Mid North Coast Rural Palliative Care Project – Link Nurse Education 2004

The Dying Experience

Physiological signs and transitions to death

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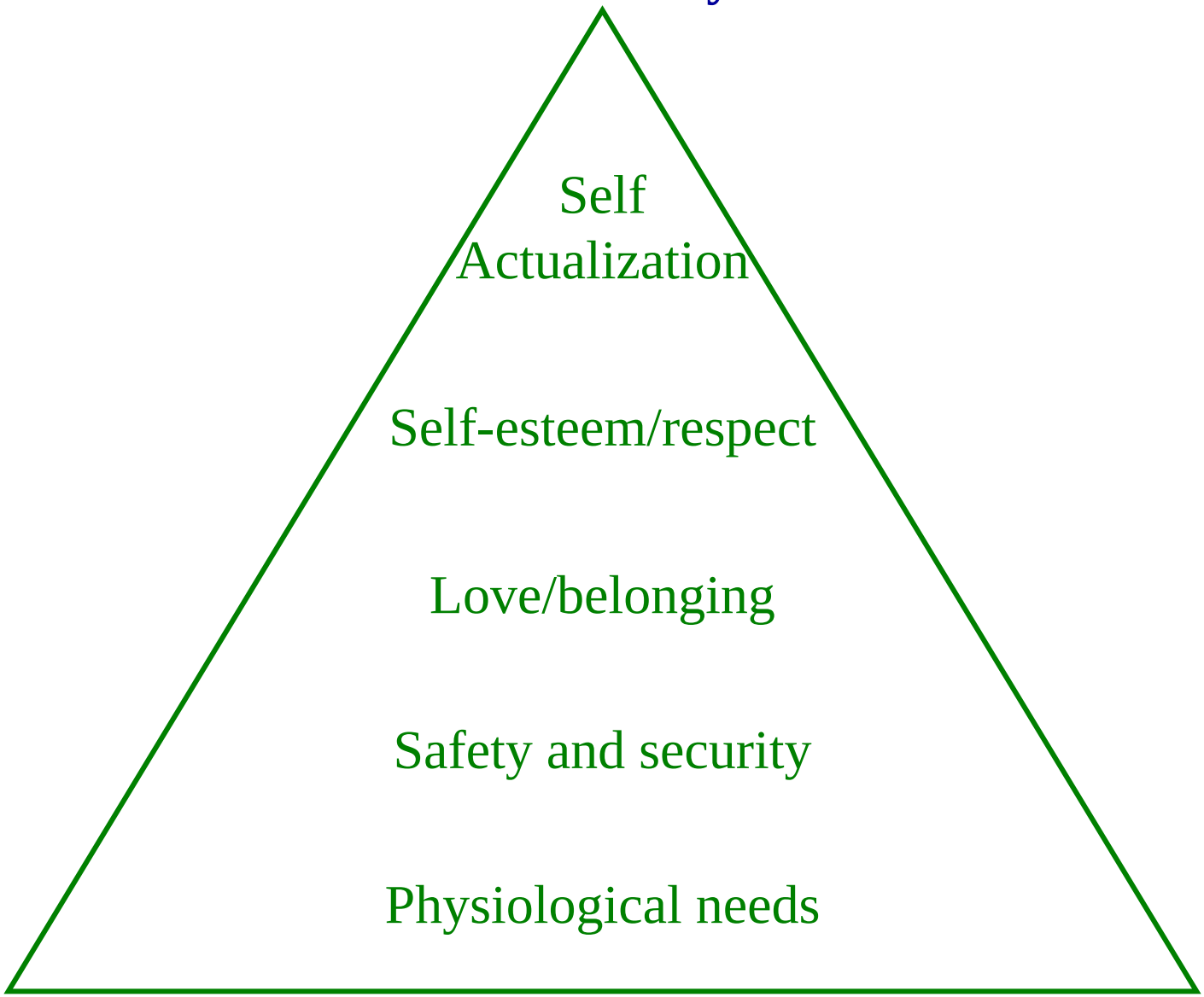
End-of-life Care

- Dying trajectory
- Goal more focused on existential issues - meaning, affirmation of life, spiritual comfort
- Unfinished business - forgiveness - reconciliation
- Family/friends needs for comfort and information
- Anticipatory grief

End-of-life Care

- Physiological signs - palliative treatment
- Meticulous physical care - including symptom control
- Consider the environment of care
- Spiritual care - rituals, ceremonies etc

Maslow's Hierarchy of Needs



Dying - Physical Changes

- Weakened circulation and pulse
- Limbs become cold, may have bluish tinge indicating peripheral shutdown
- Dusk appearance of nails, fingers, toes and lips
- Colour changes to skin generally, particularly the face - cyanosis
- Cheyne Stokes' breathing - alternating gasping and cessation

Dying - Other Events

Physical:

- Reduced level of consciousness
- Gurgling - usually oral-pharyngeal
- Incontinence
- Terminal restlessness
- Metaphysical experiences - hallucinations, visual images, flash of sudden alertness

Dying Events

- Confusion
- Moaning, calling out
- Inability to swallow
- Spiritual distress

Easing the Transition

- Be sure no further investigation of the change is necessary
- Gentle care and support for the dying person and their family/friends, explain the change where necessary
- The resident may settle with the presence and comfort of others, or
- Sedation is in order

Terminal Restlessness

Some signs:

- Agitation
- Restlessness
- Muscle twitching
- Occasional convulsions
- Confusion

Possible Causes of Terminal Restlessness

- **Disease symptoms** - Hypoxia, infections
- **Disease end-stage** - CNS tumors, dementia-HIV, Alzheimer's disease, organ system failure
- **Chemical imbalance** - Hypocalcaemia, hypornatremai, uremia, hepatic failure

Possible Causes

- **Physical discomfort** - constipation, dyspnea, pain, urinary retention
- **Psychologic** - depression, sensory overload, or sensory deprivation
- **Emotions/spiritual** - anxiety, fear, guilt, spiritual distress, unfinished business
- **Medication** - anticholinergics, benzodiazepines, opiates, steroids, *withdrawal syndrome*

Cheyne Stokes' Breathing

- Common indication of imminent death and normal process
- Also associated with opioid drugs.

Helping the transition - positioning and supportive care for family/friends

Supportive Care

- Being there
- Sedation may help
- Remaining diligent by checking for treatable causes

Easing the Transition

- **Moaning and calling out** - change of position, reassure family/friends
- **Gurgling** - secretions collect in oral pharynx oscillating with respirations can be very distressing for family/friends, suctioning can cause discomfort and should be avoided - instead:

  - Hyoscine or atropine s/c may help
  - Change client's position
  - Don't over hydrate

Easing the Transition

Exemplary nursing care

- Body care
- Compassion
- Caring
- Comforting

Rituals and Ceremonies

- Culturally specific rituals integral to the grieving process of family/friends
- Examples - body preparations, gatherings, prayers

Process of Dying

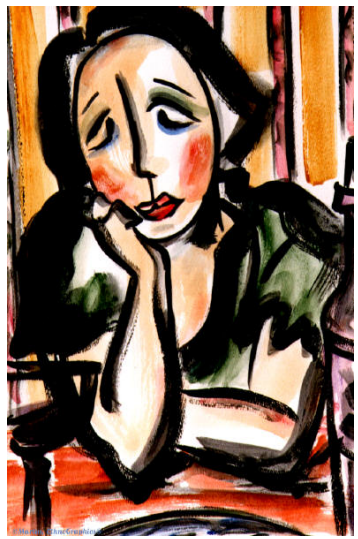
- Physical dimensions
- Social dimensions
- Psychological dimensions
- Spiritual - metaphysical and existential

Respect and Dignity

The moment of death is a sacred interval when the environment of care gains new significance



Loss, grief and bereavement



Definitions

- **Loss:** experience of separation from something or someone that we have an emotional attachment
- **Grief:** pain and suffering experienced after loss
- **Mourning:** period of time during which signs of grief are made visible
- **Bereavement:** process of losing a close relationship

(Small, L. 2001. Theories of grief: a critical review. In. J. Hockey, J. Katz and N. Small (Eds.). *Grief mourning and death rituals*. Buckingham. Open University Press.

Types of Loss

- Independence
- Physical capacity
- Mental faculties
- Ability to communicate
- Ability to physically express love and affection
- Social position and functions
- Time with friends
- Ability to interact with the environment
- Freedom to move

Kubler-Ross Five Stages of Grief

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

Colin Murray-Parkes

- Alarm
- Searching
- Mitigation
- Anger
- Guilt
- New identity

Beverley Raphael

- Shock
- Numbness and disbelief
- Separation pain
- Psychological mourning process – intense re-experiencing of the whole history of the relationship
- Reintegration

C.S. Lewis

No one ever told me grief felt so much like fear. I am not afraid, but the sensation is like being afraid. The same fluttering in the stomach, the same restlessness, the yawning. I keep swallowing,

(Lewis,CS. 1966, A grief observed, London, Faber & Faber)

Experience of Grief

- Feelings - sadness, guilt, anxiety, loneliness, hopelessness
- Physical sensations - hollowness in the stomach, tightness in the chest and throat, breathlessness, sensitive to noise
- Cognitive disturbances - confusion, preoccupation, hallucinations, dreams
- Behavior changes - sleep disturbance, absent mindedness, restlessness, crying, anger

Characteristics of Normal Grief

- Feelings and emotions
- Physical sensations
- Cognitions
- Complex behaviors

Learning from Own Losses

"Only people who avoid love can avoid grief"

John Branter

Reflection

What is your vulnerability?

Who are you who comes to give care?

Dame Cicely Saunders

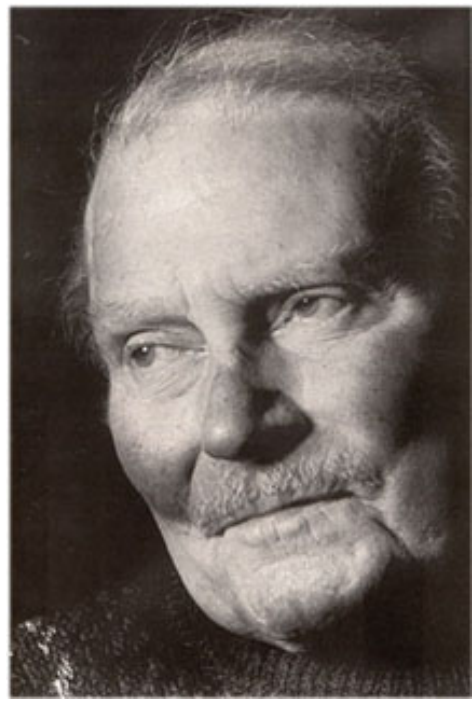
How people die remains in the memories of those who live on

All our years, all the memories





This is me behind the mask of years; still here although my voice is faint and eyes awash with ages' tears



Hudson, R. and Richmond, J. 1996. *Unique & Ordinary*. Melbourne. Ausmed, p. 14.







Joan Erikinson
92yrs old

We will do all we can to help you live



You matter because you are you



50 years of being us
was suddenly
transformed to just me

Married for life

DeSpelder, L and Strickland, A. (1999).The last dance. 5th ed.Mountain view, Mayfield Publishing Company



You matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die

Dame Cicely Saunders. Founder of the modern hospice movement

References

1. Kuebler, K., Berry, P. and Heidrich, D. (2002). End of life care, Clinical practice guidelines, Philadelphia, Saunders.
2. Hockey, J., Katz, J., and Small, N. (Eds.)(2001). Grief, mourning and death ritual, Buckingham, Open University Press.