time comes, we will all demand relief from pain and suffering that is tailored to the needs of us and our families.
- ✧ Nurses remain highly trusted and held in high regard (Gallup poll)
- ✧ When given the time and resources, the nursing team can make a unique contribution to providing palliative care to patients and families



One final thought...

- ✧ We tend to look at caring as an attitude of the strong towards the weak, of the powerful towards the powerless, of the haves towards the have-nots. When we honestly ask ourselves which persons in our lives mean the most to us, we often find it is those who, instead of giving advice, solutions or cures, have chosen rather to share our pain and touch our wounds with a gentle and kinder hand. The friend who can be silent with us in a moment of despair or confusion, who can stay with us in an hour of grief and bereavement, who can tolerate not knowing, not curing, not healing and face with us the reality of our powerlessness, that is the friend who cures. (Nouwen, 1990)



With gratitude...

- ✧ Joy Buck, RN, MSN, Ph. D.
- ✧ Mary Campbell, Ph. D., RN
- ✧ Deb Childs, MS, RN, NEA-BC
- ✧ Mary Ersek, Ph. D., RN, FAAN, FPCN
- ✧ Ginger Marshall, ACNP, ACHPN
- ✧ Judy Lentz. RN, MSN, OCN, NHA
- ✧ Joanne Reifsnyder, Ph. D., ACHPN

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