NURS1004 Physical Dimensions of Being Human

Lifespan development

End of the Lifespan: Loss, Grieving and Death

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Session Outline

- Introduction
- Loss, Grief, Bereavement and Mourning
- Death Through the Lifespan
- Responses to Dying
- Process of Dying
- Dying with dignity
- The role of the nurse in working with families/caregivers of dying people
Introductory thoughts

• Loss is experienced at some point in life.
• Death is an inevitable part of life.
• Development - the way it is thought of
  - how we cope with the death of loved ones
  - coming to terms with the reality of our own ultimate deaths
• The meaning of death for the individual – how we choose to live our life
  - level of death anxiety

‘Death.. is an event that puts the whole meaning of life into question…death confronts us with the fact that purpose is not enough. We live by meaning’ (Steindl-Past 1977, p. 22 in Bjorklund 2011).
Loss

**Loss** - An actual or potential situation in which something that is valued is changed or is no longer available

**Examples include loss of:**

- Body image
- A significant other
- A sense of wellbeing
- A job
- Personal possessions
- Beliefs

(Dries 2012 in Berman et al.)
Types of Loss

• **Actual loss** - Can be recognised by others

• **Perceived loss** - Is experienced by one person but cannot be verified by others

• **Situational loss** – The loss of one’s job, the death of a child or the loss of functional ability due to an illness or injury

• **Development loss** – Losses that occur in the process of normal development

(Dries 2012 in Berman et al.)
Sources of Loss

• **Loss of an aspect of oneself** - A body part, a physiological function or a psychological attribute

• **Loss of an object external to oneself** – Money, house, pets

• **Separation from an accustomed environment** – Student leaving home to attend university

• **Loss of a loved or valued person** – Through illness, divorce, separation or death

(Dries 2012 in Berman et al.)
Death through the Lifespan - Longevity

- Recent historical changes in nutrition, medical care and control of preventable diseases has meant dramatic increases in life expectancy
- Dramatic increase at extreme upper limit – disproportionate number of people living to advanced old age
- Types of work in 10 years for people in health and helping professions reflects population ageing
e.g., widowhood counselling may become as common as marriage counselling, as much retirement planning as career planning
- Increased longevity means less common losses will be more traumatic
- Long lives tend to run in families – genetic predisposition
- Role of lifestyle and quality of living environment
- Indigenous Australians face barriers at all levels – diagnosis; access to medical tests; hospital admissions; access to surgical procedures; choice and social support in decision-making

(Peterson 2010)
Indigenous Australians

These figures may *underestimate* actual number of deaths

(Peterson 2010, p. 543)
Development of knowledge, beliefs and feelings about death

Children’s beliefs:

> Children as young as 4-6 years understand death but only if they have a concept of “life” as a core biological concept

> Not until 7-8 years do children fully appreciate death

> Understanding requires appreciating three properties:
  - *irreversibility* – death is final
  - *non-functionality* – dead people do not breathe
  - *universality* – death is inevitable for everyone

> Experience of having a pet aids death understanding

(Peterson 2010)
Jaakkola, Carey & Slaughter (1999) studied Australian children’s understanding of death. Gave interview questions see Box 18.4 for examples. Some 4-6yr olds could answer a number of questions correctly if they had a concept of life as a biological process. (in Peterson 2010 p. 547)
Development of knowledge, beliefs and feelings about death cont.

Adolescence and adulthood:

> Cognitive development combines with access to new information. Stimulates relativistic and dialectical thinking.

> Concerns about possibilities of transformed consciousness or other forms of existence after death may intensify in late adolescence with formal-operational reasoning skills.

> Four Meanings of Death for adults:
  – Death as an organiser of time
  – Death as a punishment
  – Death as a transition
  – Death as loss
Development of the Concept of Death

<table>
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<tr>
<th>Age</th>
<th>Beliefs/attitudes</th>
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| Infancy to 5 years | Does not understand concept of death.  
                       Infant’s sense of separation forms basis for later understanding of loss and death.  
                       Believes death is reversible, a temporary departure or sleep.  
                       Emphasises immobility and inactivity as attributes of death.                                                                                      |
| 5 to 9 years    | Understands that death is final.  
                       Believes own death can be avoided.  
                       Associates death with aggression or violence.  
                       Believes wishes or unrelated actions can be responsible for death.                                                                                 |
| 9 to 12 years   | Understands death as the inevitable end of life.  
                       Begins to understand own mortality, expressed as interest in afterlife or as fear of death.                                                      |
| 12 to 18 years  | Fears a lingering death.  
                       May fantasise that death can be delayed, acting out defiance through reckless behaviours (e.g. dangerous driving, substance abuse).  
                       Seldom thinks about death, but views it in religious and philosophic terms.  
                       May seem to reach ‘adult’ perception of death but be emotionally unable to accept it.                                                              |
| 18 to 45 years  | Has attitude towards death influenced by religious and cultural beliefs.                                                                                                                                         |
| 45 to 65 years  | Accepts own mortality.  
                       Encounters death of parents and some peers.  
                       Experiences peaks of death anxiety.  
                       Death anxiety diminishes with emotional wellbeing.                                                                                                |
| 65+ years       | Fears prolonged illness.  
                       Encounters death of family members and peers.  
                       Sees death as having multiple meanings (e.g. freedom from pain, reunion with already deceased family members).                                   |

(Dries 2012 in Berman et al.)
Death through the Lifespan - Death anxiety

- Includes preoccupation with death and intensity of fear of dying
- Students who complete courses on death and dying at university experience greater death anxiety at end of course than at beginning
- Gender differences – women report more fear than men, but no differences on physiological measures
- Fear of time running out may intensify fears of dying
- However, recent experiences with friends’/relatives’ deaths may help alleviate anxiety
- Storey (1987) – men worried more than women over their own death; women worried more about the dying of loved ones or the human species (Peterson 2010)
Death anxiety as a multidimensional construct (Kastenbaum, 2000):

1. concern about physical degeneration
2. concern about time left to live
3. concern about pain, stress and fear at death
4. spiritual and emotional feelings about death and what may follow (Peterson 2010)
Death Anxiety Quiz Scoring

Scoring
Agreement with items 1, 4, 8, 9, 12, 13, and 14 and disagreement with 2, 3, 5, 6, 7, and 15 is scored as indicative of death anxiety.

Responses to Dying

- **Grieving** - Includes denial, guilt, anger, despair, feelings of worthlessness, crying and inability to concentrate. They may extend to thoughts of suicide, delusions and hallucinations

- **Fear** - The feeling of disruption that is related to an identifiable source

- **Hopelessness** - Occurs when the person perceives no solutions to a problem

- **Powerlessness** - Person perceives a solution to the problem but does not believe that it is possible to implement the solution

- **Risk for Caregiver Role Strain** – Ongoing responsibilities = extreme stress, anger and exhaustion

- **Interrupted Family Processes** - Family may be unable to meet the physical, emotional or spiritual needs of the members and may have difficulty communicating and problem solving (Dries 2012 in Berman et al.)
Process of Dying

> Death viewed as a developmental process itself
> Kubler-Ross (1975) – complete conscious awareness of death is necessary for full psychological health of both the dying and the bereaved. **Five stages:**

*Denial:*

> Stage of shock and disbelief
> May last few seconds to few months

*Anger:*

> Period of generalised rage against everyone
> “Why me?”
> Particularly difficult for loved ones and medical staff
Process of Dying cont.

*bargaining:*

> Recognition that cure is impossible, but willing to promise
> Religious authority, doctor, or internalised
> Inevitable outcome is making full use of time left

*Depression:*

> Time of profound sadness
> Reactive depression – mourning losses already suffered
> Proactive depression – mourning future losses

*Acceptance:*

> Final farewells except for closest confidant/s
> Serenity not resignation; without bitterness (Peterson 2010)
Critique of Kubler-Ross’ theory

> Derived solely from intuition-based counselling experiences

> Question of whether stages apply to everyone and in same order

> Implicit prescription of one “right way” to die

> Kastenbaum (1975, 1998) – variables that affect progression through stages:
  - *Cause of death* – some not diagnosed or no warning
  - *Sex differences* – men more concerned with own pain and dependency; women worried about impact on others
Critique of Kubler-Ross’ theory cont.

- **Cultural, ethnic and sociocultural factors** – beliefs about meaning of life and death; styles of expressing emotion

- **Historical events** – during peace times death is for very old or ill; during war or disaster anyone may die

- **Personality and cognitive style** – how the person has lived; coping strategies developed earlier in life

- **Developmental level and current goals** – timing of death in relation to person’s ongoing life activities

- **Social and physical surroundings** – differences in social supports and demands e.g., dying alone/ with friends etc. affects experience of death

(Peterson 2010)
Dying with Dignity

Rights of the dying

> Free choice during the dying process includes:
  - the right to choose to know or not (exact nature of a terminal condition)
  - the right to refuse medical treatment
  - the right to choose to die at home
  - the right to opt for euthanasia

> Advance Directive/Living will – legally binding document that includes information on kinds of medical treatment desired. To apply when person is unable to express wishes

> Power of attorney – legally authorised person to make relevant decisions including resuscitation.

*Enduring Power of Guardianship*

(Peterson 2010)
Hospice care / Palliative care

> Alternative to traditional hospital care
> Based on holistic concepts, emphasises quality of life rather than cure
> Dying patients in more humane, relaxed environment
> Health practitioners, clergy and volunteers deal with physical, psychological and spiritual needs
> Supports client and family through the dying process and supports the family through bereavement
> Pain-reducing drugs used to keep person comfortable; life-sustaining machinery avoided
> Hospice patients suffer less anger, depression, anxiety and hostility towards spouse than in traditional hospital

(Dries 2012 in Berman et al; Peterson 2010)
Palliative Care

An approach that improves the quality of life of individuals and their families facing the problem 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 Organisation, n.d.)

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- Integrates the psychological and spiritual aspects of client care (Dries 2012 in Berman et al; Peterson 2010)

‘Story of David Tasma’ (Field 2005 in Bjorklund 2011)
Palliative Care cont.

• Offers a support system to help clients live as actively as possible until death

• Offers a support system to help the family cope during the client’s illness and in their own bereavement

• Uses a team approach to address the needs of clients and their families, including bereavement counselling, if indicated

• Will enhance quality of life and may also positively influence the course of illness

• Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life

(Dries 2012 in Berman et al; Peterson 2010)
Supportive care

Providing Physical Support:
- Provide personal hygiene measures
- Control pain
- Relieve respiratory difficulties
- Assist with movement, nutrition, hydration and elimination
- Provide measures to support sensory changes
Supportive care

Providing Spiritual Support:

• Facilitate expressions of feelings
• Prayer
• Meditation
• Reading and discussion with appropriate clergy or a spiritual advisor

Supporting the Family:

• Provide an empathetic and caring presence
• Explain what is happening and what to expect
• Have a calm and patient demeanor
• Encourage to participate in the physical care as they are able:
  - Assist with bathing
  - Speak or read to the client
  - Hold hands
Grief, Bereavement and Mourning

• **Grief** – Total response to the emotional experience related to loss

• **Bereavement** – Subjective response experienced by surviving loved ones with whom there was a significant relationship

• **Mourning** – The behavioural aspect through which grief is eventually resolved or altered

(Dries 2012 in Berman et al.)
Types of Grief Responses

- **Abbreviated grief** – Brief but genuinely felt
- **Anticipatory grief** – Experienced in advance of event
- **Disenfranchised grief** – When a person is unable to acknowledge the loss to other persons
- **Complicated grief** – When strategies to cope are maladaptive

Many different forms – Complicated

(Dries 2012 in Berman et al.)
Bereavement

> Kubler-Ross – bereaved people progress through same stages as dying person

> Other factors include:
  - Nature of relationship with dying person
  - Personal, religious and environmental factors
  - Preparation for death

> Cannot underestimate emotional effect of death of spouse

> Death more a tragedy for survivors than for victim

Loss can lead to gains and bereavement to personal growth
# Perspectives on the Stages of Grieving / Bereavement

**Engel (1964) – Six stages**

1. Shock and disbelief
2. Developing awareness
3. Restitution
4. Resolving the loss
5. Idealisation
6. Outcome

**Sanders (1998) – Five phases**

1. Shock
2. Awareness of loss
3. Conservation/withdrawal
4. Healing: the turning point
5. Renewal
Perspectives on the Stages of Grieving / Bereavement cont.

• **Martocchio (1985)**
  - Five clusters
    1. Shock and disbelief
    2. Yearning and protest
    3. Anguish, disorganisation and despair
    4. Identification in bereavement
    5. Reorganisation and restitution

  – Three responses
    1. Avoidance
    2. Confrontation
    3. Accommodation
Perspectives on Grieving / Bereavement

Manifestations of Grief

• Verbalisation of the loss
• Crying
• Sleep disturbance
• Loss of appetite
• Difficulty concentrating

Factors Influencing the Loss and Grief Responses

• Age
• Significance of the loss
• Culture
• Spiritual beliefs
• Gender
• Socioeconomic status
• Support systems
• Cause of loss or death
Widows & Widowers

Death of a spouse one of the most stressful experiences the average man or woman is ever called to face.

> Immediate emotional calamity gives way to building a new single life
> Widows & widowers are found to have higher levels of ill health in the first months an years after the spouse’s death
> Widows are less likely to remarry after becoming a widowed than men are

Development as a widow - Woodfield and Viney (1984-85) based on Kelley’s (1955) personal construct theory (in Peterson 2010)

> During initial phase of bereavement, emotions fluctuate across the following:
  - Shock and numbness
  - Stress and threat
  - Anger
  - Anxiety
  - Guilt
  - Sadness and despair
Identity as a widow

- Emotional states may motivate search for new identity
- Revised self-concept may be richer
- Influenced by quality of previous identity
- Lopata (1975) – developmental theory of widowhood
- Absence of clearly defined *widowhood role* intensifies identity crisis in Western society
- Style of widowhood adopted affected by personality, past experiences and present opportunities

(in Peterson 2010)
Patterns of widowhood (Lopata 1975)

- *Liberated widows* – successful identity reconstruction; secure, well-rounded sense of identity

- *Merry widows* – successful identity; energy devoted to social activities

- *Individualistic working widows* – less adapted; devoted to career or home life

(in Peterson 2010)
Religion and culture dictates:

- ‘Bad’ deaths vs ‘good’ deaths
- Preparation of the body
- Autopsy
- Organ donation
- Cremation
- Prolonging life
- Death-related rituals
Practices common to many communities:

- When returning the person’s belongings, it is very important that any item belonging to the client is accounted for.
- If a person dies at home, the house may be marked and abandoned for some time by its residents.
- If the person dies in hospital, a selected family member will be required to escort the body home.
- Wailing and self-mutilation are practices in some communities.
- Not calling the deceased by name.
- Tributes paid for many years.
- Funerals and rituals - common across cultures as an acceptable way of expressing grief.
The role of the nurse in working with clients, families/caregivers of dying people

Facilitating Grief Work

• Explore and respect ethnic, cultural, religious and personal values

• Teach what to expect in the grief process

• Encourage the client to express and share grief with support people

• Teach family members to encourage the client’s expression of grief

• Encourage the client to resume activities on a schedule that promotes physical and psychological health
The role of the nurse in working with clients, families/caregivers of dying people

Providing Emotional Support

• Use silence and personal presence

• Acknowledge the grief

• Offer choices

• Provide appropriate information

• Suggest additional resources
Final Thoughts

‘…it is no longer feasible to divide the lifespan into two halves, one characterised by freshness, growth and excitement and the other by ageing, decay and loss. Instead, the two dialectic processes of development and decline are part of the entire pattern of lifelong psychological growth, beginning at the moment of birth (sic) and not ending until the last breath is drawn’ (Peterson 2010, p. 566).

‘Although there are typical ways of behaving at every age, there are always exceptions to the rule – individuals who break the pattern, being unusually early or unusually late in their progress from childhood to old age. There are amazingly mature children who become virtuosos at tender ages and there are childlike adults who refuse to age, either physically or mentally, at the usual rate. The significance of these two messages is clear enough: age rules exist, but they are there to be broken. Exceptional individuals will always ignore them and will write symphonies at 9 and elope at 90’ (Morris 1983 in Peterson 2010, p. 566).
References


