Bereavement and Grief
Missouri Hospice and Palliative Care Association
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Outline
- Discuss grief
- Discuss bereavement
- Open discussion of care of the grieving family and bereavement care

Causes of Suffering
- Anxiety, depression, delirium
- Difficulty maintaining personal dignity
- Loss of significant aspects of who they were
- Lack of closure in important relationships
- Feelings of spiritual separation
- Inability to distinguish meaning in their life
What is a Good Death

- Attain a sense that who and what they have been will persist
- Time to say goodbyes
- Legacies have been established
- Affairs have been settled
- Relationships brought to acceptable closure

Physical Causes of Suffering

- Fatigue and pain (70%)
- Restlessness/agitation/delirium (60%)
- Noisy or moist breathing (60%)
- Urinary incontinence/retention (50%)
- Dyspnea (20%)
- Nausea and vomiting (10%)

Facts about Cancer

- 1.4 million people diagnosed yearly in US
- 570,000 deaths yearly
- 5-year survival 50% 1974 and 66% 2004
- Second leading cause of death in US
- Grief and bereavement substantial
Definitions

- **Grief**: normal reaction to loss
- **Physical death**: death of body
- **Symbolic/social death**: divorce/loss of job
- **Bereavement**: period after a loss during which grief is experienced and mourning occurs
  - Time depends on association to person, time spent in anticipation
- **Mourning**: process by which people adapt to loss
  - Influences-cultural customs, rituals, societal rules

Phases of Life-Threatening Illness

- **Before the diagnosis**: period when person first realizes they may have illness
- **Acute phase**: person forced to understand illness and make decisions
- **Chronic phase**: coping with demands of life and treatment/side effects
- **Recovery or death**: recovery means coping with mental, physical, religious and financial effects
  - Terminal means turning to comfort and relief from pain

Pathway to Death

- **Rapid**: MVA, ruptured AAA or acute MI
- **Long and slow**: chronic diseases, cancer in the 21st century peaks and valleys
- **Very long and very slow**: frailty-dementia and debility
Anticipatory Grief

- Normal mourning that happens when death is expected
  - Depression, concern for patient, adjusting to changes
  - Does not always occur
  - Some people believe anticipatory grief is rare (grieving before someone dies may make the mourner feel like they have abandoned the dying patient)
  - Expecting the death may make the mourner’s attachment to the dying patient stronger
  - Patient may become more withdrawn when family experiences too much grief

Grief symptoms felt before death of patient

- First recognize terminal prognosis of an illness
- First realize major changes are coming
- Fear of losing independence/changing roles

Predictors

- Female gender
- Adult children
- High perceived stress
- Difficulty coping

PT JB 1/17/17 Bereaved PB, spouse

- Married 22 years, JB had Parkinson’s for 22 years and PB was his caregiver
- Grieved death of spouse and also loss of roll wife/caregiver
- Other loss felt was loss of her dreams/“Golden years”
Phases of Grief

- Shock and Numbness: family cannot believe death has occurred
- Yearning and Searching: survivors experience separation anxiety, frustrated trying to find and bring back the lost person
- Disorganization and Despair: family depressed and has difficulty planning for the future
- Reorganization

Mechanics of Grief

- Sigmund Freud: “grief work”, finish one job before the next job
- Elizabeth Ross: 5 stages: denial, anger, bargaining, depression, acceptance
- Bowlby and Parkes: grief in terms of phases
- J.W. Worden: 4 tasks: accept reality, experience pain, adjust to life without loved one and invest emotional energy in new life

Common Feelings/Behaviors

- Fear or anxiety
- Anger or guilt
- Depresssion or despair
- Separation or longing
- Sudden wave of mental pain
- Confusion/mobility to think
- Tearfulness or crying
- Sight
- Restlessness
- Yearning
- Helplessness
- Relief
- Disbelief
- Hope
Elements of grief

- Who died? acquaintance or loved one
- What was relationship? best friend, wife, accountant
- What was cause? expected vs traumatic/suicide

Common to Us All

- Life- all are born
- Death- all of us will die
- Grief- all of us will grieve between birth and death
- TAXES

Common Physical Symptoms

- Decreased or increased appetite
- Decreased energy/weakness of muscles
- Nausea and diarrhea
- Decrease or increase sex drive
- Inability to sleep/sleeping too much
- Feeling something stuck in throat
- Tightness in chest/breathlessness
- Increased sensitivity to noise
Normal Grief

- PT JG 2/2/17 Bereaved AG, spouse
- High school sweethearts married 59 years, AG sat at the bedside, reporting "I cannot imagine waking up and not having our morning coffee together—that was OUR time."
- AG comes to support group and reports "Life will never be the same without her, but I have to move on.
- Still weeps from time to time

Goals of grief counseling

- Helping bereaved accept the loss
- Helping the bereaved express feelings (anger, guilt, anxiety, helplessness, sadness)
- Helping bereaved live without the person, make decisions alone
- Helping bereaved separate emotionally, make new relationships
- Providing support at important times, birthdays and anniversaries
- Describe normal grieving
- Provide continuous support
- Help bereaved understand methods of coping

Six Tasks of Grief Therapy

- Ability to experience, express, adjust to painful changes
- Find effective ways to cope
- Establish a continuing relationship with person who died
- Stay healthy and keep functioning
- Re-establish relationships and that others have difficulty empathizing
- Develop healthy image of oneself and the world
Complicated Grief

- Associated with adjustment disorders (depressed, anxious, substance abuse, PTSD)
- Identified by extended length of time of the symptoms
- May present as complete absence of grief and mourning
- Factors contributing (sudden death, gender of mourner, relationship)
- Grief reactions that result in extreme depression, more substance abuse should be treated in standard fashion

Complicated Grief

- PT DM 9/9/2014 but diagnosed 5/16 Bereaved BB, Mother
- PT was dying of Ovarian Cancer, Mother, even at the bedside in Hospice, never accepted the terminal diagnosis-“I am not ready for this”, blamed doctors, nurses and medical system for failing daughter
- Grieved PT was never able to have children
- Found out at the bedside in Hospice, her constant female companion was her lover, and her brother is also openly gay
- Now saying she has nothing to live for, denies she will harm herself, goal is to move “away from this horrible city”

Prolonged Grief Disorder

- 10-20% mourners experience PGD
- Anxiety and depression commonly occur with this
- Bereaved individuals feel “stuck”, not able to move on
- Experience
  - Longing or yearning for person that passed
  - Sense of loneliness
  - Ruminate about the loss
  - Social isolation
  - Intense sorrow and/or regret
  - Meaningless feeling
Risk Factors for PGD

- Childhood abuse or neglect
- Psychiatric history of depression/other illnesses
- Childhood separation anxiety
- Level of family cohesion/community support
- Conditions of death (trauma/rapidly progressive disease)

Treatment of PGD

- Begin cognitive-behavior therapy (CBT)
- Detailed account of months/weeks prior to death
- Personal/psychiatric history
- Define aims of therapy
- Challenge thinking errors:
  - Stop “all or nothing” thinking my life is ruined
  - Negative predictions never be happy again
  - Negative thinking should everyone be as beautiful
  - Inappropriately anger directed
  - Training in modifying techniques
- Set achievable goals; gradation of activities
- Encourage expression of grief
  - Begin behavior modifying techniques
- Set attainable goals; gradation of activities
- Daily activity record

Delayed Grief

- Bereaved, RH, walked into Hospice House January 2017, asking about treatment of grief
- Her Mother died 10 years ago in New York, her Mother was abusive and emotionally neglectful
- Biggest fear was “to become my Mother”, battles low self esteem and still hears her Mom say “you are not good enough”
- Went to grave sight for the first time and said “I am good enough and have made something of myself”
Response to grief

- Hinder grieving person
  - Common clichés: "God's will, time heals all wounds, he's out of pain, get on with life, tears won't bring him back"
  - These are all inappropriate and diminish the person's loss

- Heal the grieving person
  - Provide support: be there
  - Provide guidance: what can I do for you
  - Provide a sounding board: listen

Collective Grief

- Grief felt by a group, community, country (natural disaster, death of a public figure)
- PT SH 1/16/2017

- Officially bereaved was son who came to visit infrequently and just slept on the couch, went through her purse looking for money
- Came malnourished, diseased, stoic and cantankerous
- We got snippets of her life history, she shared recipes, and we came to love her as we came to understand her emotional shortcomings
- We still refer to that room as her's (room#)

Forgotten Grievers-Physicians

- Personal loss: did I fail this patient
  - What could I have done better or different
- Limitations: did I not learn something
  - Finally realize they cannot save, help and cure everyone
- Guilt: cannot accept limitations as human beings
  - Finally accept death as a natural part of life
Physician Grief

Relational factors
- Close to patients/families
- Patient transference
- Young patient
- Long term relationships
- Unexpected deaths

Contextual factors
- Unprepared families/patients
- Unrealistic expectations
- Excessive treatments
- Physician blame/negligence
- Chaotic high-need families

Physician Culture

- Stigma of death and dying
- Affect as weakness
- Culture of cure
- Gendered

"It is hard. Let it be hard…it is rich"

- Caring for dying children is a great privilege and a heavy burden
- We inevitably fall in love with our patients
- It is exhausting, challenging and frustrating
- But no where else in the world to be
- Sometimes it is hard to remember…we did not cause the disease
- Duty to provide care, even when our best therapies fail
At least we can send flowers...

- Doctor-patient relationships are built on trust
- Can cause profound emotional implications
  - Deal with families mourning
  - Help the doctor not feel defeated in leave-taking
  - Sharing in the family's bereavement helps medical team grieve
  - Medical team shares the family's pain

Bereavement

Can I see another's woe
And not be in sorrow too?
Can I see another's grief
And not seek for kind relief?
William Blake

Most individuals cope with grief without professional help
- Keep busy
- Maintain sense loved one is "still with them"
- Draw support from family and friends
Emotional Tasks of Bereavement

- Finding meaning
- Restoring integrity
- Managing affect
- Managing emotions
- Realigning relationships

Loss attachment theory

- Revise internal models
- Status, power and control lost: plans must change
- Identity is altered
- Accept reality intellectually and emotionally
- Adjust to environment: deceased is missing

Mourning=Healing

- Give sufficient warning of pending death
- Provide notice of imminent death
- Palliative care available
- Honor/respect cultural and religious practices
- Follow up with survivors
Principals of Self-Care

- See your limits with compassion
- Set up a schedule that is sane
- Know what practices and activities refresh you
- Actively involve/include/support other caregivers
- Develop a plan doing your work mindfully and restoratively

When There Are No Words

- “I am so sorry” is direct and the truth
- True communication
  - The presence
  - The look
  - The touch
  - The shared silence
  - Communication is clear

Neil Spector MD

“to recognize that we are in control of our own bodies and destinies can be a powerful step towards true healing”
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