EMOTIONAL AND PSYCHOLOGICAL ISSUES OF DYING AND DEATH

MAXXINE RATTNER, M.S.W., R.S.W
C. ELIZABETH DOUGHERTY, M.S.W., R.S.W

PALLIATIVE CARE FOR THE NON-SPECIALIST
MAY 23, 2014

CONFLICTS OF INTEREST

- None to report

OBJECTIVES

- To acknowledge the context of dying/death in acute care settings
- To identify challenges associated with dying/death in acute care settings
- To recognize emotional and psychological issues in dying and death
- To explore what HCPs can do to support patients, families, and themselves

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TOTAL CARE

- Physical care is crucial for patients and families, but is only one component of total care.
- Although a medical model may focus on physical aspects, patients and families tend to view end of life with broader psychosocial and spiritual meaning, shaped by a lifetime of experiences.

Steinhauser, K, et.al. (2000). Factors considered important at the end of life by patients, family, physicians and other care providers. *JAMA*, 284 (19), 2476-82.

EMOTIONAL, PSYCHOLOGICAL, SOCIAL, PHYSICAL AND SPIRITUAL ISSUES OF DYING AND DEATH

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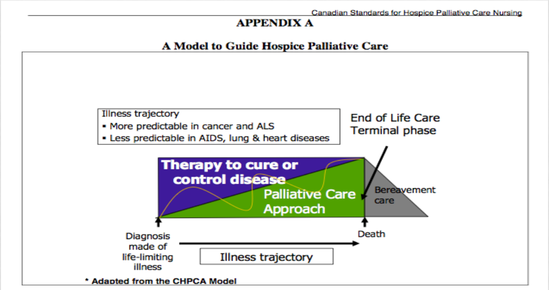
PALLIATIVE CARE VS. END-OF-LIFE (EOL) CARE

Palliative Care

- approach that improves the quality of life of **patients and their families** facing the problems associated with **life-threatening illness**, through the **prevention and relief of suffering by means of early identification** and impeccable assessment and **treatment of pain and other problems, physical, psychosocial and spiritual**

World Health Organization, 2014

NEW MODEL OF CARE


Canadian Standards for Hospice Palliative Care Nursing

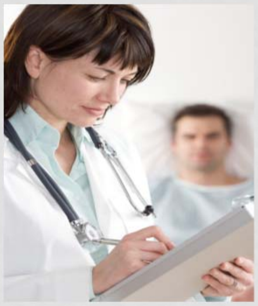
APPENDIX A

A Model to Guide Hospice Palliative Care

* Adapted from the CHPCA Model

PALLIATIVE CARE IS "ACTIVE" CARE

"No further active care, transfer to Palliative Care"



PALLIATIVE CARE VS. END-OF-LIFE (EOL) CARE

End-of-life Care

- the point in time during palliation where the end of one's life becomes more imminent
- The Oxford Handbook of Palliative Care defines EOL care as an important part of palliative care that refers to the care of a person during the last part of their life – a point at which it has become clear that an individual's disease is in progressive decline

Reith & Payne (2009). Social work in end-of-life and palliative care. Chicago; Lyceum Books Inc.
Watson, Lucas, Hoy & Bock (2009). The Oxford Handbook of Palliative Care. Oxford University Press.

DEATH AND DYING IN ACUTE CARE

- Are emotional and psychological needs of patients and families being met in the acute care settings?
- Are there barriers to delivering emotional and psychological support?
- Do you currently provide emotional and psychological support to patients and families in your practice?

CANADIAN CONTEXT

- Almost 70% of deaths occur in hospitals
  - Chronic diseases account for 70% of deaths
- In Ontario (2002-5)
  - 84% of people with cancer visited the ER in the last 6 months of their lives,
  - 40% visited the ER within the last two weeks of their lives
- 70-84% of Canadians dying either do not have access to, or do not receive hospice palliative and end-of-life (EOL) care services

(Canadian Hospice Palliative Care Association, 2014)

DYING AND DEATH IN ACUTE CARE

- The vast majority of Health Care Professionals (HCPs) provide at least some care for people with life-limiting illness as an integral part of their role
  - "Generalist Palliative Care" is provided to those affected by a life-limiting illness delivered by HCPs who are not part of a Palliative Consult Team
- Studies identify that generalists:
  - often feel ill-equipped to manage palliative patient care needs
  - struggle identifying when a palliative care may be appropriate

Frey, R, et. al. (2013). Clinical staff perceptions of palliative care-related quality of care, service access, education and training needs and delivery confidence in an acute hospital setting. *BMJ Supportive & Palliative Care*. 0, 1-9

CHALLENGES

- Acute care hospitals focus on short-term episodic care and interventions and treatments aimed at cure, creating an environment where death is seen as a failure, or where death is denied.

Bloomer, M, et.al., (2013). The “dis-ease” of dying: Challenges in nursing care of the dying in the acute hospital setting. A qualitative observational study. *Palliative Medicine*, 27(8), 757-764.

CHALLENGES

- Caring for the dying is challenging as staff are often under-resourced.
- Time is often short from formal diagnosis to recognition of dying/death.

Bloomer, M, et.al., (2013). The “dis-ease” of dying: Challenges in nursing care of the dying in the acute hospital setting. A qualitative observational study. *Palliative Medicine*, 27(8), 757-764.

CHALLENGES

“In addition to dealing with a population under extreme stress, staff are continually required to ‘shift gears’ while working simultaneously with patients and families at differing points on the loss trajectory”

Dean RA.. Occupational stress in hospice care: Causes and coping strategies (1998) *Am J of Hospice and Pal Medicine* 15. pp.151-4

CHALLENGES

- Major challenge to the provision of palliative care is identifying and meeting the needs of diseases other than cancer.
- Recognizing the dying phase is a challenge for patients with progressive long-term neurological conditions (PLTNC)
  - unpredictability of disease trajectory (varied by disease and individual)
  - may have multiple acute episodes of deterioration requiring high level of clinical input
  - difficult to predict whether a person would respond and recover

Wilson, E. et.al. (2011). Perspectives of staff providing care at the end of life for people with progressive long-term neurological conditions. *Palliative and Supportive Care*. 9 (4), 377-385.

CHALLENGES

- Among the emotional challenges described by HCP was the need to revisit “patient-focused decision-making”, without leaving the full burden of complex treatment decisions with families alone

Bruce, AB. & Boston, P. (2008). The changing landscape of palliative care: emotional challenges for hospice palliative care professionals. Journal of Hospice & Palliative Nursing. 10 (1), 49-55.

CHALLENGES

- Patients with chronic illnesses encounter repeated hospitalizations, often resulting in a change in the patient’s health status – and eventually confronting the patient’s imminent death

Spichiger, E. (2010). Patients’ and families’ experience of their relationship with professional healthcare providers in hospital end-of-life care: an interpretive phenomenological study. *Journal of Hospice & Palliative Nursing*. 12 (3), 194-202.

CHALLENGES

- The unpredictable nature of a terminal illness means reversible and irreversible events and declining health are interwoven with periods of stability - patients live with knowing that death will come, but not knowing where or when

Hutchings, D. (2007). Struggling in change at the end of life: a nursing inquiry. Palliative and Supportive Care. 5 (1), 31-39.

"(the Team) often expresses concerns... we'll see people going for tests or for a treatment course and they're actually very near death and you wonder, it raises those questions... the struggle is greater than I've ever experienced in my past"

Bruce, AB. & Boston, P. (2008). The changing landscape of palliative care: emotional challenges for hospice palliative care professionals. Journal of Hospice & Palliative Nursing. 10 (1), 49-55.

CHALLENGES → OPPORTUNITIES

EMOTIONAL & PSYCHOLOGICAL ISSUES

- Each individual will have a unique emotional/psychological reaction to their illness and impending death
- Nature of patient/family response will depend on:
  - Stage in life cycle
  - Illness history
  - Loss history (including past experiences of dying/death)
  - Coping style/personality
  - Cultural values
  - Spirituality and/or religious affiliation
  - Presence/absence of support network
  - Additional stressors (e.g. Financial, etc.)

EMOTIONAL & PSYCHOLOGICAL ISSUES

- "Feelings of grief, sadness, despair, fear, anxiety, loss and loneliness are present, at times, for nearly all patients facing the end of their lives"
- "In spite of such painful feelings, many patients, even those with significant vulnerabilities, are able to achieve a high degree of equanimity and acceptance of their illness and its prognosis"

Block, S. (2011). Psychological issues in end-of-life care. *Journal of Palliative Medicine.* 9 (3), 751-772.

EMOTIONAL & PSYCHOLOGICAL ISSUES

- Anticipatory grief and mourning
- "Total Pain"
- Death Anxiety
- Hope and meaning

ANTICIPATORY GRIEF/MOURNING

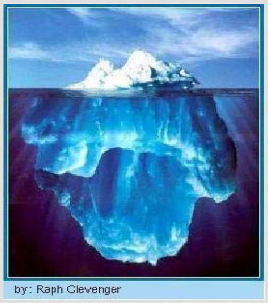
- Experience of anticipated/future losses – physical, psychological, social, emotional, spiritual
- Will change over time throughout the dying process
- Individuals coping with the same death may respond to the experience differently

Kehl, K. (2005). Recognition of support and anticipatory mourning. *Journal of Hospice and Palliative Nursing*. (7) 4, 206-211.

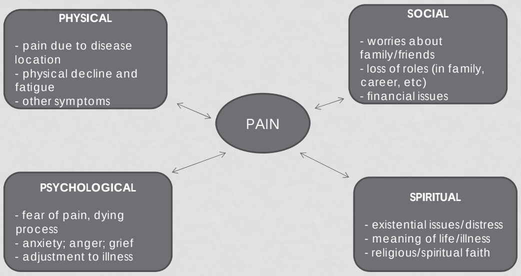
TOTAL PAIN ~DAME CICELY SAUNDERS

- pain can have physical, psychological, social, emotional, and spiritual components
- individualized to each patient`s particular situation

Mehta, A. & Chan, L. (2008). Understanding of the concept of "Total Pain": a prerequisite for pain control. Journal of Hospice and Palliative Nursing. 10 (1), 26-32.



TOTAL PAIN



PHYSICAL

- pain due to disease location
- physical decline and fatigue
- other symptoms

SOCIAL

- worries about family/friends
- loss of roles (in family, career, etc)
- financial issues

PAIN

PSYCHOLOGICAL

- fear of pain, dying process
- anxiety; anger; grief
- adjustment to illness

SPIRITUAL

- existential issues/distress
- meaning of life/illness
- religious/spiritual faith

DEATH ANXIETY

- the apprehension generated by death
- manifests in each person differently
- include fears about process of dying, death itself, or what happens afterward
- amplified in those not accepting of impending death
- can occur in patients, families and HCPs

Bloomer, M, et.al. (2013). The "dis-ease" of dying: Challenges in nursing care of the dying in the acute hospital setting. A qualitative observational study. Palliative Medicine 27(8), 757-764.

"The expectation
that we can be immersed
in suffering
and loss daily
and not be touched by it
is as unrealistic as expecting
to be able to walk through
water without getting wet"

Remen, R.N. (2006). *Kitchen table wisdom: Stories that heal.* NYC: Penguin

HOPE AND MEANING

- some patients/family members are able to find meaning, purpose and peace in direction relation to living with life-limiting illness/anticipating death
- others experience loss of meaning
- the impact of future hopes on present coping
- Reframing hope within context of dying
- "Double awareness"

Block, S. (2011). Psychological issues in end-of-life care. *Journal of Palliative Medicine.* 9 (3), 751-772.

ROLE OF HEALTH CARE PROFESSIONAL

- The goals are different, as time is limited
- The services provided need to be flexible and "transition" with the identified needs
- No one has to resolve all conflicts and problems before dying – some can't or won't
- Increased comfort is a primary goal (physical and psychological)
- The survivor(s) eventually become the client(s)

SUPPORT FOR PATIENTS AND FAMILIES

- When HCPs took time to give explanations in terms they understood, allowing time for decision-making the experience was positive
  - Explanations about what was happening and what to expect were experienced as welcomed support
  - When HCPs meet informational and support needs, they can minimize the emotional burden of decision making at EOL

Radwany, S. et. al. (2009). End of life decision making and emotional burden: Placing family meetings in context. *American Journal of Hospice and Palliative Medicine*. 26 (5), 376-383.

SUPPORT FOR PATIENTS AND FAMILIES

- the importance of responsive, empathic presence of HCPs amidst changing needs – whether physical or psychological
  - care that is patient/family-focused and responsive, rather than prescriptive and generalized
  - prioritized being treated as person, rather than being seen solely in terms of their illness
  - importance of being allowed to express their feelings
  - presence of a HCP was important during the active work of processing the diagnosis and prognosis

Sampson, C. et al. (2014). The practice of palliative care from the perspective of patients and carers. *BMJ Supportive & Palliative Care*.

"I would have been here sooner if not for a wonderful caring nurse in the hospital."

SUPPORT FOR PATIENTS AND FAMILIES

- Emotional experience of care rated the most significant aspect documented by patients and families
- aspects of care contributing to the patients and families ability cope:
  - Access to practical help
  - Access to specialist knowledge
  - Interprofessional communication
  - Coordination of resources
  - Safe to express positive and negative emotions
  - Recognition that EOL presented a crisis for the whole family

Sampson, C. et al. (2014). The practice of palliative care from the perspective of patients and carers. *BMJ Supportive & Palliative Care*.

SUPPORT FOR PATIENTS AND FAMILIES

- Quality care at the end of life is highly individual and should be achieved through a process of shared decision making and clear communication that acknowledges the values and preferences of patients and their families

Steinhauser, K, et.al. (2000). Factors considered important at the end of life by patients, family, physicians and other care providers. *JAMA*, 284 (19), 2476-82.

We jump into stories that are unfolding and lived long before we arrived…

SUPPORT FOR PATIENTS AND FAMILIES

- Time spent preparing patients and family members with advanced illness may help to:
  - Reduce anxiety and fear
  - Increase competence/confidence in caregiving
  - Prepare for/acknowledge losses
  - Explore new roles/responsibilities
  - Facilitate access to services/supports

HOW HCP CAN HELP?

- Starting where the patient/family is…

The most important way in which to help is to be available to listen actively, non-judgmentally, and with acceptance, allowing the patient to express emotions and feelings without fear.

Rando, T. (1984) Society of Social Work Leadership in Healthcare Best Practices Paper.

HOW HCP CAN HELP?

- Family meetings are an effective way to bring together an interprofessional team
  - Highlights patient and family goals of care, creating an individualized care plan
  - Varied perspectives to convey information, provide support and resources to the patient and family
  - Provides an environment to explore identified concerns
  - Facilitates planning

HOW HCP CAN HELP?

- strive as an Interprofessional team to explore the balance of technical expectations with existential, spiritual, and psychological needs while supporting dying patients and their families
- draw on the breadth of expertise from within the team (RN, MD, SW, OT, PT, SC, RT, RD, SLP, Pharm.)
- educate and inform patient and family while understanding their goals and developing a flexible and responsive care plan

THE CASE OF MS. N.

- 46 y.o. woman admitted to G.I.M via ER
- Admitted for pain and severe N&V 2nd to advanced Ovarian CA
- Single-mother with 3 children (21yo, 15yo, 13yo)
- Had been bedbound at home x 2 weeks and refusing to access I/P care (PPS 40)
- Children had been providing care at home
- 21 y.o. dtr called 911 and Pt brought via EMS
- Children unaware of Pt's initial diagnosis

THE CASE OF MS. N.

- Emigrated from the Ukraine with her husband ~1990
- No family in Canada
- Husband killed in an industrial accident (no WSIB)
- Ms. N. worked 2 factory jobs
- lives in basement apartment with children
- Began getting symptomatic – did not seek care
- No workplace benefits – no LOA/meds
- CA undiagnosed until detected on workup during this admission

THE CASE OF MS. N.

- Identify the emotional and psychological issues for Ms. N.
  - How would you respond?
- Identify the emotional and psychological issues for the family of Ms. N.
  - How would you respond?
- Identify the emotional and psychological issues for HCPs working with Ms. N and her family.
  - How would you respond?

STRATEGIES FOR SELF-CARE

> “We each need to be aware of where we’re at,
> to notice the emotional residue
> that’s perhaps sticking to us,
> to have a place in space to really look
> at how we’re being affected
> and how we’re affecting others
> and the care we’re giving.
> So it takes diligence; it takes work
> and I think it enables us to continue to do this work…”

Bruce, AB. & Boston, P. (2008). The changing landscape of palliative care: emotional challenges for hospice palliative care professionals. Journal of Hospice & Palliative Nursing. 10 (1), 49-55.